Appendix B

Findings and Critical Appraisal Tables

Review question 1 and 2. Identifying, assessing and reviewing care and support needs

a) What are the views and experiences of older people with learning disabilities and their carers about how health, social care and housing needs are identified, assessed and reviewed?

b) What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed?

Review question 1 and 2 – Findings tables – views and experiences data answering both RQ1 and RQ2

1. Bigby C, Bowers B, Webber R (2011) Planning and decision making about the future care of older group home residents and transition to residential aged care. Journal of intellectual Disability Research 55: 77–89

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'This study examined perceptions held by family members, group home staff and organisational managers about the future of older residents and the	**Participants:** Service users and their families, partners and carers Professionals/practitioners. **Sample size:** Total 17 'clusters' of participants, carers and staff around older people with learning difficulties. Each cluster included a family	**Narrative findings – qualitative and views and experiences data:** **Families and wellbeing:** Families and siblings are the forefront over overseeing care and support: 'My attempt is to every couple of weeks to get out there and see him … simply to keep a tap on exactly how he is because I tend to feel myself that it's best just to keep an eye on him otherwise in the end you're just leaving it up to them' (p781). Families kept an eye on general wellbeing and also fulfilled	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
decisions made that a move to residential aged care was necessary' (p777). **Methodology:** Qualitative study **Country:** Not UK Australia **Source of funding:** Not reported	member (1 or more), a supervisor and a manager from the home. One cluster had no family in it. 120 interviews with 59 individuals. **Follow-up:** Two interviews across the 12 months after the start of the study. **Costs** Not reported.	other roles, like being a contact for medical staff or housing issues. Some were very involved in the day-to-day management of care, this did not extent to 'hands on' care but more of a guardianship role. **The future:** Many families had hoped that their relative would be cared for in the group home for their whole lives. Some had invested in their care in the hope they would provide long-term care. Two families described their disappointment when they found that staff could not accommodate escalating needs: 'Well, the reason we'd started the farm was that as the people aged they would be there for life' (p782). Some families had not considered the possibility that their relative would need to move to an old people's home or a care facility. 'they said we'll keep them all their life and there was an old people's home around further and I thought well that's what they'll do, they'll all go on to the next stage'. (p782). For some, the interview process prompted families to consider future plans. 'I haven't thought about it. There's been no plan, no thinking, and no discussion at all … And somehow in my mind I thought there was some magic place within Bethel they moved them on, but I'm realising that	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		there isn't and he will become part of the aged care federal government system which is absolutely terrifying' (p782).	

		‘I fully expect that one day he will be in a nursing home because the staff won’t be able to manage 5 elderly men who will all have some form of dementia’ (p782). Families described the realisation that their relative’s current accommodation would no longer be able to meet their needs. It was felt that their health would be jeopardised if they stayed in their current setting. **Staff perspectives:** Staff acknowledged that resident would need to move on once their needs ‘crossed a line’. Views varied about how health needs would escalate to reach this point. Staff in general said that residents would move on when it was felt that their needs would be better met elsewhere. When their condition changed and the staff were not equipped to provide care. ‘The person has actually been assessed as needing nursing home care, we can’t provide that care …’ (p782). Staff suggested that families were resistant to the idea that the current group home may not be suitable for their relative forever. The findings show that the staff ‘drew a line’ when they felt that they could no longer fulfil ‘duty of care’ (p783). This decision was not objective and highly variable. This depended on the home and the staff group.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Factors like 'medical procedures, mobility issues and personal care tasks' (p783). 'Unless it becomes really a proper nursing thing that they need injections or they needreally complex dressing and things like that, wound care and things like that because we just don't have that care. But if it's short-term that's not a problem, we're talking about long term' (p783). More senior members of staff were aware of how their organisation needed to respond to the problem of older people with learning difficulties ageing and needing more care. Senior staff could do little, beyond training staff, to make the environment more suitable for advancing needs. During the 18-month study, 17 residents made the decision to move. Six moved and the rest did not because there was a delay or the decision was overturned. **Each decision is different**	

		Common to decision: how significant the change in care and support needs, impact of changes on staff and other residents, and how flexible the home could be to these needs. An acute episode or stressful situations happening in the house were often a trigger for the move. Some moves were made in crisis and others were done overtime with family input. 'So, he, [HM] told me to more orless start to look for alternative accommodation because they couldn't manage in the house, you know?' (p784); '. . one day one woman rang me up, not from the house, to say you'll have to find a home for Walter, you'll have to put him in an aged care, we can't keep him any longer … And I got such a shock …' (p784). Sudden moves left people feeling bewildered and some resisted the proposed move. 'After a while I got cross, and I rang them and I said: "I think you are trying to push him out. Well, I don't like any of the places that the broker has sent us to, and other places, and I don't, and he's lived there for 35 years … This is, it's his home, you know, it's like his family too up there' (p785). Other residents had a two-year planning process around the move due to a steady decline over time. 'Well, in this particular house, it was mooted that maybe we might move, especially Tony who was becoming wheelchair-bound to another newer place that has great wide corridors and all the	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		rest of it but we talked with family and that and we felt that that may have been more stressful for him. That we knew that the move to a nursing home was going to be inevitable and another move in between would probably be too much' (p785).	

2. Bigby C, Webber R, Bowers B (2015) Sibling roles in the lives of older group home residents with intellectual disability: working with staff to safeguard wellbeing. Australian Social Work 68: 453–68

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'This study was an exploration of the roles siblings play in the lives of older people with intellectual disability who live in group homes, and relationships between residents'	**Participants:** Service users and their families, partners and carers, service user's siblings. **Sample size:** Professionals working around 13 individuals. **Outcomes measured** Family or caregiver related outcomes: Views on the	**Narrative findings – qualitative and views and experiences data:** The findings in the paper that relate to this question are the ones that include themes around monitoring needs and coordinating formal care. Siblings reported having a variety of levels of involvement. From 'keeping an eye on things' (p458) to monitoring the care provision 'I want to pre-empt anything that might go wrong' (p458).	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
siblings and group home staff' (p455). **Methodology:** Qualitative study **Country** Not UK, Australia. **Source of funding:** Voluntary/charity.	involvement of siblings in the care of service user. Satisfaction with services: Discussion on the role of siblings in the organisation of care. **Follow-up:** No follow-up. **Costs:** Not reported.	Siblings commented that their involvement was often informal. Some said that they were only informed when there was considered to be a major change or decision. Others were invited to help coordinate care. 'They [staff] did initiate finding the specialist, talking to people … so they did show the initiative there, but then they brought the information to me and we discussed it and agreed on who would be the best person, and that we would go together and talk to the person' (p458). Siblings described themselves working in an advocacy role for their brother or sister. The paper describes the role of siblings as emotional support relating to their care, by going to medical appointments and discussion implications. 'A sister explained that she debriefed with her sibling after medical appointments, saying "I always take her [sister] for something, sort of a treat and definitely a cuppa … and give her a chance to bring up anything that might be worrying her" (p459). Some siblings expressed uncertainty about their role in decision-making around care, and who the medical professional or care staff would go to for guidance. Communication with group home staff is a theme of the analysis. Siblings described how they appreciated an 'easy partnership' (p460) with staff. 'Siblings talked about being in a team with staff, with one saying, "I feel that we are a good	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		team" (13F2), and another that it has been "very comfortable, the communication's good … the staff and I are involved from the word go" (p460). Siblings described how to maintain good communication with staff through announcing their visits, or sometimes not voicing every concern for fear of alienating the professionals. Group home staff also commented on the importance of involving siblings and gaining their respect. 'Managerial staff adopted proactive strategies to bring siblings around to their point of view ... one manager described this approach, saying "we start to have the conversation [with the sibling] to assist and facilitate the conversation to get to the point where it needs to be" (p461). Disputes between staff and siblings around care were resolved through good communication. But there is discussion of disputes around care not being resolved. 'I was never actually informed about this [decision for brother to go on holiday] until it was too late … and so I hadn't been consulted or advised of anything, just came like a bolt out of the blue' (p461).	

3. Bowers B, Webber R, Bigby C (2014) Health issues of older people with intellectual disability in group homes. Journal of Intellectual and Developmental Disability 39: 261–9

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'This paper explores how group home staff interprets and respond to symptoms of illness in older group home residents.' (p.262) **Methodology:** Qualitative study. **Country:** Not UK, Australia, **Source of funding:** Government, Australian Research Council.	**Participants:** Professionals/practitioners; group home staff. **Sample size:** Total 30 staff members interviewed. **Follow-up:** Follow-up interviews were conducted by telephone 6 months later. **Costs:** Not reported.	**Narrative findings – qualitative and views and experiences data:** **Monitoring health needs** Staff stated that all residents kept appointments with GPs for general health checks. These appointments led to diagnosis of a variety of conditions like; diabetes, high blood pressure, cholesterol issues and others. Staff spoke highly of the work of GPs with residents. 'Oh, they have their own doctor who they've been going to see for, oh, 5 years, 4 years, something like that. And she's an excellent, excellent with them' (p264). Staff worked with GPs to make appointments accommodate the needs of service users. This included elongating appointment times, establishing consistency in providers, have appointments at home, and taking care not to mention anything that might be alarming. Some staff described bad experiences with GPs '… she's got Barrett's disease … And they took her to the local GP, to get a referral for the follow-up, and he said: "Well, yes it doesn't really matter that the follow-up hasn't happened, because, after all, she's not normal" … And then they changed doctors, after that' (p264).	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Staff were not medically trained to they relied on the expertise of GPs and others to make diagnosis and follow-up issues. Some staff were not sure whose responsibility it was to follow up tests. 'Yeah but ultimately, whose responsibility is all that. Do I have to push it? Should someone else?' (p264). There was variation among staff about responding to screen requests for issues like breast cancer or cervical cancer. 'We had a gentleman with Down syndrome and he was terrified of doctors and we couldn't get an injection and we couldn't do a blood test. We couldn't do anything. So, what we did instead of taking him to the doctor we brought the doctor here' (p264). Some respondents said that residents would not tolerate such tests, which other had developed strategies to encourage residents to encourage services users to have the tests like prostate examinations. Some staff did not think that such tests were appropriate. 'We get a lot of feedback from doctors, especially about female's pap smears. Well they're not sexually active so they don't need a pap smear' (p264). Some staff were unwilling to collect urinary of faecal samples, and there was a lack of awareness about the importance of faecal occult blood tests for people in residential settings. But some staff tried to follow up on screening requests. Not many group home staff said that they had systems in place for follow up or	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		monitoring heath concerns. There was a lack of policy for this kind of activity. Some group homes left follow up to the individual or family members and this meant that issues could be overlooked. Staff described incidents where residents might be exhibiting symptoms for some time before they were dealt with. Sometimes changes were tough to be related to aging and so were not addressed quickly. Some group home staff commented that there were delays in seeking care. **Delays were caused by:** • Symptoms being attributed to aging: 'he's wanted to sleep a lot longer. I think it's just age and you know walking it takes a lot of energy and I think it's just ageing more than anything else' (p266). • Residents were perceived as 'difficult'. 'He's up at the toilet … I believe that it's a boredom thing, not so much boredom because he does a lot of things' (p266). • Issues attributed to dementia. In the case of challenging or unusual behaviour staff sometimes assumed that disruptive behaviour was the onset of dementia. One resident was described as getting up in the night often and disturbing other residents. The problem was later found to be a serious prostate issue. The knowledge that dementia is prevalent	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		among people with learning difficulties led to staff assuming dementia rather than seeking medical advice. **Communication** Staff felt that the difficulty in identifying health issues was often down to the older person's communication difficulties: '… communicate: I don't know, Trevor wouldn't really tell you even if something was sore or stiff anyway' (p266). **Training** Staff often has no formal training for their roles, and not usually any medical experience. Staff felt that the difficulty in identifying health issues was often down to the older person's communication difficulties. A manager commented that staff would benefit from more training: 'I'd love to have more training in dementia for them [staff] as well because people are very quick to put labels on other people, you know, you've really got to know a little bit more about what is dementia' (p266). **Relation to other conditions**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Another reason for delays was that symptoms were attributed to existing conditions, and other possibilities were not explored. **Independence and privacy** Some residents were independent in their personal care and this meant that staff were not aware of problems that may not be clear when they were clothed. Staff were concerned about preserving privacy and did not see problems.	

4. Carling-Jenkins R, Torr J, Iacono T et al. (2012) Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments. Journal of intellectual and developmental disability 37: 54–60

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The aim of this paper was to report on the experiences of families and other carers in seeking a diagnosis and	**Participants:** Service users and their families, partners and carers Families, carers (not OPLD themselves) Professionals/practitioners	**Narrative findings – qualitative and views and experiences data:** **The dementia diagnosis** Families weren't aware that their relative had the potential to develop Alzheimer's as a result of their Down syndrome - they didn't know about the link between the two conditions. The psychiatric assessments that resulted in the diagnoses	**Overall assessment of internal validity:** + **Overall assessment of**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
supporting people with Down's syndrome and Alzheimer's disease who had lived most or all of their lives with family. **Methodology:** Qualitative study. Interviews plus audit of health records. **Country:** Not UK, Australia. **Source of funding:** Voluntary/charity, Alzheimer's Australia.	**Sample size:** Three individuals made up the 'case studies'. For each person up to 4 informants in both paid and unpaid care were interviewed. **Costs** Not reported.	for all 3 people were initially sought after changes in their behaviour. For example, Maria who used to be the life and soul of the party became increasingly withdrawn. **Overshadowing** This happened in all 3 cases. Services and families continued to attribute behaviour changes to the Down's syndrome rather than contemplating that it may be caused by the early stages of Alzheimer's. The result among families was denial and doubt about the diagnosis and among practitioners it led to the provision of poor or inappropriate support and a lot of mismanagement. This was only addressed when crisis point was reached, either in the family or in the aged care facility. For Jan, the result of the diagnostic overshadowing was that she was placed in the aged care facility without a comprehensive handover from the hospital regarding her dementia diagnosis. Consequently, she was perceived as misbehaving and the other residents abused her. As a result, her parents became distressed. For Maria, who lived at home, her mother distrusted the dementia diagnosis. Maria's sister tried to obtain support for her from aged care services but was refused due to age and disability. The family finally reached crisis, unable to access appropriate supports. The authors observed that 'problem behaviours' were attributed to the	**external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		person's DS, which distracted families and practitioners from considering the potential for Alzheimer's disease. Overshadowing also masked people's increasing care needs associated with the progressive degenerative nature of Alzheimer's. They suggest that aged care workers are less likely to have experience of LD so overshadowing is likely when adults receive care in those facilities. Overall, there was a lack of knowledge about Alzheimer's in people with DS and a lack of expertise in identifying and addressing their care and support needs.	

Review question 1and 2 – Critical appraisal tables – views and experiences data answering both RQ1 and RQ2

1. Bigby C, Bowers B, Webber R (2011) Planning and decision making about the future care of older group home residents and transition to residential aged care. Journal of intellectual Disability Research 55: 77–89

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'This study examined	**How well was the data collection carried out?**	**Does the study's research question match the review question?**	**Overall assessment of**

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
perceptions held by family members, group home staff and organisational managers about the future of older residents and the decisions made that a move to residential aged care was necessary' (p777). **Methodology:** Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. Study 'examines the interface in the case of group homes' residents between the plans made by parents for post parental care and service system	Appropriately. Methods are described in detail and speak to research questions. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate. Sampling was purposive and carried out in 13 group homes. **Were the methods reliable?** Reliable. Interviews were carried out with several people 'clustered' around each resident. The first round of interviews was in depth and follow-ups were briefer and captured	Yes. Collecting views on the decisions around an older person move from group homes to care home facilities. Staff and family carer views. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. The views describe how a person's accommodation needs correlate with their health and social care needs.	**internal validity:** ++ **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
responses to their age associated changes' (p779). **How defensible/rigorous is the research design/methodology?** Defensible. Data taken from a larger study on people with learning difficulties moving into residential care. Interviews are appropriate.	changes to the resident's needs. **Are the data 'rich'?** Rich. Data well-presented and themes clearly described. Lots of original data to illustrate points. **Is the analysis reliable?** Reliable. Analysis used 'grounded dimensional analysis'. Interviews were recorded and transcribed and analysis was carried out by 3 members of research team. **Are the findings convincing?** Convincing. Reporting is clear. Interview data is	Interviews gathering staff and family carer's views and experiences. **Does the study have a UK perspective?** No. Australia.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	presented to illustrate points. **Are the conclusions adequate?** Somewhat adequate. The study does not discuss its limitations but it does place this research within the context of other research and justifies its place in exploring the difficulties in responding to escalating needs.		

2. Bigby C, Webber R, Bowers B (2015) Sibling roles in the lives of older group home residents with intellectual disability: working with staff to safeguard wellbeing. Australian Social Work 68: 453–68

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim 'This study was an exploration of the roles siblings play in the lives of	**How well was the data collection carried out?** Somewhat appropriately. Details of the interviews are scant, we are given	**Does the study's research question match the review question?** • Partly The review questions are very broadly	**Overall assessment of internal validity:** + **Overall assessment of**

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
older people with intellectual disability who live in group homes, and relationships between residents' siblings and group home staff' (p455). **Methodology** Qualitative study. **Is a qualitative approach appropriate?** Appropriate given the aims of the study. **Is the study clear in what it seeks to do?** Clear. Study lays out aims with clarity. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. The study states in aims to elicit the social constructions of participants, so a qualitative approach using	no example questions or discussion guides. They were 60 to 90 minutes and followed up every 6 months for 3 years via telephone. **Is the context clearly described?** Clear. The context is described, and interviews were carried out in a variety of group homes. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. The views were gained in a variety of different locations and views are varied. There is no discussion of the effect of sampling on the data. **Were the methods reliable?** Somewhat reliable. We are not given a great deal of detail about how the data was collected, collated and analysed. But there is detail about how data was coded. **Are the data 'rich'?** Rich.	about the involvement of siblings. But the findings do touch on the identification, assessment and review of care needs. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval has been gained. **Were service users involved in the study?** No. Service users were not expressly interviewed. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the**	**external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
semi-structured interviews in appropriate. But the analysis methods and sampling are not well enough justified to warrant a higher score.	**Is the analysis reliable?** Reliable. Results are described thematically and in depth. **Are the findings convincing?** Convincing. The study uses a lot of verbatim quotes and reporting is clear. **Are the conclusions adequate?** Adequate.	**guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. Australian study.	

3. Bowers B, Webber R, Bigby C (2014) Health issues of older people with intellectual disability in group homes. Journal of Intellectual and Developmental Disability 39: 261–9

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: This paper explores how group home staff interpret and respond to symptoms	**How well was the data collection carried out?** Somewhat appropriately. The interview style is described but we are	**Does the study's research question match the review question?** Yes. The aims of this study fit well with the research question. The views and	**Overall assessment of internal validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
of illness in older group home residents' (p262). **Methodology:** Qualitative study. **Is a qualitative approach appropriate?** Appropriate for gaining views. **Is the study clear in what it seeks to do?** Clear. The aims are very brief but clearly stated. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Methods are relatively well discussed Interviews were unstructured initially and more focused later. Interviews were conducted over the phone and in person. We do not gain any detail of the participants, in terms of	not given much information about how data was recorded or stored. Just that it was recorded and transcribed. **Is the context clearly described?** Unclear. We are given very little data about the participants, where they worked, or who they supported. We only get general information about the group home where they worked. We are told that they did not have formal training in care, but no other details are given. **Was the sampling carried out in an appropriate way?** Not sure. It is difficult to say because we do not know how many staff are employed overall, who was approached for interview and who declined. We are also not told if anyone dropped out or left employment before follow-up. Some staff were interviewed twice, some 6 times. We are not given detail of who was interviewed how many times. Total 83 interviews conducted.	experiences of practitioners relate to how health needs are assessed in a group home setting. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethics committee approved. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Group home setting. **Does the study relate to at least 1 of the activities covered by the guideline?**	**Overall assessment of external validity:** ++

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
age, gender, and ethnicity. Nor do we learn how long that had been employed as care workers or their background. The paper does give reasonable rationale for its qualitative style and the type of data it aims to elicit. 83 interviews were conducted.	**Were the methods reliable?** Somewhat reliable. Information about the methods has some gaps. Particularly around sample and data collection. We are also given little information about analysis. The number of interviews has the potential to elicit rich views data. **Are the data 'rich'?** Mixed. Much of it is descriptive, but some verbatim quotes are given. **Is the analysis reliable?** Somewhat reliable. Data was thematically analysed and grounded theory was used to interpret results. **Are the findings convincing?** Convincing. Findings are presented thematically and original data is included. Original data is coded to interviewee. **Are the conclusions adequate?** Somewhat adequate. The themes seem plausible and this study does tell us something valuable about the experiences of staff in group homes	Yes. Identification and assessment of health and care needs. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Practitioner views on the identification and assessment of health needs. **Does the study have a UK perspective?** No. Australia.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	working with older people with learning difficulties. The issues presented give us a sense of the kind of barriers that exist for staff referring older people for medical assessment and how they interpret changes in behaviour. The study does not engage well with its limitations.		

4. Carling-Jenkins R, Torr J, Iacono T et al. (2012) Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments. Journal of intellectual and developmental disability 37: 54–60

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim The aim of this paper was to report on the experiences of families and other carers in seeking a diagnosis and supporting people with Down syndrome and Alzheimer's disease who had lived most or all of their lives with family.	**How well was the data collection carried out?** Appropriately. The data collection methods are clearly described and include a range of data sources. The appropriate data were collected to address the research question and data collection and record-keeping seem to be systematic. **Is the context clearly described?** Unclear. We know that the 3	**Does the study's research question match the review question?** Partly. Although it does not provide an enormous of data on the subject the study does focus on the identification of care and support needs for adults with LD and dementia. It does not however investigate views and experiences of assessment. **Has the study dealt appropriately with any ethical concerns?**	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. Interviews plus audit of health records. **Is a qualitative approach appropriate?** Appropriate because the research seeks to illuminate subjective experiences. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. The 3 'participants' were recruited from a larger study and the only rationale provided for them to participate in this study was that they had lived with their families for most of their lives (the others in the larger study	individuals ('participants') at the centre of the case studies have DS and Alzheimer's disease and that they have lived with their parents for most of their lives. We know very little about the interviewees apart from their relationship with the participants. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. The 3 participants were recruited from a larger study and we do not know how those participants were recruited. The interviewees were recruited because of their relationship (paid or unpaid carer) with the participant. There is no explanation for why those specific respondents were chosen as opposed to others. **Were the methods reliable?** Somewhat reliable. Data were collected via more than one method, which in theory facilitates triangulation. However, the only results presented appear to be from the interviews rather than the guided	Yes. Ethical approval for this research was obtained through both Monash University, Australia, and La Trobe University, Australia. **Were service users involved in the study?** No. Neither as participants nor as co-researchers although the aim of the study was to investigate the views/experiences of carers and practitioners. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
had all lived in institutions since they were young). Qualitative data analysis is briefly but clearly justified.	medical file audits so it is not clear how the file audits contribute to answering the research question. **Are the data 'rich'?** Mixed. The contexts of the data are described fairly well but it is not always clear which respondent has made a particular point. Responses are compared and contrasted across cases, with themes identified. **Is the analysis reliable?** Somewhat reliable. It is unclear whether more than 1 researcher themed and coded transcripts/data. There's no evidence that participants fed back on the transcripts although the accuracy of the timeline and factual details gathered via the medical file audits was checked with families and practitioners. **Are the findings convincing?** Convincing. Findings are fairly clearly presented and they answer the research question. They're well supported with original data.	**guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. Australia.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Are the conclusions adequate? Somewhat adequate. Conclusions are plausible in light of the reported findings however due to the small sample size the generalisability is limited. There is only a brief mention by the authors of this study limitation. Practice implications are discussed briefly.		

Review question 1 only – findings tables – the views and experiences of people using services, their families and carers

1. Bowey L, McGlaughlin A (2005) Adults with a learning disability living with elderly carers talk about planning for the future: aspirations and concerns. The British Journal of Social Work 35: 1377–92

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity Rating
Study aim: To identify current and future housing and support needs of adults with a learning disability	**Participants:** Service users and their families, partners and carers.	**Narrative findings – qualitative and views and experiences data:**	**Overall assessment of internal validity:** +

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity Rating**
living with carers aged over 70. This paper presents only the views of adults with a learning disability (views of carers presented in a separate paper). **Methodology:** Qualitative study. **Country:** UK. **Source of funding:** Not reported.	**Sample size:** Total 41 adults with learning disabilities; 62 family carers over the age of 70. **Costs?** No.	**Mutual support** Total 34 (83%) said that they helped out at home. Participants valued their mutually supportive relationships involving both practical tasks and emotional support and saw it as part of every day of family life. 'I love helping my mum, with washing up, with cleaning, I do lots' (p1383). 'My mummy looks after me, and I look after her' (p1383). Others were carrying out more intensive tasks that they had to take on when their carers started to need more support, blurring the distinction between clear roles of 'carer' and 'cared for': 'She relies on me to help her out, cause she can't do things like she used to' (p1383). 'It's difficult thinking of living with someone else if my Mum's here. If she falls down, I want to be there to lift her up' (p1383).	**Overall assessment of external validity:** +

		Mutual support impacted on the participants' willingness to plan for the future, as they were concerned about how their carer would cope if they lived elsewhere. The needs of both parties need to be considered in tandem if successful future planning is to be achieved. **Desire to move** Total 11 (27%) participants expressed a desire to live elsewhere when asked whether they would prefer to remain living where they live now or somewhere else – 30 (73%) said that they did not want to move to alternative housing, despite there being a likely need for some kind of alternative housing provision or support in the future once their cares die or become unable to care. **Concerns about carers** A large number of participants expressed concern about the ill health or death of their carers – this was especially pronounced for those who had a lone carer. Participants were conscious of their carers' ill health and had often undertaken responsibility for helping the carer in an emergency. 'When my mum is poorly, there's a button on the telephone, I press it, tell them my mum is poorly and they come in an ambulance. I'm so worried about her, what's gonna happen' (p1384).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity Rating
		This issue is particularly pertinent to those living with lone carers as it is more likely that they will have already experienced the loss of 1 parent or carer. However, those with dual carers also raised the issue, emphasising that many participants were well aware of the inevitability of the death of those close to them and the potential crisis approaching in the future. **Planning for the future** When asked whether they had previously been given the chance to discuss planning for the future, 28 said they had been involved in such discussions and 13 (32%) said they had not. The majority of those that had discussed future plans had not made concrete plans. However, they were able to give quite in-depth answers about what was important to them in terms of their future housing. The availability of appropriate support was viewed as high on the list of priorities for where they might live in the future, as was remaining within their local area, where they could stay close to friends and family and a neighbourhood they were familiar with. 'I've talked to Mum and Dad. I'd probably want to live on my own with someone coming in to help me, but I don't want to until I have to' (p1387).	

<table>
<tr><th>Research aims</th><th>PICO (population, intervention, comparison, outcomes)</th><th>Findings</th><th>Overall validity Rating</th></tr>
<tr><td></td><td></td><td>Opportunities for independence were viewed as extremely valuable; they wanted the chance to do more for themselves and to learn new skills. Others expressed that they would need some support and reassurance in becoming more independent because they lacked the confidence to try new things by themselves.
Total 30 (73%) were aware that their carers would not always be available and that they would need to consider alternatives to their present housing and support. The 30 people who were aware of the need to plan for the future were asked about where they might like to live when this time came.
Future housing preferences of service users interviewed (n=41).
<table>
<tr><th>Future housing preference</th><th>No.</th><th>%</th></tr>
<tr><td>Shared house</td><td>10</td><td>24</td></tr>
<tr><td>Self-contained accommodation within a shared building</td><td>7</td><td>17</td></tr>
<tr><td>With another relative (i.e. sibling)</td><td>6</td><td>15</td></tr>
<tr><td>Alone</td><td>2</td><td>5</td></tr>
<tr><td>With a partner</td><td>1</td><td>2</td></tr>
</table></td><td></td></tr>
</table>

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity Rating**
		Support within the family home after parental death Unsure 2 5 Unaware of the future need 11 27 **Total 41 100** While participants were able to give some idea of their preferred future housing, they found it difficult to talk about specifics, especially the number of people that they would want to share with. Although participants were aware of a potential need for a change in housing or support in the future they were reluctant to discuss plans with family and professionals. It was a very difficult subject as they had generally spent their entire lives living with their families. 'It's difficult to talk about it and to think about it. We haven't got around to talking about it yet, it's too difficult' (p1386). The prospect of moving was daunting for many participants. They often stated that they would prefer to remain at home for as long as possible but that they would move when it became necessary. 'I'll stay with my Mum; she doesn't want to part with me. But I understand that if she can't cope I'll have to go somewhere, like if she's too ill and can't cope, if 'owt happens to her' (p1386).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity Rating
		It was difficult to consider future planning when participants felt that they had somewhere suitable to live with their families: 'I've wouldn't mind living somewhere different for a while. I wouldn't mind living on my own. I could do my own cooking and thing. It's difficult really. I think maybe I would like to stay with Mum and Dad for now actually. But maybe I could move one day' (p1387). Those who had already discussed and planned their moves spoke confidently about the future and valued that their carers had been involved in the plan. 'I've talked to my social worker about it [future plans]. We've been talking about it in a review, my Mum brought it up. She's all for it because she's 72 so in case she goes. I'm all for it. I mentioned t before, we discussed it before but it didn't happen then. So we talked about it in the review so they put my name down on a list for housing and then they found a bungalow. I'm going to be living on my own with some support' (p1388). A plan for the future was reassuring for participants and they had begun to look forward to the prospective move. 'It'll make me more confident, more sure. Ooh, I think it'll be good, getting more independent. I'm looking forward to it ...' (p1388).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity Rating
		Proactive planning gave service users greater control over decisions about how and where they live, which made them feel empowered. This is in stark contrast to when housing is considered in a response to a crisis situation. Concerns about moving in relation to plans about moving participants raised a number of concerns. They were worried about leaving carers, especially carers for whom they have provided some degree of support. Others were unsure how they would cope in another environment, and availability of appropriate support was again brought up as an issue. 'I would be worried, yes, because I've never done it before, that's what it is. It's a big step but I'd like to give it a go. I'd like a carer someone to come and visit' (p1389). Some adults with learning disabilities needed significant reassurance that support will be available for them. They were very anxious about living alone: 'We talked about it [future plans]. I didn't like the idea at all, not of living on my own, I'd burn everything. I might have an accident on my own. I'd be frightened, I might have an accident' (p1389). Others were fearful of living in shared accommodation as they were unsure how they	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity Rating
		would get on with other people, and were worried that people would take their belongings and 'torment' them. There were also concerns about self-contained accommodation, highlighting the need for people with learning disabilities to have access to information on existing options, which would help them think through the advantages and disadvantages of each.	

2. Coyle CE, Kramer J, Mutchler JE (2014) Aging together: sibling carers of adults with intellectual and developmental disabilities. Journal of Policy and Practice in Intellectual Disabilities 11: 302–12

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'The purpose of this study was to explore the transition of care to sibling carers of people with disabilities after their parents are no longer providing primary support	**Participants:** Service users and their families, partners and carers – sibling carer. **Sample size:** Total 15 in-depth semi-structured interviews.	**Narrative findings – qualitative and views and experiences data** Study identified 3 key themes from the interviews. All related to sibling carers. The first relates to the impact of aging on the caring role. The second was the importance of planning on the sibling carer role and third on support systems. **Ageing**	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
to the individual with a disability' (p304). **Methodology:** Qualitative study. Semi-structured interviews. **Country:** Not UK, USA. **Source of funding:** Not reported.	**Follow-up:** No follow-up. **Costs:** • Not reported.	Dementia and Alzheimer's was a common issue in older people with learning difficulties. Sibling carers found it difficult to achieve a diagnosis of dementia or Alzheimer's. 'I was asking her about what she did yesterday afternoon and she didn't remember at all … day to day you sort of notice certain things' (p305). Carers found that as the symptoms of dementia worsened, they had to care more and more for their sibling. Older people with learning difficulties became less mobile, exhibited unpredictable behaviour, and lost communication ability. 'That's why I left my job. My school day was interrupted with phone calls about medical issues. I was going … every two weeks probably and … would … stay for three, or four or five days … We were then faced with all of the kinds of challenges that families face with AD. [Alzheimer's] became the primary, pressing issue' (p306). Ageing resulted in a need to change accommodation. **Planning** Sibling carers had to plan for their sibling's future care and changing condition. 'I'm sure he'll live for a long time … [I'm] worrying about making sure that I'm alive	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		too. I'm beginning to think about what we should plan for him, you know, in 10–15 years down the line – where he should live. Should I work on a retirement home?' (p307). Taking over caring activities from parents could be sudden and unplanned. Siblings said that they needed to plan for a situation where they may not be around either. This was felt to be a key component of the sibling carer role. **Support systems** Siblings struggled to gain adequate support. Support for older people with learning difficulties changes as their family's age. Other siblings had some role in caring, but the level of their involvement varied. Help within the family tended to decrease over time: 'I have one sibling who [provides direct care] every Sunday … and gives Jane her lunch … bathes … dresses her and hangs around with her … but that's planned and scheduled. [The support I provide] is like if Jane is up in the middle of the night, I am up in the middle of night and I have trouble going to the work the next day. It affects my life tremendously as far as work is concerned' (p309). Sibling carers found that it was difficult to secure care	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		from formal providers. This was often in response to changing needs. Sibling carers are well placed to notice changes in their sibling's condition, but there was a lack of formal support: 'The group home that he went to was not prepared for [someone with] Alzheimer's disease … The transition wasn't smooth … Thing that we agreed would happen just didn't happen' (p309). Sibling carers needed support for disability and ageing and often service that they had used for some time were no longer relevant which led to stressful transitions to new services. Sibling found it challenging to coordinate care.	

3. Dillenburger K, McKerr L (2011) 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. British Journal of Learning Disabilities 39: 29–38

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To explore the issues related to caring and future planning for older caregivers of	**Participants:** Service users and their families, partners and carers.	**Narrative findings – qualitative and views and experiences data**	**Overall assessment of internal validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
adult sons/daughters with intellectual and/or developmental disabilities in Northern Ireland. **Methodology:** Qualitative study. **Country:** UK, Northern Ireland. **Source of funding:** Voluntary/charity, Changing Ageing Partnership (CAP) Research Seed Grant.	**Sample size:** Total 29 caregivers of 27 adult dependents, 17 caregivers took part in interviews by themselves and 12 took part in interviews as a couple.	**Future planning** The vast majority had not made long-term plans for the future care of their sons or daughters (n=21; 72%). 'I know I should be thinking about it ... Any one of his two siblings would take him but I have a thing about that. They were curtailed [when growing up] and they never ever complained. So I think it's a terrible burden to ask them now to go back and even ask their youngsters to share … the old "handicapped" uncle' (p39). Others were clear about what would happen because they had made plans: e.g., that their daughter would take the house and look after their son with disabilities. 24% (n=7) were worried about their own health and well-being, and future planning (10%; n=3). 'Our biggest problem, as far as [our children] are concerned, is how long are we able to go on? We think a lot about that ... and we haven't come up with an answer' (p34). Some parents even expressed that their son's/daughter's own death was preferable to being taken into care. 'I really don't want him in a home, so I just hope that God will take him before he takes us, but that's not always that way, so you have to think of these things' (p39).	**Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Participants spoke of anxiety that thinking about what will happen if they die causes their son or daughter distress – this panic that their children had voiced themselves prevented parents from discussing future planning with them. The majority of participants (66%; n=19) had not discussed future provision with social services. 'I don't see them or know anything about them. I know they are there but someone said it's pretty hard to get your social worker, so I haven't bothered' (p39). Most participants (72%; n=21) had not considered making financial arrangements for the future, despite knowing that they 'should be thinking about it' (p39). The importance of future planning was understood by the majority of participants but there was still reluctance to have to 'face up to it' and as a result many participants never acted on it.	

4. Hole RD, Stainton T, Wilson L (2013) Ageing adults with intellectual disabilities: self-advocates' and family members' perspectives about the future. Australian Social Work 66: 571–89

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The authors aimed to gain a better understanding of the needs, hopes and desires for the future of ageing adults with intellectual disabilities and family members of adults with intellectual disabilities. **Methodology:** Qualitative study. **Country:** Not UK, British Colombia, Canada. **Source of funding:** Government: British Columbia Ministry of Children and Family	**Participants:** Service users and their families, partners and carers – 11 ageing adults with intellectual disabilities and 11 family members. **Sample size:** Total 22 (11 self-advocates and 11 family members). **Costs:** • Not reported.	**Narrative findings – qualitative and views and experiences data** **Views of self-advocate – future plans and hopes** When asked about retirement the majority said they wanted to continue with activities they currently enjoy. Not everyone wanted to stop working. Some wanted to travel. One man said retirement and travel would give him the chance to think about what living arrangements he wanted. The authors observe, 'The diversity of views with respect to future plans and desires points to the importance of assessing each individual's needs and wishes when planning with them for their future' (p576). **Future concerns** These included concerns relating to relationships and security, particularly about ageing parents, living arrangements and loneliness. Concerns about ageing parents reflected self-advocates' unease about their own future as well as worries for their parents' wellbeing. For example, 'if my dad dies, what will the future be for me?' (participant #10) (p576). Future living arrangements were a big concern,	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Development and Community Living		particularly the prospect of having no choice about where they could live. People already felt lonely and were concerned that old age would exacerbate this, because they'd no longer be able to get out. Note: despite expressing concerns for the future only 1 of the 11 were engaged in any kind of future planning. The 1, who was planning, was making lists of her preferences just in case there came a time when she could no longer express herself. **Family members' view** They were very concerned about the future, which felt uncertain. Most talked about the importance of planning for later life but only 3 had done anything about this. Those who had planned said having a support worker or champion was very important. It was often a crisis – e.g. 1 of the parents becoming ill – that highlighted the need for future planning. Those who hadn't done any future planning said it was because they felt burnt out from years of advocacy or that felt disconnected from services and support. Views are summarised under the theme "Proactive planning for the future" – planning that's pre-emptive rather than responding to a crisis was said to be crucial. People wanted plans in place to protect their family	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		members' financial security, accommodation (stability being very important), legal issues and choice and self-determination. **Accommodation** Some described how they had moved the adult son/daughter out of the family home so they wouldn't have to be uprooted after their parents died. It also meant they could get used to living without their parents before the crisis occurred. Legal issues and financial security – attending to legal issues included making sure the adult with learning difficulties had an advocate and had their legal rights protected. 'Microboards' were also mentioned as a means of future planning (they're made up of family and close friends who form a non-profit society to address the person's support needs). Ensuring financial security was seen as very important. Microboards can also manage the person's benefits and inheritance. **Self-determination** It was important for choice and self-determination to remain a feature of ageing adults' lives. When ageing adults were able to exert independence and choice in the face of age-related changes or crises, they were	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		better able to live the lives they desired. Two things impacted the planning process: social networks (informal) and system structures (formal). **Informal** Family members pointed out that changing social networks as everyone gets older (and people die or move away) impact planning for the future. Family relationships and networks were obviously complicated. Some participants anticipated that siblings would assume the caretaker role when parents passed away while others said they didn't want the siblings to be 'burdened'. For example, '...They have an excellent relationship and I think that's really important too … I don't now want that [responsibility] falling on her, I really don't. I don't think that's fair' (participant #13) (p581). **Formal** This included, funding, lack of formal supports and frustrations with systemic issues. People worried about whether (in light of cuts to public services) there'd be any funding in future (after they'd died). Waiting lists for services, staffing (and continuity of staff) and the availability of respite during crises were also major	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		concerns. Family members also discussed frustrations with having to deal with multiple systems, lack of accessible information about support and services, and concerns about future services. 'If you were to just even phone the local office, just the first contact you make there is a challenge for any of us to wade through the voicemail options that are given on the phone ... their forms, none of them are worded appropriately too. For people with limited understanding or comprehension, all those things, it's just very poor and it's a complicated Ministry...for anybody to deal with' (participant #12)' (p582).	

5. Innes A, McCabe L, Watchman K (2012) Caring for older people with an intellectual disability: a systematic review. Maturitas 72: 286–95

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To critically evaluate available research literature on ageing	**Participants:** Service users and their families, partners and carers. Professionals/practitioners.	**Narrative findings – qualitative and views and experiences data** Note that only very few findings are relevant to review questions 1 and 2.	**Overall assessment of internal validity:** -

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity rating**
among people with an intellectual disability. **Methodology:** Systematic review. **Country:** Range of countries – an international search of English language studies. **Source of funding** Not reported.	**Sample size:** Total 42 papers were included. **Costs:** Not reported.	The 42 papers were categorised as studies with a service user perspective (13), studies of carers of older people with intellectual disability (14) and studies of service provision for older people with ID (15). **Planning for the future (from studies of carers)** Although older carers were fearful for the future they were often unwilling or unable to undertake forward planning. Others hadn't got round to it, especially those who were coping well. Another reason for not having done any future planning was a lack of confidence about the available housing options (perhaps because of a bad experience in the past). Carers (and practitioners) had worries about the risks associated with independent living. Older carers need proactive support with future planning. **Identifying needs (from service provision focused studies)** In ID settings, changes experienced because of ageing were attributed to 'old age' but in generic ageing services (e.g. older people's homes), they were thought to be due to the person's ID. The authors observe that this means the person may not receive appropriate care and treatment.	**Overall assessment of external validity:** +

6. Towers C (2013) Thinking ahead: improving support for people with learning disabilities and their families to plan for the future. London: Foundation for People with Learning Disabilities

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To explore how support can be improved for people with learning disabilities and their families to plan for the future. **Methodology:** Qualitative study. Workshops were held with people with learning disabilities. Workshops were also held for carers of people with learning disabilities. A survey of 300 parents of a son or daughter with learning disabilities aged over 18 years	**Participants** Service users and their families, partners and carers. No information given on the characteristics of the workshop attendees – neither those who had a learning disability, nor family carers. For the survey, 300 parents with a son or daughter with learning disabilities aged 18 or over. **Sample size:** Survey: 300 adults of sons or daughters with learning disabilities aged 18 and over. Workshop: no sample size given for workshop attendees.	**Narrative findings – qualitative and views and experiences data:** **Survey** Parents have an extremely high level of anxiety and fear about the future. Parents felt they had to fight to secure appropriate care and, even then, they often lost it. One mother commented (in the open-ended question): 'In my experience, all the help has been in response to my requests for information – in other words, the help has to be actively sought out' (p13). From other open-ended responses it was clear that there was a lack of clear and accurate information to help with planning. Parents responded by saying they would find the following helpful. Information on: - power of attorney and appointees - organisations such as Housing Options or Shared Ownership Homes - advocacy and finances. Support provided in the form of: - an independently resourced support group, available	**Overall assessment of internal validity:** - **Overall assessment of external validity:** +

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity rating**
was conducted to gather quantitative and qualitative information on what they would find most helpful. **Country:** UK. **Source of funding** Voluntary/charity, funders of Thinking Ahead Foundation for People with Learning Disabilities.		for each family, run by people with learning disabilities, parents, some professionals (if invited) allies and friends	

		- learning from the experience of other carers or someone who has lost parents and who can highlight all the issues that came up and what worked for different scenarios - regular national, regional and local webinars and workshops on wills, trusts, person-centred planning, support planning, housing options, how to form housing cooperatives/associations, sources of funding for housing cooperatives/associations. A total of 83% of parents were either extremely worried or worried about whether their son or daughter would have a place to live where they were happy once they were no longer able to care for them. A total of 86% were either extremely worried or worried about whether their son or daughter would get the support they need. The survey showed that parents have little trust in the care system to help them plan for the future. The majority doubted that anyone would speak up for their son or daughter to ensure they had a good life or that anyone would help make sure that decisions were made in their son's or daughter's best interest. Parents also worried about whether anyone would make sure that their daughter or son was safe and well. Total 79% of parents were either worried or extremely worried about whether their son or daughter would have friends and feel part of their community. In answer to all 6 aspects of worrying about the future the percentage of	

		parents who were either worried or extremely worried was either above or just below 80%. The highest percentage worried about whether their son or daughter would have somewhere to live where they would be happy and whether they would get the support they need. **Future housing planning** Participants were asked whether a professional had ever spoken to them about whether they would like support to look at options for where their son or daughter might live in the future. Less than a quarter (22.3%; n=67) said that a professional has spoken to them and that they had made plans. Over a third (36.5%; n=110) replied that they had never spoken to a professional about housing options and 25.2% (n=76) said that they had spoken to someone but nothing happened. The remaining 15.9% (n=48) had said that a professional had spoken to them and they did a bit of planning. **Making a person-centred plan** The majority (38.5%; n=115) of parents said that no one had ever spoken to them about making a person-centred plan outlining, for example, who the important people are in their son's or daughter's life and what helps them to keep safe and well. A further 55 (18.4%) parents said that a professional had spoken to them but nothing had happened. A fifth of parents (20.7%; n=62) responded by saying that a professional had spoken to them and plans	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		had been made. Emergency situations: nearly half of parents (45.3%; 134) replied that nobody had ever spoken to them about where their son or daughter might stay or who might support them in an emergency (e.g. in the case of a sudden hospital admission). Just over a quarter (25.7%; n=76) said that someone had spoken to them and they did make plans. **Workshops with people with learning disabilities** Participants felt that too many restrictions were placed on their lives – the focus was on their learning disability and not on their abilities and potential. There was fairly large agreement between participants that they were 'wrapped in cotton wool' which potentially hampers the development of confidence and coping skills for when parents or carers may no longer be around. Participants said it was important to prepare them to cope with bereavement to lessen terrible feelings of loss when a parent dies. Messages included: 'We need to be less protected', 'We need to go to funerals', 'We need our families to talk to us when people are really ill or dying' (p15). Participants emphasised the importance of friendships in helping build strength, self-esteem and a sense of safety. Those without good friends were seen as targets	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		– they could be taken advantage of by people pretending to be their friend. Most participants said that they needed to be involved in making plans. One participant said: 'Having a plan has put my mind at rest' (p15). But there was a strong emphasis on the need to go step by step, and for others to stick to the plan and not ignore it.Findings from workshops with parents and siblings: parents and siblings said that they felt the need to be protective because of their experiences – including bullying and hate crime. They admitted 'we need to be less protective but the world feels very unsafe' (p16). Talking about the future was difficult as 'we're looking at a time when we are not here to protect and that is what we have done over the years' (p16). It also meant having to face up to their own mortality. Participants were also concerned that planning for the future would mean that their son or daughter would have to leave the family home. The poor quality of support was a huge concern to family carers. There was a consistent message that people who would support their relative were lacking the appropriate attitude, knowledge or skills. They wanted support staff to have better contracts with higher pay, good career options and more training.	

		Support from siblings was valued but inconsistent. Parents were reluctant to make plans around siblings owing to a lot of them being in uncertain situations themselves. Circles of support: families were unsure who to ask to contribute to planning for the future because they did not know how to get people from a younger generation to be involved in their relative's life. Still, circles of support were referenced a possible lever for change. 'You could use a circle of support to introduce the topic of planning for the future. It shows us there are other people who will be there after we have died which is often hard to believe as a parent' (p17). **What families said would help** Person-centred planning was understood to be valuable as it allowed their son or daughter to have a say in their future. Emergency planning was also an important step in making parents feel at ease about the future. Lack of information on housing and support: families felt let down by the lack of information on housing and support options. This was crucial to their ability to move forward. Many parents, especially those over 60, did not know the difference between residential care and supported living; they were unaware that supported living could provide 24-hour support and it was not just for those who could do many things for themselves. When asked what would help most with future planning, families replied most frequently that they needed someone who they could trust to support them over a number of years. 'It needs to	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		be someone who knows the family, not a stranger coming in and saying “you need to plan”’ (p17).	

7. Willis DS, Wishart JG, Muir WJ (2011) Menopausal experiences of women with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 24: 74–85

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To identify levels of knowledge of the menopause and of its health and reproductive implications among women with intellectual disabilities. **Methodology:** Qualitative study. **Country:** UK.	**Participants** Service users and their families, partners and carers – 45 women with intellectual disabilities (17 with Down’s syndrome and 28 non-Down’s syndrome. **Sample size:** Total 45 women: 10 pre-, 15 peril- and 20 post-menopausal (as established by gatekeeper and carer reports and from information	**Narrative findings – qualitative and views and experiences data** **Menstruation** When asked why they had periods, one (DS) woman attributed them to getting pregnant. Only 4 non-DS women linked periods to having children. Four women with DS described periods as being painful, 1 saying ‘it was like a nightmare …’ (p78). Two of the women with DS also spoke about the ‘messy’ aspect of having periods. Two of the non-DS women mentioned painful periods without being prompted and 6 mentioned their dislike for them. When asked more directly about any pain associated with periods, 21 of the non-DS women responded that they did experience pain, and 17 had tablets to help alleviate it. When participants were asked	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	provided by the women in their interviews).	if they thought they would always have periods, 12 of them (4 DS and 8 non-DS) said they thought they would; 16 women did know that they would stop. The rest said they did not know or weren't sure. When asked if they knew why periods stopped, most women did not respond. While none of the women in this study themselves reported that they were currently on or had previously taken contraceptive medicine, 2 of the 10 pre-menopausal women were known to be on contraception (1 oral, 1 by injection), as were 2 of the older women who were now post-menopausal (1 oral, 1 by injection). Menopausal knowledge/experiences: 23 women (9 DS, 14 non-DS) had not heard of the term 'menopause', 'the change of life' or 'the change'; 17 women (5 DS, 12 non-DS) said they had. Twelve (6 DS and 6 non-DS) said they had been told about the menopause either by a doctor or nurse (5), a member of care staff (3) or a family member (4) but few could recall details. Five non-DS women understood the menopause in relation to getting older and mentioned that periods stopped with age, with 1 adding you can no longer have children once it had happened.	

Review question 1 only – critical appraisal tables – the views and experiences of people using services, their families and carers

1. Bowey L, McGlaughlin A (2005) Adults with a learning disability living with elderly carers talk about planning for the future: aspirations and concerns. The British Journal of Social Work 35: 1377–92

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Study aim: To identify current and future housing and support needs of adults with a learning disability living with carers aged over 70. This paper presents just the views of adults with a learning disability (views of carers presented in a separate paper). **Methodology:** Qualitative study. **Is a qualitative approach appropriate?**	**How well was the data collection carried out?** Not sure/inadequately reported Information provided about the development of the questionnaire and the steps taken to make it accessible to this population. However, there is little information given on the methods of data collection. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. All known adults with a learning disability living in the locality with carers over the age	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Partly. Participants and their carers were reassured about anonymity and confidentiality and that the research would not result in any changes to their current living arrangements. **Were service users involved in the study?** Yes. Service users were involved as participants but not as co-researchers.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Appropriate. Researchers were keen to give a voice to adults with learning disabilities as they felt their views were distinctly lacking from the research literature. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible.	of 70 were identified. Total 108 families were originally contacted, 10 were under the age of 70, 36 other families refused to take part because of lack of time or interest. Therefore the research sample potentially comprised 62 adults with a learning disability. However, 18 lacked the required the communication skills necessary to take part in an interview. In 3 cases a professional intervened to withdraw the person with a learning disability from the study owing to anxiety around the issue. A total of 41 adults with learning disabilities participated in the research. It is a notable consideration that all participants were white. Although efforts were made to include those who had not been active users of services for a few years, those who were completely unknown to services were not included in the study. The lack of diversity results from both the (relatively younger) age and (lack of)	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	engagement with services of black and minority ethnic families. **Were the methods reliable?** Not sure. Methods for analysis are not reported in any detail. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.		

2. Coyle CE, Kramer J, Mutchler JE (2014) Aging together: sibling carers of adults with intellectual and developmental disabilities. Journal of Policy and Practice in Intellectual Disabilities 11: 302–12

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'The purpose of this study was to explore the transition of care to sibling	**How well was the data collection carried out?** Not sure/inadequately reported. We are not given much detail about	**Does the study's research question match the review question?** Partly. It had a degree of relevance, but the focus strays from the identification,	**Overall assessment of internal validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
carers of people with disabilities after their parents are no longer providing primary support to the individual with a disability' (p304). **Methodology:** Qualitative study. Semi-structured interviews. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Qualitative interviews are appropriate to elicit views from carers. A follow-up interview would have been beneficial. Details of the	the interviews themselves. There is no detail on their duration. We are given some examples of questions asked but no more detail of probes or prompts. **Is the context clearly described?** Clear. We learn that the carers were found via a support project database. **Was the sampling carried out in an appropriate way?** Appropriate. Purposive sampling was used. **Were the methods reliable?** Somewhat reliable. Interviews were recorded and transcribed. Coding was done independently, it was not cross-referenced or double screened. **Are the data 'rich'?** Mixed. Many of the results are described within themes. There is rich data, but more would be helpful. **Is the analysis reliable?** Reliable. Coding used Vivo software. Initial codes were developed and	assessment and review of care needs. It also looks at the circumstances of the carers and their capabilities. **Has the study dealt appropriately with any ethical concerns?** No. No mention of ethics. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Older people with a learning difficulty. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. A variety of settings, community and group homes. **Does the study relate to at least 1 of the activities covered by the guideline?**	**Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
discussion guides is sparse and we are not told the duration of interviews.	secondary coding was used to isolate secondary themes and detail. **Are the findings convincing?** Convincing. Original data is used, but the quotes are not referenced. Overall the detail and themes are convincing. **Are the conclusions adequate?** Adequate. The study adequately discusses its limitations, implications for policy and practice and the implication of the study on research.	Yes. Identification, assessment and review of care and support needs, specifically related to ageing. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Some of the views are about the personal circumstances of the carer, so less relevant. **Does the study have a UK perspective?** No. USA.	

3. Dillenburger K, McKerr L (2011) 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. British Journal of Learning Disabilities 39: 29–38

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To explore the issues related to caring and future planning for older caregivers of adult	**How well was the data collection carried out?** Appropriately. In cases where recording was not acceptable to the interviewee (n=9) notes were taken	**Does the study's research question match the review question?** Partly. 'Future planning' only represents one part of the study question. Study also looks at views and experience of	**Overall assessment of internal validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
sons/daughters with intellectual and/or developmental disabilities in Northern Ireland. **Methodology:** Qualitative study. **Is a qualitative approach appropriate?** Appropriate. Study aimed to allow older caregivers to tell their own story and be given a voice to do so. Qualitative approach therefore appropriate. **Is the study clear in what it seeks to do?** Mixed. **How defensible/rigorous is the research design/methodology?** Defensible.	during the interview and full account was written up immediately afterwards. Interviews lasted 45–60 minutes and were in a location chosen by the participant. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Not sure. Convenience sampling. The study first reports that caregivers were recruited through community self-help groups, but then later states: 'a convenience sample was recruited from charities, and support groups [...] and additional personal contacts'. **Were the methods reliable?** Reliable. Caregivers were also given the GHQ-12 interview to complete after the interview to give reliable quantitative data on psychological health. **Are the data 'rich'?** Mixed.	long-term care and service arrangements, health and psychological needs and 'future planning'. **Has the study dealt appropriately with any ethical concerns?** Yes. Queen's University of Belfast School Research Ethics Committee granted ethical approval for this study. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the**	**Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Is the analysis reliable? Reliable. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Adequate.	**guideline?** Partly. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. **Does the study have a UK perspective?** Yes. Northern Ireland.	

4. Hole RD, Stainton T, Wilson L (2013) Ageing adults with intellectual disabilities: self-advocates' and family members' perspectives about the future. Australian Social Work 66: 571–89

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The authors aimed to gain a better understanding of the needs, hopes, and desires for the future of ageing adults with intellectual disabilities and family members of adults	**How well was the data collection carried out?** Appropriately. Data collection methods are clearly described and they are appropriate for eliciting people's concerns about the future. A mixture of group and individual interviews were conducted and this is	**Does the study's research question match the review question?** Partly. The study's research question was specifically about future planning rather than the identification, assessment and review of needs. **Has the study dealt appropriately with any ethical concerns?**	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
with intellectual disabilities. **Methodology** Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. It seeks to understand people's concerns about the future in terms of their own care and support or the care and support of family members (namely, sons or daughters). **How defensible/rigorous is the research design/methodology?** Defensible. The design of the study is appropriate to the research question and a clear rationale is given for the sampling, data	clearly justified. Data collection, with the use of interview guides and record keeping were systematic (interviews were tape recorded and transcribed verbatim). **Is the context clearly described?** Unclear. Apart from the recruitment criteria, the characteristics of the participants and settings are not clearly defined. No observations were made, just single interviews (either individually or in groups). **Was the sampling carried out in an appropriate way?** Somewhat appropriate. 'Community organisations supporting self-advocates and family members were asked to post and distribute project information. Individuals were invited to contact the research team either directly or through a representative to request additional information or arrange participation' (p573). **Were the methods reliable?** Reliable. Data collection methods	Yes. Ethics approval was granted by the University of British Columbia Behavioural Research Ethics Board. **Were service users involved in the study?** Yes. They are involved as respondents and there is also mention of a 'self-advocate consultant' contributing to the development of the interview schedule. It is unclear whether this is a person with a learning disability. **Is there a clear focus on the guideline topic?** Partly. Future planning is not explicitly stated in section 1.3 of the scope although the issue is referenced in the 'context'. The Guideline Committee felt that future planning is an important aspect of the identification and assessment of needs. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The self-advocates are all 50+ years so not necessarily 'older' but relevant to the guideline population in	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
collection and data analysis techniques used.	were confined to interviews but since the aim was to gather people's views and concerns about the future, the lack of opportunity this provides for triangulation seems acceptable. **Are the data 'rich'?** Mixed. The findings are well supported with direct quotes from the interview data but the contexts of the respondents are not described in any detail. **Is the analysis reliable?** Reliable. Analysis certainly seems systematic and reliable. Thematic analysis was conducted and this involved the research team meeting to evaluate the coding framework and to synthesise the categories and concepts into themes. In addition, 'The team held analytic meetings to discuss and monitor coding consistency and thus to address the analytic validity of identified themes' (Morse and Richards 2002). In addition, the research team met to ensure that the findings were	that they are considering issues relating to ageing. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Partly. In the sense that future planning is an aspect of the identification and assessment of needs. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. Study done in British Columbia, Canada.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	internally consistent and supported by the data (p575). **Are the findings convincing?** Convincing. Data are referenced and findings appear internally consistent. **Are the conclusions adequate?** Adequate. The findings seem relevant to the aims of the study and there are clear links between the data and conclusions. The conclusions are plausible and coherent although it is not clear whether alternative explanations for the findings have been explored. The authors do discuss the study limitations, namely the small sample.		

5. Innes A, McCabe L, Watchman K (2012) Caring for older people with an intellectual disability: a systematic review. Maturitas 72: 286–95

Internal validity – inclusion criteria and search	**Internal validity – assessment and analysis**	**External validity**	**Overall validity rating**
Study aim: To critically evaluate available research literature on ageing among people with an intellectual disability. **Methodology:** Systematic review. **Appropriate and clearly focused question?** No. The review isn't very focused, aiming to review evidence about 'ageing among people with an intellectual disability' rather than a specific aspect of that. It's clearly relevant to the overall guideline topic and provides some data relevant to a range of our review questions but nothing in-depth about any one of them. The population is clearly	**Study quality assessed and reported?** No. Apart from stating that 'the review reveals a lack of robust research evidence concerning the lives of older people with ID' there is no suggestion that critical appraisal of included studies was conducted, no mention of CA tools and no quality ratings for the included studies. **Adequate description of methodology?** • No. The search teams, databases, dates and population were clearly described but there was no reference to analysis or synthesis, which is a significant weakness. **Do conclusions match findings?** Yes	**Does the study's research question match the review question?** Partly. It's about ageing among people with a LD rather than specifically about the identification and assessment of needs or future planning (although some findings do touch on these issues). **Has the study dealt appropriately with any ethical concerns?** Not reported. **Were service users involved in the design of the study?** No. **Is there a clear focus on the guideline topic?** Yes. But not specifically questions 1 and 2. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the**	**Overall assessment of internal validity:** - **Overall assessment of external validity:** +

Internal validity – inclusion criteria and search	Internal validity – assessment and analysis	External validity	Overall validity rating
defined but interventions, settings, comparators and outcomes are not. Inclusion and exclusion criteria are clear although some exceptions (around age) were clearly made in the screening process. **Inclusion of relevant individual studies?** Somewhat relevant. It's notable that papers were excluded where they related to: diabetes, epilepsy, cancer, depression, oral health, cognitive behavioural therapy and condition specific papers such as Prader Willi syndrome, autism and Down's syndrome. The rationale for this exclusion was to present an overview of aging generally with an		**guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Was the study conducted in the UK?** Yes but this is a review of international research.	

Internal validity – inclusion criteria and search	Internal validity – assessment and analysis	External validity	Overall validity rating
intellectual disability. Unfortunately this is likely to have resulted in issues around the identification and assessment of care and support needs – in particular, diagnostic overshadowing – not being covered by the review. **Rigorous literature search?** Partly rigorous. The literature search seems fairly rigorous for identifying the studies that would answer the review question. However, the exclusion of condition specific papers is likely to have lost a lot of relevant data. The dates for the search were given (initially 1980–2011 but then revised to 1990–2011 due			

Internal validity – inclusion criteria and search	Internal validity – assessment and analysis	External validity	Overall validity rating
to the availability of online resources). The review did not include hand-searching of key journals and reference lists.			

6. Towers C (2013) Thinking ahead: improving support for people with learning disabilities and their families to plan for the future. London: Foundation for People with Learning Disabilities

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To explore how support can be improved for people with learning disabilities and their families to plan for the future.	**How well was the data collection carried out?** Not sure/inadequately reported. **Is the context clearly described?** Unclear. Little info given on	**Does the study's research question match the review question?** Partly. Looks at level of worry about the future and how much help they have had in planning for the future.	**Overall assessment of internal validity:** - **Overall assessment of external validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Methodology: Qualitative study. Workshops were held with people with learning disabilities. Workshops were also held for carers of people with learning disabilities. A survey of 300 parents of a son or daughter with learning disabilities aged over 18 years was conducted to gather quantitative and qualitative information on what they would find most helpful. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Mixed. **How defensible/rigorous is the research design/methodology?**	recruitment processes or where or how focus groups took place. **Was the sampling carried out in an appropriate way?** Not sure. **Were the methods reliable?** Not sure. **Are the data 'rich'?** Mixed. No context given with data, however perspectives of both people with learning disabilities and their families are provided. **Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Somewhat convincing. Findings are presented fairly clearly and are internally coherent. Some original extracts are included but little context given. **Are the conclusions adequate?** Inadequate.	**Has the study dealt appropriately with any ethical concerns?** No. Not reported. **Were service users involved in the study?** Yes. They were involved as participants in the workshop but not as co-researchers. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. No age given for the participants of the workshop for people with learning disabilities. Families interviewed had children aged 18 or over, but they were considering planning for the future when they will be older. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Not sure. Not enough info given to make judgement.		**Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. **Does the study have a UK perspective?** • Yes.	

7. Willis DS, Wishart JG, Muir WJ (2011) Menopausal experiences of women with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 24: 74–85

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To identify levels of knowledge of the menopause and of its health and reproductive implications among	**How well was the data collection carried out?** Appropriately. **Is the context clearly described?** Clear: 3 women requested that their carers were present for the interview;	**Does the study's research question match the review question?** Partly. **Has the study dealt appropriately with any ethical concerns?** Yes. Study approved by the Multi Centre	**Overall assessment of internal validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
women with intellectual disabilities. **Methodology:** Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible.	the other women were interviewed in private. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Through local gatekeepers access was gained to 77 women but the total pool size is not known because different gatekeepers operated at different levels of confidentiality. Exclusion criteria: women with profound intellectual disabilities, hysterectomies, who had never menstruated or had a current diagnosis of dementia. **Were the methods reliable?** Somewhat reliable. Data collected by just 1 method, but methods and findings discussed alongside other studies. **Are the data 'rich'?** Mixed. **Is the analysis reliable?** Somewhat reliable. Multi-staged narrative analysis. Unclear how many people were	Research Ethics Committee for Scotland who advised that all participants to be approached through local gatekeepers. Consent was gained from the women and their immediate carers. **Were service users involved in the study?** Yes. Were involved as participants but not as co-researchers **Is there a clear focus on the guideline topic?** Partly. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	**Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	involved in the analysis. The authors became familiar with each transcript before formulating categories around basic themes, findings and issues. This approach allowed the researchers to become familiar with the material in an area which has previously been under-researched. **Are the findings convincing?** Somewhat convincing. Findings were mostly coherent, but there was a lack of clarity around certain areas, especially that of contraception. The study reported that a woman with intellectual disabilities said she didn't think her periods would stop 'because of the pill' (p24). Later on, it says 'none of the women in this study themselves reported that they were currently or had previously taken contraceptive medication' (p24). **Are the conclusions adequate?** Somewhat adequate.	**(For views questions) Are the views and experiences reported relevant to the guideline?** • Yes. **Does the study have a UK perspective?** Yes .	

Review question 2 only – findings tables – views and experiences

1. Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1) 42–8

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To explore knowledge and understanding of the menopause in the carers of women with intellectual disabilities – to gather their experiences of supporting the women under their care through the menopause – to identify what additional help would assist carers	**Participants:** Professionals/practitioners. Experience of working in intellectual disability services ranged from less than a month to 45 years (mean 11.9 years). Mean length of experience of working with the named woman was 7.1 years (range from less than a moth to 45 years). **Sample size:** Total 69 formal carers (i.e. paid staff) of 45 pre-, peri-, and postmenopausal women with intellectual disabilities (11 from day care settings and 58 from residential	**Narrative findings – qualitative and views and experiences data**	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

in providing better support to women with intellectual disabilities through this transitional period. **Methodology:** Qualitative study. One-to-one interviews. **Country:** UK. **Source of funding:** Funded by the Baily Thomas Charitable Trust.	settings). Women they were providing care for had to be aged between 35 and 65 years and have a diagnosis of mild to severe intellectual disability.	**Carer report: general health** When carers were asked about screening for specific aspects of female health responses were inconclusive. It was hard to determine whether women had received breast and cervical cancer screening because documentation was poor and carer knowledge was very varied – which was partly attributable to the fact that some of the carers worked in day care services. Some carers felt that breast and cervical screening should definitely be within the remit of the residential home, but the majority of carers felt that the procedures could be traumatising for the women in their care, with some voicing doubt over whether or not the women they cared for would cooperate. Data showed that 15 of the women with intellectual disabilities were eligible for breast cancer screening (were aged >50), but that only 4 of the women had received it. Only 15 carers reported that the woman/women they supported had been screened for cervical cancer. An assumption of sexual inactivity by the GP or a refusal of permission by the woman's guardian were given as reasons for non-participation. **Carer report: menopausal experiences universality** Individual significance of the menopause as a life event and the fact that all women who menstruate, irrespective of disability, will experience menopause as part of the natural ageing process. Carers spoke about what words they would use and how they would support women in	

		adapting to these changes by drawing on their own or friends' experiences of this stage of life to help them understand that what is happening to them is also happening to other people. One carer responded: 'I think [menopause] is not a term I would use with the women ... We would try and simplify things you know and try and explain the best way we could really, you know, how your periods are stopping now and this is quite natural and it happens to everybody ...' (p45). **Entanglement** Carers described problems they had distinguishing behaviours such as mood swings (as a menopausal symptom) from other challenging behavioural characteristics of the women with intellectual disabilities under their care. Just over half of the carers said that they would have problems identifying if the woman with intellectual disabilities was experiencing problems relating to the menopause. A minority said that they if they knew the woman well they'd be able to tell that if they had menopausal symptoms such as hot flushes or irregular periods. **Resilience** When asked how they thought the women they supported would cope with the menopause, responses fell into 2 contrasting descriptive categories – those who	

		would be accepting (the most frequent) and those who would have difficulties coping. One carer said: ‘I think it must be quite difficult for them because they are not really understanding what is happening and it can be quite scary for them, you know, quite frightening not understanding ...’ (p46). Carers had conflicting views on whether the women should know about the implications that the menopause had for their fertility. Almost all carers felt that if the women would at least be able to broadly understand what they were being told, they should be informed about the menopause. However, some carers raised concerns about unnecessarily worrying the women, and questioned how much the women would actually take in if details of menopause were explained to them in full. **‘Ignorance is bliss’** Carers believed that the women’s knowledge of menstruation and menopause was generally very poor, with just over half responding that the women they supported would only have a very limited understanding of the reproductive significance of either. About 2/3 of carers reported that they would not understand that the menopause meant that they could no longer have children. ‘Although the majority of carers reported that the women had told them that they never wanted children, some had never actually broached this subject, one saying specifically that she would never discuss it	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		unless it was brought up by the woman herself'(p46). Other carers spoke of women they cared for who had expressed a wish to start a family and get married (despite being in their 60s) or adopt a child. Other carers also indicated that some of the women would have been aware that they would not be allowed to have children. One carer spoke of the issues surrounding public acceptance of women with intellectual disabilities having relationships and children. '... folk are just getting used to the fact that some of these people have sexual relationships ... I don't think women with learning difficulties have enough choice [in terms] of the support they have to bring up a child ...' (p46). **Carer reports: responsibility and training needs** Carers reported that the person who explained the menopause to women with intellectual disabilities would be someone they knew and trusted. A few thought it was the responsibility of the GP or a nurse, but the majority identified the person's key worker as the best person. Carers felt that the sex of the person did not matter for discussing general health problems with the women, but reported overwhelmingly that female carers would be preferred if talking about 'women's problems'. All carers (including the male ones) said they would feel comfortable talking to the women under their care about	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		the menopause and that they would answer any questions to the best of their ability. Many also drew attention to the need for better training on how to do this should it become their responsibility. Information or training that was identified by the carers as useful included: - symptom identification - advice on explaining physiological changes - information on alternatives to hormone replacement therapy. Type of resources suggested as useful for women with intellectual disabilities were: - talking books - videos - booklets. Several carers recognised that few women with intellectual disabilities had the opportunities to talk to others about the menopause and specifically suggested that a local women's group or menopause clinic would be helpful as it would allow the women to talk to other women going through the same experience.	

Review question 2 only – critical appraisal tables – views and experiences

1. Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1): 42–8

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To provide findings to complement those from a parallel study which explored the experiences and knowledge of 45 women with intellectual disabilities regarding the menopause. Specific aims of this study are: to explore knowledge and understanding of the menopause in these women's carers; to gather their experiences of supporting the women under their care through the menopause; to identify what additional help would assist carers in providing better support to women	**How well was the data collection carried out?** Appropriately. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Carers were sourced through home/day centre managers, and were recruited from a range of settings (both residential and day care) but there is no more information given on sampling process. **Were the methods reliable?** Somewhat reliable. **Are the data 'rich'?** • Mixed.	**Does the study's research question match the review question?** Partly. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethics approval gained from the NHS's Multi-Centre Research Ethics Committee (MREC), the NHS Lothian's Local Research Ethics Committee and Research Development Department and regional social work departments/local authorities. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the**	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
with intellectual disabilities through this transitional period. **Methodology:** Qualitative study. One-to-one interviews. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible.	**Is the analysis reliable?** • Somewhat reliable – 10% of transcripts were analysed by a fellow researcher who was not part of the research team and was very experienced in working with people with intellectual disabilities. A high level of consensus was reached in relation to identified themes. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Adequate.	**guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. **Does the study have a UK perspective?** Yes.	

Review question 3. Information, advice and training to older people with learning disabilities

a) What is the effectiveness and cost-effectiveness of providing information, advice and training to older people with learning disabilities?

b) What are the views and experiences of older people with learning disabilities about information, advice and training?

c) What are the views and experiences of health, social care and other practitioners about information, advice and training for older people with learning disabilities?

Review question 3 – findings tables – effectiveness

1. Van Puyenbroeck J, Maes B (2009) The effect of reminiscence group work on life satisfaction, self-esteem and mood of ageing people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 22: 23–33

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To explore 'what is the effect of a narrative reminiscence group programme on subjective well-being of ageing people with	**Participants:** Service users and their families, partners and carers. **Sample size:** 41 older people with learning disabilities completed the	**Effect sizes** The study was not able to confirm the presence of effects of reminiscence group work, as p23 stated: 'The quasi-experimental pre-test–post-test design did not detect any changes in life satisfaction and perceived self-competence.'	**Overall assessment of internal validity (qualitative):** + **Overall**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
intellectual disabilities?' (p24). **Methodology:** Quasi-experimental pre-test post-test design. **Country:** Belgium. **Source of funding:** Not stated.	study. They were in 6 groups on 6 separate sites. **Intervention:** A 'narrative reminiscence' group programme. **Describe intervention:** 'The reminiscence group work sessions (experimental sessions) were based on a method for group reminiscence among people with dementia, as described by Bruce et al. (1999). Important characteristics of that method are: weekly group work sessions, reminiscence themes (set and prepared in advance) and abundant use of visual triggers that are kept in a reminiscence suitcase. This programme was adapted to the needs of people with	For mood, a quasi-experimental ABA-design did not yield an experimental treatment effect. However a significant increase in scores was observed over time. Personality characteristics 'extraversion' and 'emotional stability', but not 'memory specificity' were found to be significant covariates for the mood scores. Future research might want to look at the intervention's effectiveness with a depressed older population with learning disabilities, rather than a mental health group, as this may be where it is more useful. **Narrative findings** 'Interviews conducted before and after the programme resulted in positive appraisals of the programme as well as a worthwhile and meaningful activity for ageing people with intellectual disability' (p23).	**assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	intellectual disabilities' (p27). 'The main goal of the sessions was to elicit specific and 'positive' remembrances about the past, making use of the trigger objects in the reminiscence suitcase' (p28). **Delivered by:** The author/researcher facilitated the sessions, supported by a care worker at each care facility. **Duration, frequency, intensity, etc.:** There were 12 weekly sessions – the first 3 were control sessions, then 6 intervention sessions, followed by 3 further control sessions. **Content/session titles:**		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	'The total programme consisted of 12 sessions: three "current topics" sessions (control phase), namely "Who am I?/Family" (with a thematic stress on the present situation), "My house/My room" and "Television", 6 group reminiscence sessions on different reminiscence topics (experimental phase), namely "Household", "Games and toys", "School days", "Food", "Church–Religion" and "Travels–Holidays", followed by – again – 3 "current topics" sessions (control phase), namely "Music–parties", "Video-mail" and "Evaluation"' (p27). **Location/place of delivery:**		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	At 6 care facilities across Belgium. **Comparison intervention:** 'Dummy' sessions with reminiscence themes that didn't actually involve personal reminiscence tasks. **Outcomes measured** **Service user-related outcomes** Subjective wellbeing was conceived as composite of 3 attributes, measured using the following tools. 1) Life satisfaction – the short version of the Intellectual Disability Quality of Life (IDQOL) Scale (Hoekman et al. 2001). 2) Self-perceived		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	competence – the Pictorial Scale of Perceived Competence and Social Acceptance of People with Intellectual Disabilities (PSPC) (Goverts et al. 2000). This is an adapted Dutch version of the scale that Harter and Pike (1984) developed to assess children's perceptions of their own abilities and social acceptance. 3) Mood/interest – the Mood Interest and Pleasure Questionnaire (MIPQ) (Ross and Oliver 1999). Two intermediating variables were also measured: 1) Personality – the Five Factor Personality Inventory (FFPI) (Hendriks et al.		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	1999) is an instrument to assess a person's position on the dimensions extraversion, agreeableness, conscientiousness, emotional stability and autonomy (the so called 'big 5' factors of personality). 2) Memory specificity – the present authors used VITESSA (Video Time/Event Sampling Software) (Van Puyenbroeck et al. 2005) to code the memories of the participants for their level of specificity (SPEC). **Family or caregiver related outcomes:** Structured interviews were conducted with the support workers before and after the programme. Two		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	questions addressed the especially important issue of goal attainment. **Follow-up:** After every session. **Costs:** Not reported.		

Review question 3 – findings tables – the views and experiences of people using services, their families and carers

1. Cardol M, Rijken M, van Schrojenstein Lantman-de Valk H (2012) People with mild to moderate intellectual disability talking about their diabetes and how they manage. Journal of Intellectual Disability Research 56: 351–60

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The study aimed to answer the following 2 research questions: '(1) What perceptions	**Participants:** Service users and their families, partners and carers. People with mild to moderate intellectual disabilities and diabetes, taken from a national	**Narrative findings** Among the 7 themes found, 4 referred in some way to advice and training received (or lack thereof). **Theme 4 – unanswered questions** Unanswered questions were coupled with concerns and fearful thoughts, e.g. 'can I get rid of it' or 'will I live long'.	**Overall assessment of internal validity:** + **Overall**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
of diabetes do people with mild or moderate ID have? (2) What factors are related to the self-management of the disease?' (p352). **Methodology:** Qualitative study. Semi-structured interviews. **Country:** The Netherlands. **Source of funding:** Other. Part of a larger study by the Dutch diabetes association in which people with intellectual disabilities and	panel. **Sample size:** 17 interviews were conducted, at which point the authors reached data saturation and so conducted no further interviews. **Intervention:** No. **Follow-up:** None. **Costs** Not reported.	For consolation they often reported trying not to think about it. **Theme 5 – check-ups without asking questions** Participants attended medical appointments when they were told to, but very rarely asked questions about diabetes. For some reason, possibly related to fear or suspecting they might not be given answers in a comprehensible way, they felt unable to. Being accompanied by an adult or by trusted carers was appreciated because information could be relayed to them later on. **Theme 6 – intentions to self-manage are related to understanding, motivation and special occasions** It was highlighted that none of the participants had received written diabetes information in a way they could understand. They relied heavily on relatives for information. **Theme 7 – self-management is related to feelings of self-efficacy, support, health condition, mood and contextual factors.** As well as understanding, confidence was important for allowing the person to use their knowledge in order to self-manage. They required the ability to grow confident, and	**assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
diabetes, their relatives and professional staff were interviewed.		some settings such as community housing, did not always facilitate this well.	

2. Willis DS (2008) A decade on: what have we learnt about supporting women with intellectual disabilities through the menopause? Journal of Intellectual Disabilities 12: 9–23

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: This study aimed to 'explore the women's understanding and knowledge of the menopause and look at the information that was available to them' (p13). **Methodology:** Qualitative study. Semi-structured	**Participants:** Service users. Older women with intellectual disabilities. **Sample size:** 18 women. **Follow-up:** None. **Costs:** Not reported.	**Narrative findings** Feelings and experiences around menstruation and menopause were discussed, including signs and symptoms. Most relevant was the discussion on sources of information and education. Twelve of the 18 women had received no information or help about the menopause. Three reported having heard some information on the television, and 1 reported having read about it in a book – although the author believed this was being confused with the initial conversations that they had had prior to the research.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
interviews. **Country:** UK. **Source of funding:** Not reported.		When asked if they felt that more information would be useful they did not express a preference. The author believed this reflected being used to being told what was best to do, and a struggle to formulate and then ask for advice themselves. The author concluded that there is a lack of information on menopause made available in an appropriate format to older women with intellectual disabilities. The study also highlights stigma towards this group and reproduction generally.	

3. Young AF, Naji S, Kroll T (2012) Support for self-management of cardiovascular disease by people with learning disabilities. Family Practice 29: 467–75

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: This study 'set out to explore service users', carers' and health professionals' views and strategies for self-	**Participants:** Service users: 14 people with LD interviewed. Professionals/practitioners: 11 care staff (1 was a family carer) and 11 health professionals.	**Narrative findings** The study found 4 main themes on supporting and advising people with learning disabilities to self-manage cardiovascular disease (extracted from pp470–2). **Strategies for using knowledge and creating routines** The main health improvement messages such as healthy	**Overall assessment of internal validity:** ++ **Overall assessment of external**

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity rating**
management and the nature of support needed for optimal self-management of CVD by people with LD' (p467). **Methodology:** Qualitative study. In-depth semi-structured interviews based on vignettes with accompanying pictures. **Country:** UK. **Source of funding:** Voluntary/charity. Chest Heart and Stroke Scotland, (minor research award).	**Sample size:** 14 people with ID, 11 care staff and 11 health professionals. **Follow-up:** No follow-up. **Costs:** Not reported.	eating and regular exercise are already well known to carers, professionals and to people with ID themselves. Strategies were used that tap into this knowledge. One was to take an 'incremental approach' to encouraging exercise, food preparation etc. Another was to use 'socialisation' such as membership of clubs that involve an element of exercising or a walk to get to where their social life is. Another strategy was substituting healthy options – e.g. low fat equivalents of food they like, cycling rather than driving etc. Staff outlined how important it was that steps to improve health behaviour were coordinated across the board – e.g. avoiding where carers help with a healthy shop but then a sibling brings along a big bag of sweets. Understanding the prerequisites for self-management support – all participants said it was crucial to involve the person with ID, and they added that participation needed to be 'carefully pitched to be meaningful for each individual'. Perceived ownership of the strategies by the individual was considered important. So was supporting choice and assisting planning. Also it was important that encouragement was continuous and consistent across areas of their lives, and involved some reward planning.	**validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Primary and secondary supporters of self-management – it was generally agreed that the support of front-line carers was most essential. Health professionals were seen as more distant, and care staff felt a pre-existing good interpersonal relationship was key. People with ID had a broader view – that it didn't matter who was encouraging them, it could be everyone in some way. They felt that the 'directive authority' of doctors was important to them – they have the knowledge and authority and they valued this. **Self-management implementation** All participants said turning something from a plan into a reality was the hardest part, requiring considerable personal resources and discipline from all involved. Knowledge itself was not enough to ensure action, although lack of knowledge exacerbated the problem. Support on all fronts is needed.	

Review question 3 – findings tables – health, social care and other practitioners' views and experiences

1. Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1): 42–8

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To provide findings to complement those from a parallel study which explored the experiences and knowledge of 45 women with intellectual disabilities regarding the menopause. Specific aims of this study are to explore knowledge and understanding of the menopause in these women's carers – to gather their experiences of supporting the	**Participants:** Professionals/practitioners. Experience of working in intellectual disability services ranged from less than a month to 45 years (mean 11.9 years). Mean length of experience of working with the named woman was 7.1 years (range from less than a month to 45 years). **Sample size:** 69 formal carers (i.e. paid staff) of 45 pre-, peri-, and postmenopausal women with intellectual disabilities (11 from day care settings and 58 from residential settings). Women they were providing care for had to be aged between 35 and 65 years and have a	**Narrative findings** **Carer report: general health** When carers were asked about screening for specific aspects of female health, responses were inconclusive. It was hard to determine whether women had received breast and cervical cancer screening because documentation was poor and carer knowledge was very varied – which was partly attributable to the fact that some of the carers worked in day care services. Some carers felt that breast and cervical screening should definitely be within the remit of the residential home, but the majority of carers felt that the procedures could be traumatising for the women in their care, with some voicing doubt over whether or not the women they cared for would cooperate. Data showed that 15 of the women with intellectual disabilities were eligible for breast cancer screening (were aged >50), but that only 4 of the women had received it. Only 15 carers reported that the woman/women they supported had been screened for cervical cancer. An assumption of sexual inactivity by the GP or a refusal of permission by the woman's guardian were given as reasons for nonparticipation.	**Overall assessment of internal validity:** + **Overall assessment of external validity: +**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
women under their care through the menopause – to identify what additional help would assist carers in providing better support to women with intellectual disabilities through this transitional period. **Methodology:** Qualitative study. One-to-one interviews. **Country:** UK. **Source of funding:** Voluntary/charity.	diagnosis of mild to severe intellectual disabilities.	**Carer report: menopausal experiences** The following 4 overarching themes emerged: universality, entanglement, resilience and 'ignorance is bliss.' **Universality** Individual significance of the menopause as a life event and the fact that all women who menstruate, irrespective of disability, will experience menopause as part of the natural ageing process. Carers spoke about what words they would use and how they would support women in adapting to these changes by drawing on their own or friends' experiences of this stage of life to help them understand that what is happening to them is also happening to other people. One carer responded: 'I think [menopause] is not a term I would use with the women ... We would try and simplify things you know and try and explain the best way we could really, you know, how your periods are stopping now and this is quite natural and it happens to everybody ...' (p45). **Entanglement** The second most frequent theme was entanglement. Carers described problems they had distinguishing	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Funded by the Baily Thomas Charitable Trust.		behaviours such as mood swings (as a menopausal symptom) from other challenging behavioural characteristics of the women with intellectual disabilities under their care. Just over half of the carers said that they would have problems identifying if the woman with intellectual disabilities was experiencing problems relating to the menopause. A minority said that they if they knew the woman well they'd be able to tell that if they had menopausal symptoms such as hot flushes or irregular periods. **Resilience** When asked how they thought the women they supported would cope with the menopause, responses fell into 2 contrasting descriptive categories – those who would be accepting (the most frequent) and those who would have difficulties coping. One carer said: 'I think it must be quite difficult for them because they are not really understanding what is happening and it can be quite scary for them, you know, quite frightening not understanding ...' (p46). Carers had conflicting views on whether the women should know about the implications that the menopause had for their fertility.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Almost all carers felt that if the woman would at least be able to broadly understand what they were being told, they should be informed about the menopause. However, some carers raised concerns about unnecessarily worrying the women, and questioned how much the women would actually take in if details of menopause were explained to them in full. **'Ignorance is bliss'** Carers believed that the women's knowledge of menstruation and menopause was generally very poor, with just over half responding that the women they supported would only have a very limited understanding of the reproductive significance of either. About 2/3 of carers reported that they would not understand that the menopause meant that they could no longer have children. 'Although the majority of carers reported that the women had told them that they never wanted children, some had never actually broached this subject, one saying specifically that she would never discuss it unless it was brought up by the woman herself' (p46). Other carers spoke of women they cared for who had expressed a wish to start a family and get married (despite being in their 60s) or adopt a child. Other carers also	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		indicated that some of the women would have been aware that they would not be allowed to have children. One carer spoke of the issues surrounding public acceptance of women with intellectual disabilities having relationships and children. '... folk are just getting used to the fact that some of these people have sexual relationships ... I don't think women with learning difficulties have enough choice [in terms] of the support they have to bring up a child ...' (p46). **Carer reports: responsibility and training needs** Carers reported that the person who explained the menopause to women with intellectual disabilities would be someone they knew and trusted. A few thought it was the responsibility of the GP or a nurse, but the majority identified the person's key worker as the best person. Carers felt that the sex of the person did not matter for discussing general health problems with the women, but reported overwhelmingly that female carers would be preferred if talking about 'women's problems'. All carers (including the male ones) said they would feel comfortable talking to the women under their care about the menopause and that they would answer any questions to the best of their ability. Many also drew attention to the need for better training on how to do this should it become	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		their responsibility. Information or training that was identified by the carers as useful included: - symptom identification - advice on explaining physiological changes - information on alternates to hormone replacement therapy. Type of resources suggested as useful for women with intellectual disabilities were: - talking books - videos - booklets. Several carers recognised that few women with intellectual disabilities had the opportunities to talk to others about the menopause and specifically suggested that a local women's group or menopause clinic would be helpful as it would allow the women to talk to other women like themselves going through the same experience.	

Review question 3 – critical appraisal tables – effectiveness

1. Van Puyenbroeck J, Maes B (2009) The effect of reminiscence group work on life satisfaction, self-esteem and mood of ageing people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 22: 23–33

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To explore 'what is the effect of a narrative reminiscence group programme on subjective well-being of ageing people with intellectual disabilities?' (p24). **Methodology:** Other. Quasi-experimental pre-test post-test design. **Is this study a prospective evaluation?** Yes, prospective. **Description of theoretical approach?** Partly. Page 24 outlines the following: cognitive theories about the autobiographical memory suggest that detailed storytelling, e.g. the ability to generate specific memories, is related to more psychological well-being. Accordingly, previous	**Was the exposure to the intervention and comparison as intended?** Yes. No deviations were described. **Was contamination acceptably low?** Partly. All participants did both conditions in an ABA style, and crossover effects were considered and accounted for in the analysis and appraisal. **Were outcomes relevant?** Yes. The rational for each outcome measure was accounted for in the theoretical underpinning of the study.	**Does the study's research question match the review question?** Yes. Effects of a training intervention for older people with learning disabilities. **Has the study dealt appropriately with any ethical concerns?** Partly. Some consideration given to ethics within the design, e.g. making sure everyone receives the same intervention and travelling between on account of limited mobility of participants. Details on consent procedures or	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
experimental comparative research has found significant positive effects of reminiscence on self-esteem, life satisfaction, mood and depression. Ageing people with intellectual disabilities are at an increased risk of having mental health problems, especially depression/mood disorders. The effects of reminiscence work on subjective wellbeing of people with intellectual disabilities have not been evaluated so far. **How was selection bias minimised?** No comparison group. All participants took part in both conditions (dummy and reminiscence). **Were participants blinded?** Blind. Participants were not aware until afterwards which sessions were the	**Were outcome measures reliable?** Yes. Detailed metrics and background were given for all measures. **Were all outcome measurements complete?** Yes. Measures and their interactions reported in good detail. **Were all important outcomes assessed?** Yes, including a specific focus on acceptability and enjoyment of the programme. **Was follow-up time meaningful?** Partly. It captured the immediate impact well, but no long term effects - which may have been the most relevant as this was not currently a low-mood population (e.g. look for resilience). **Were the analytical methods appropriate?** Yes. Yes, efforts were taken to compare over time and look	approval board are not given though. **Were service users involved in the design of the study?** No. However the outcome measures used were ones that had been previously developed with people with learning disabilities. **Is there a clear focus on the guideline topic?** Yes. Pioneers the use of an established therapeutic training technique with older people with learning disabilities. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Ageing	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
true reminiscence sessions, and which were the dummy sessions. **Were providers blinded?** Not blind. The researcher who ran the sessions and assessed the outcomes was not blinded. **Were investigators, outcome assessors, researchers, etc., blinded?** Not blind. The researcher who ran the sessions and assessed the outcomes was not blinded. **Did participants represent the target group?** Partly. Participants were older people with mild to moderate learning disabilities. Within the participant set was a reasonable mix of age, gender and functioning. However the study's rationale suggested reminiscence was effective	for intervention effects as well as crossover effects, and the effects of several demographics – just the findings were not especially conclusive. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Partly. Participants did all conditions. **Was intention to treat (ITT) analysis conducted?** Not reported. **Was the study sufficiently powered to detect an intervention effect (if one exists)?** Not reported. No, and this design wouldn't be ideal for detecting one anyway – due to order effects and no control group. **Were the estimates of effect size given or calculable?** No. Probably would have needed a far larger	people with learning disabilities. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Six long-term care facilities in Belgium. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Partly. The aim is highly relevant. While not a great study of effectiveness, it gives some useful insights and lessons on feasibility of this kind of intervention for a field that's in its infancy.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
to alleviate mood disorders and this was not controlled for participation. **Were all participants accounted for at study conclusion?** Yes. Two dropouts at the very start from initial 43, and these are discussed.	sample as it was looking to make improvements in healthy people, and only looking short term. May not even be possible with this design type. **Was the precision of intervention effects given or calculable? Were they meaningful?** Not reported. **Do conclusions match findings?** Yes. The conclusions were modest in a way that was similar to the findings, they couldn't really show an effect and the only finding they could be confident in was that the intervention was acceptable to the participants.	**Was the study conducted in the UK?** No. Belgium.	

Review question 3 – critical appraisal tables – the views and experiences of people using services, their families and carers

1. Cardol M, Rijken M, van Schrojenstein Lantman-de Valk H (2012) People with mild to moderate intellectual disability talking about their diabetes and how they manage. Journal of Intellectual Disability Research 56: 351–60

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The study aimed to answer the following two research questions: '(1) What perceptions of diabetes do people with mild or moderate intellectual disability have? (2) What factors are related to the self-management of the disease?' (p352). **Methodology**: Semi-structured interview. **Is a qualitative approach appropriate?** Appropriate to the objectives. **Is the study clear in what it seeks to do?** Clear. Seek the perceptions of people with intellectual disabilities and diabetes, and ask them about factors that are related to self-management.	**How well was the data collection carried out?** Somewhat appropriately. The interview protocol was developed together with a person w intellectual disabilities, and involved the use of pictographs to help with comprehension. The researcher conducted all the interviews themselves, which may leave some room for bias. **Is the context clearly described?** Clear. Detailed outline of the settings and context is given on pp353/4. **Was the sampling carried out in an appropriate way?** Appropriate. The panel used for recruitment is outlined in detail at the bottom of p353. The panel is deliberately representative of the wider Dutch population, and from within this subset an opportunity sample of those with LD and diabetes was approached. Not all were	**Does the study's research question match the review question?** Partly. The study relates to management of diabetes, but advice and training is related to the ways that older people with learning disabilities cope. **Has the study dealt appropriately with any ethical concerns?** Yes. Privacy protection guidelines and Dutch ethics laws were followed. All participants were given information in written and oral form before being asked to consent to participation. **Were service users involved in the study?** Yes. The interview protocol was developed with people with	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
How defensible/rigorous is the research design/methodology? Defensible. The interviews were grounded in theory (Leventhal's Common Sense Model 1997) and had objectives on what they sought to understand which required a qualitative approach.	interviewed – at least 24 were identified but they stopped at 17 once they had met data saturation. However this is standard practice in a study that seeks qualitative data rather than details about numbers in a population. **Were the methods reliable?** Somewhat reliable. The interview protocols were developed from a strong theoretical foundation alongside people with intellectual disabilities themselves, and the interviews were conducted accessibly and consistently. The only issue is that the same one researcher conducted the interviews and analysis and write-up, which may lead to some undue influence at across these stages.	intellectual disabilities, and it evolved as data was collected based on the feedback of the participants. **Is there a clear focus on the guideline topic?** Partly. Relates to older people with learning disabilities, but the focus here is more on the absence of training rather than what works. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. People with learning disabilities and diabetes. Not all were aged over 40, but vast majority were and diabetes has a significant age component.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Are the data 'rich'? Rich. Themes are logical and backed up with a strong set of quotes. **Is the analysis reliable?** Reliable. The analysis was well described and theoretically grounded on p254, and other researchers were brought in to verify and develop the findings. **Are the findings convincing?** Convincing. Logical themes that are well supported by quotes. **Are the conclusions adequate?** Adequate. They match closely with the findings and bring them back into the broader context.	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Living at family home or in supported accommodation. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. They are relevant to the guideline, and the overlap between Q3 and Q7. **Does the study have a UK perspective?** No. Netherlands.	

2. Willis DS (2008) A decade on: what have we learnt about supporting women with intellectual disabilities through the menopause? Journal of Intellectual Disabilities 12: 9–23

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: This study aimed to 'explore the women's understanding and knowledge of the menopause and look at the information that was available to them' (p13). **Methodology:** Qualitative study. Semi-structured interview **Is a qualitative approach appropriate?** Appropriate. A qualitative approach allowed for detailed insight into knowledge, understanding and experiences of training as per the objectives. **Is the study clear in what it seeks to do?** Clear. The objectives make this clear. **How defensible/rigorous is the research design/methodology?**	**How well was the data collection carried out?** Appropriately. The data collection methods are clearly described and justified using semi-structured interviews aided with prompts, both developed with experts by experience. The process of recording and transcribing the data for analysis appears to be consistent and appropriate. **Is the context clearly described?** Clear. The context is given and the author justifies their decisions. Interviews were conducted in a setting of the participant's choice for their comfort, and without the presence of a carer to avoid particular bias – however this may in turn increase the risk of biasing influence from the researcher.	**Does the study's research question match the review question?** Partly. Among other topics it concerns the information and advice received by older women – but overall may more closely match question RQ5. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval and consent procedures are well detailed and justified. **Were service users involved in the study?** Yes. As well as being subjects, people with learning disabilities were used to pilot the questions, aids and prompts used.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Defensible. Is convincingly described and justified by the author on p13, and seems appropriate to the study objectives.	**Was the sampling carried out in an appropriate way?** Not sure. The participants were identified through a gatekeeper, who was a consultant psychiatrist in intellectual disability. The relationship between this gatekeeper, the participants, and the researcher is not clearly described – but there is a chance that influence due to the power of this relationship may have had some effect. This is briefly mentioned but not further discussed at the end of the paper. **Were the methods reliable?** Somewhat reliable. The interview asks about what it intended to ask about. However it does not verify this through seeking other sources of insight such as the views of carers or health staff – with the exception of where a search is undertaken for electronic resources on menopause.	**Is there a clear focus on the guideline topic?** Partly. It concerns the lessons learned about helping older people with learning disabilities, but only partly focuses RQ3's specific topic of advice and training. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. They were visited in a setting of their choosing. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Are the data 'rich'? Poor. The main points of the data are described but with little depth or detail, and with few direct quotes. Diversity among perspectives is quite crudely described, using approximations of how many participants answered in a particular direction compared to another. There was some contrast between groups, but not much. **Is the analysis reliable?** Unreliable. The author is transparent about their methods but they did no cross-checking with second researchers. The analysis was subject to their own interpretations and biases. **Are the findings convincing?** Convincing. The findings address the objectives in a coherently framed way, with an acceptable (if not overly rich)	**Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	level of depth, diversity and direct quotes. **Are the conclusions adequate?** Adequate. The conclusions are sufficiently grounded in the findings, and other previous research is utilised to try and explain them. There is consideration to implications, and also some to alternative explanations and some of the limitations of the research.		

3. Young AF, Naji S, Kroll T (2012) Support for self-management of cardiovascular disease by people with learning disabilities. Family Practice 29: 467–75

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: This study 'set out to explore service users', carers' and health professionals' views and strategies for self-management and the nature of support needed for	**How well was the data collection carried out?** Appropriately. Interview guideline outlined, and interviews transcribed and coded by the researcher, and a	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Study	**Overall assessment of internal validity:** + + **Overall assessment of**

optimal self-management of CVD by people with LD' (p467). **Methodology:** Qualitative study. In-depth semi-structured interviews based on vignettes with accompanying pictures. **Is a qualitative approach appropriate?** Appropriate. Seeking to understand the experiences and preferences of older people and their carers. **Is the study clear in what it seeks to do?** Clear in its aim to explore service users', carers' and health professionals' views and strategies for self-management. Methodology well-honed to find detailed qualitative answers to this. **How defensible/rigorous is the research design/methodology?** Defensible. The sample criteria are refined to meet the question. The	reasonable proportion checked by an external researcher. **Is the context clearly described?** Not sure. Place and context of recruitment is very clear, however authors don't explain where the interviews themselves took place. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Recruited through local GPs over a 10-month period, but as numbers weren't high they also switched to recruiting in local learning disability services. Not entirely consistent method, but a practical solution to low sample numbers. **Were the methods reliable?** Reliable. Sought to combine insights from all the major groups involved, bring these together, and draw	was board approval, with a rigorous informed consent process outlined including a supporter. **Were service users involved in the study?** Yes. Service users were the participants, and their opinions were consulted open-endedly. **Is there a clear focus on the guideline topic?** Yes. Older people with learning disabilities, and experience on how to advise and support them. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Older people with learning disabilities. **Is the study setting the same as at least 1 of the settings**	**external validity:** ++

sampling is by convenience, it's not clear what the time or resource limitations are, but it is likely this was all they could cover. It lays a modest preliminary groundwork for bigger, larger scale studies in future.	conclusions that accounted for other related research. **Are the data 'rich'?** Rich. A range of quotes to backup and depth to their themes. **Is the analysis reliable?** Reliable. Double coding and comparison by an external researcher with the work of the original researcher. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate It adds reliable depth and knowledge to the field, and gives practical advice, with reference to previous research.	**covered by the guideline?** Yes. Older people in private homes or in supported accommodation. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. Views and experiences of service users are obtained. Participants were also asked to comment and contribute to the questions as they participated. **Does the study have a UK perspective?** Yes.	

Review question 3 – critical appraisal tables – health, social care and other practitioners' views and experiences

1. Willis DS, Wishart JG, Muir WJ (2010) Carer knowledge and experiences with menopause in women with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7(1): 42–8

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To provide findings to complement those from a parallel study which explored the experiences and knowledge of 45 women with intellectual disabilities regarding the menopause. Specific aims of this study are: to explore knowledge and understanding of the menopause in these women's carers – to gather their experiences of supporting the women under their care through the menopause – to identify what additional help would assist carers in providing better support to women	**How well was the data collection carried out?** Appropriately. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Carers were sourced through home/day centre managers, and were recruited from a range of settings (both residential and day care) but there is no more information given on sampling process.	**Does the study's research question match the review question?** Partly. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethics approval gained from the NHS's Multi-Centre Research Ethics Committee (MREC), the NHS Lothian's Local Research Ethics Committee and Research Development Department and regional social work departments/local authorities.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
with intellectual disabilities through this transitional period. **Methodology:** One-to-one interviews. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible.	**Were the methods reliable?** Somewhat reliable. **Are the data 'rich'?** Mixed. **Is the analysis reliable?** Somewhat reliable – 10% of transcripts were analysed by a fellow researcher who was not part of the research team and was very experienced in working with people with intellectual disabilities. A high level of consensus was reached in relation to identified themes. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Adequate.	**Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
		Are the views and experiences reported relevant to the guideline? Partly. **Does the study have a UK perspective?** Yes.	

Review question 4: Information, advice, training and support to families, carers and advocates of older people with learning disabilities

a. What is the effectiveness and cost effectiveness of providing information, advice, training and support to families, carers and advocates of older people with learning disabilities?

b. What are the views and experiences of carers about information, advice, training and support provided to families, carers and advocates?

c. What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates?

Review question 4 – Findings tables – the views and experiences of people using services, their families and carers

1. Furniss KA, Loverseed A (2012) The views of people who care for adults with Down's syndrome and dementia: a service evaluation. British Journal of Learning Disabilities 40: 318–27

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'The article reports on a specialist service for people with Down's syndrome and dementia. The service has offered dementia screening	**Participants:** Service users and their families, partners and carers. Professionals/practitioners.	**Narrative findings:** The study identifies three main themes: Knowledge and information, coping and support, and concerns about the future. **Knowledge and Information** Paid Staff: described the knowledge they had	**Overall assessment of internal validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
and assessment to people with Down's syndrome for over 10 years and has also developed to offer support and training for carers. Semi-structured interviews were conducted with family carers, relatives and staff about the impact on them of caring for someone with Down's syndrome and how the dementia service supports them in this role' (p318). **Methodology:** Qualitative interviews. **Country:** UK. **Source of funding:** Not reported.	**Sample size:** Total 13 interviews. **Intervention:** The study reports on a service designed to support and train the carers of people with Down's syndrome and offer dementia screening and assessment. **Delivered by:** Staff members (also interviewed) **Delivered to:** Relatives and carers to people with down's syndrome. **Key components and objectives of intervention:** The study does not clearly describe the intervention. The paper is not clear about	developed from formal training around dementia in people with Down's syndrome. Knowledge was also derived from experience. Staff said that they would have liked more information about the specific issues related to dementia and Down's syndrome. 'I couldn't really be sure how much of that was connected to the dementia and how much was connected to her physical condition' (p323). Staff also said that felt that their knowledge needed to be check to find out if it was correct and relevant. Families and carers: said they only became aware of the link between Down's syndrome and dementia when the diagnosis was received. Families and carers said that they had little information about how the condition would progress and what services they could access and to know more about the relationship between Down's syndrome and dementia.	**Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	which services it is evaluating or the service that are offered. **Follow-up:** No follow-up. **Costs:** Not reported.	'We're completely blank and it would be nice to know something about it' (p323). Some carers felt that lack of information available led them to rely on informal sources of information, like word of mouth, which had sometimes led to confusion and misunderstanding. 'I only know that they can't communicate, but I don't know much about it' (p323). Families and carers said that they had begun to realise that there was information available, but it was not known about. 'You don't realise there is so much out there, you really, really don't. And unless you're told, you won't' (p323). All families and carers said that they did not have enough information about the duration of the illness or the process of the disease. 'He [consultant psychiatrist] wouldn't tell me how long it would be … because people vary, it could	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		be one or two years … I didn't quite know whether that meant he would be bad in two years or quite what' (p323). 'And I don't know what is going to happen in the end … it's the unknown, it's the dread of the unknown'. (p323). All said they lacked information about the impact of the conditions on a person with Down's syndrome. **Coping and support** The study looked at what contributed to the experience of caring. (In relation to this question, only findings related to support and information are recorded). Paid staff: reported a need for more support than usual around working with people with dementia. This support enables them to diagnose dementia and better understand the needs of the person. 'This time round, there is a clear diagnosis … it feels like there's a lot of support there' (p324).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Family carers: the study found mixed feelings among carers about support they have received from service and professionals. Negative past experience impacted on propensity to seek support. 'I don't want to go to social services or anybody unless I really have to because I'm now labelled because I've been through two complaints to get her the care she deserves …' (relative) (p324). Carers said that they have seen a lot of professionals and some said that they valued support that was based on relationships, built up over time. 'I've seen so many people! I'm getting confused who I've seen and who I haven't' (p324). Others didn't know when to ask for help. 'When do you start shouting for help?' (p324). Both staff and carers said that it was important	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		to include relatives and family carers in planning care and support for the person and keeping them informed. Some carers reported feeling excluded from care. Interviewees were asked which services they were currently receiving and what they would be interested in receiving in the future. This part of the study found that family carers found it difficult to identify which services they received. All the staff spoken to said that they had received dementia training and printed information on dementia. Some staff also reported information on: activities, home adaptations, dietary advice, risk assessments and safeguarding. Family carers requested dementia information in a printed format, and one-to-one explanation of dementia with a professional. Advice on communication strategies was another need as was support groups, information sessions and advice about behaviours and activities. Staff was keen to receive information in a variety of formats and advice on emergency planning,	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		as well as behaviour and activities.	

2. Janicki MP, Zendell A, DeHaven K (2010) Coping with dementia and older families of adults with Down syndrome. Dementia 9: 391–407

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'The authors studied a group of older carers of aging adults with Down syndrome (DS) to ascertain what effects such care giving may have on them given the presence or possibility of age-associated decline or dementia. The study also examined the	**Participants:** Service users and their families, partners and carers – primary carers. **Sample size:** Total 17 primary carers. **Follow-up:** No follow-up. **Costs:** Not reported.	**Narrative findings** Only the findings related to information, advice, training or support are extracted here. The study also looks at the medical symptoms of dementia exhibited by the adults with Down's syndrome, amount of care provided by carers and the levels of stress among carers. The relevant findings relate to decision-making around future care, adaptation to the home environment. **Decision-making** Most carers made the decision to care for the adult at home and few sought staff or agency help with this decision. Most respondents said that they planned to seek a doctor or specialist's advice around future care, when things became challenging. They said they would seek personal care assistance or the help or a sibling and some said they	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
comparative levels of care provided, key signs noted when decline was beginning, the subjective burden experienced, and what were the key associated health factors when carers faced a changed level of care' (p391). **Methodology:** Qualitative study. 'Modified Caregiver Strain Index, Caregiver Burden Survey, Caregiver Concern Survey, Family Health		would look to help from a professional 'treatment team'. The ability of the adult to remain in the home was felt to be dependent their own ability to care in the first instance, increased medical needs of the individual and also the level of support available from other family members or the availability of services to meet heightened needs. **Changes to the home environment** Carers sought help with caring tasks in a number of ways: 23.5% received respite help, 11.8% looked for training on special care and 5.9% got part-time help in the home; 41.2% received no extra help. Some carers found it hard to find appropriate support, even if they had financial assistance to pay for it: 'one parent reported she had received governmental financial supports for respite but could not find anyone to provide it' (p399). Carers reported gradual changes in the needs of their child ad for some this meant staff assistance or obtaining adaptive equipment in the home. Carers noted 'unmet needs from respite services, nutritional assistance and speech therapy' (p400).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Status Inventory, and the Caregiver Activity Survey-Intellectual Disabilities (CAS-ID)' (p395). **Country:** USA			

3. McLaughlin K, Jones A (2011) 'It's all changed': carers' experiences of caring for adults who have Down's syndrome and dementia. British Journal of Learning Disabilities 39: 57–63

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'This study aims to add to the current knowledge base by describing the information	**Participants:** Service users and their families, partners and carers – carers experiences of caring.	**Narrative findings** Only the findings relating to information, advice training and support have been extracted. Carers described information needs pre- and post-dementia diagnosis. The study organises its findings under thematic headings. **Pre-diagnosis** Information needs were at their highest before diagnosis, when	**Overall assessment of internal validity:** + **Overall assessment of**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
and support needs of carers who are caring for adults who have Down's syndrome and dementia. As a result of this study, more will be known about how information needs change as the dementia progresses as well as discussing the information needs of carers before dementia is diagnosed'	**Sample size:** Total 6 carers. **Follow-up:** No follow-up. **Costs:** Not reported.	carers had begun to notice changes in behaviour. The study found that carers did not necessarily realise the significance of the behavioural changes. Carers did not seek information or advice because they did not realise the changes could be associated with dementia. 'I didn't say anything because again I thought that perhaps it's me being a bit [pause] oh why is he doing that? But they noticed at the day centre that he wasn't opening his lunch boxes and they mentioned it to the community nurse and well she made an appointment to see the doctor' (p60). **Diagnosis** Diagnosis led to new information needs about the implications of the diagnosis and the progress of the disease. 'We had some information given to us by Dr a couple of months ago but a lot of it was verbal' (p60). Some carers had had questions about the different types of dementia. 'Although the carers noticed that the dementias produced different symptoms, they were not aware of the specific type of dementia that each adult had' (p60).	**external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
(p58). **Methodology:** Qualitative study. **Country:** UK.		'We have another service user who suffers from dementia and obviously everyone is an individual and it was totally different with him' (p60). Carers were happy to get a diagnosis but had questions about the progress of the disease. 'I would like to know how long a Down's syndrome could last with Alzheimer's' (p60). **Post-diagnosis** Post-diagnosis carers sought practical and emotional support from 'family, friends and professionals' (p60). 'Yeah as I said I'm alright for support because I've got my relative next door but if I didn't have her I probably would be glad of some support but I'm finishing now in March as I said and once that happens I'll be alright then 'cause I'll be here all the time' (p60). **Changing needs** Carers who became more involved with the care of the person with dementia had increased information needs. At first existing support was able to assist with changing behaviour due to dementia. Post-diagnosis, the increase in	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		medical appointments meant more carers involvement. Carers needed more information and more support at this stage. ‘Extra professional and familial support may now be necessary as the adult with Down’s syndrome becomes increasingly affected by the dementia’ (p61). Post-diagnosis, carers reported that their information needs lessened. Carers said that they had gathered all the information they needed about dementia symptoms and the progress of the disease. Carers believe that the disease would progress quickly and the person with dementia would need extra support. ‘I’m told that it’s going to get worse and when that happens like I said as much as I love him he’ll have to go into care. I couldn’t do it no more it’s stressful for me and hurtful for me too’ (p61). The study found that carers may be a lack of information about support available to them. Carers did not know about respite and other services. Carers learnt of extra support through interactions with professionals. Sometimes by chance. ‘The social worker has been very helpful he’s been good. He’s got respite for us you know every month we get four nights. It makes a big difference’ (p61).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'It was through the nurse that I had the chair. I was telling her how difficult it was when I was coming downstairs to the toilet with him and I couldn't get him back up. So she said about getting a chair for the bedroom for him and within a week of saying that I got the chair for the bedroom and that's a Godsend' (p61). The study surmises that information needs change with each stage of the onset and progress of dementia. Some carers amassed a lot of information at diagnosis and others sought new information as needs changed. Supported needs increased, especially if services did not have capacity to help and the carers lack support. Carers could become isolated and in financial difficulty if they could not work. 'Once my husband died I was scuppered' (p61).	

4. Tozer R, Atkin K (2015) 'Recognized, valued and supported'? The experiences of adult siblings of people with autism plus learning disability. Journal of Applied Research in Intellectual Disabilities 28: 341–51

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The study aimed to	**Participants:** Service users and their	**Narrative findings** Note: there are very few findings relevant to our review	**Overall assessment of**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
explore the potential of adult siblings to offer support to their brother or sister with autism and a learning disability. **Methodology:** Qualitative interviews. **Country:** UK. **Source of funding:** Government. ESRC.	families, partners and carers. Adults with learning disabilities were interviewed as well but not with the aim of providing data that answers own review question. Therefore the main focus here is on the findings from the interviews with siblings of adults with a learning disability. Also, professionals/practitioners. **Sample size:** Total 21. **Outcomes measured:** Satisfaction with services. Note: siblings' satisfaction with services.	question. Only 1 of the prompts in the topic guide for discussions with the siblings was likely to focus participants on the question of what support or advice they would need to help them in their role, 'What additional advice or support might be helpful to you?' (p344). Approximately a third of the siblings felt unfairly and negatively judged by professionals who didn't seem to appreciate the difficulties in juggling life, work, family and time spent with the brother or sister with a learning disability. The amount of involvement they were able to have in their siblings' lives varied and whatever they were able to manage, they wanted to be supported in this role by professionals. One problem was that siblings were often excluded from discussions which had started in the family home, so from the start they were never included in future planning. This wasn't perceived as always being the fault of practitioners, some felt their parents had acted as gatekeepers. Looking to the future, siblings felt they would be taking on more responsibilities but they would welcome support from practitioners to do this. Their experience was that practitioners weren't sufficiently proactive in the sense of future planning discussions.	**internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Follow-up: No follow-up. **Costs?** No.	**Observations from the authors' discussion** Findings suggest that it would be useful if practitioners began conversations with siblings earlier on in their lives. They could also provide information, a listening ear and practical help. Establishing a dialogue with siblings would be an important step forward compared with current practice (as described in this study). Basically, siblings need to be recognised, valued and supported in their role. The interviews suggest siblings would especially like information and advice about future care options and about bereavement support for their brother or sister. Findings seem to point to a need for training in social care organisations so that practitioners can work successfully with siblings of adults with a learning disability.	

Research question 4 – critical appraisal tables – the views and experiences of people using services, their families and carers

1. Furniss KA, Loverseed A (2012) The views of people who care for adults with Down's syndrome and dementia: a service evaluation. British Journal of Learning Disabilities 40: 318–27

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'The article reports on a specialist service for people with Down's syndrome and dementia. The service has offered dementia screening and assessment to people with Down's syndrome for over 10 years and has also developed to offer support and training for carers. Semi-structured interviews were conducted with family carers, relatives and staff about the impact on them of caring for someone with Down's syndrome and how the dementia service supports them in this role' (p318). **Methodology:** Qualitative interviews. **Is a qualitative approach appropriate?** Somewhat appropriate. The study does not state its aims that clearly, it describes itself as an evaluation but is more of a qualitative survey of user	**How well was the data collection carried out?** Appropriately. Sampling methods and procedure are well described. **Is the context clearly described?** Not sure. The context is not that clearly described. It is not clear what services the interviewees were receiving or what training the staff had on dementia care, or what services they delivered. **Was the sampling carried out in an appropriate way?** Appropriate. The sampling was carried out using a database of persons on the dementia screening database and with Down's syndrome. The study looked for interviewees who were carers to people who had Down's syndrome and dementia and lived with them. Relatives who maintained regular	**Does the study's research question match the review question?** Partly. The scope of the study is somewhat unclear. The study presents itself as an evaluation of a service delivering training and support for carers, but does not offer a detailed description of this service. However, the study does look at the information needs of family carers and staff and so has relevance to this question. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** No.	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
and practitioner views around information, support and training needs. **Is the study clear in what it seeks to do?** Mixed. The study aims to gather the view of family carers, relatives and staff about the support they receive, but the findings are not tied well to the services offered by the service being evaluated. **How defensible/rigorous is the research design/methodology?** Defensible. The methods are defensible for gathering user and practitioner views. The study used semi-structured interviews and a checklist for interviews to identify additional service needs.	contact with a relative who lived in supported living or residential care or paid staff who provided care to people with dementia and Down's syndrome. **Were the methods reliable?** Somewhat reliable. The interview procedure is relatively well described, but there is no description of bias risk. **Are the data 'rich'?** Rich. The themes are described well and quotes are provided. **Is the analysis reliable?** Reliable. Interviews were transcribed verbatim. Transcriptions were analysed using interpretive phenomenological analysis. The process is described at iterative and generated thematic analysis.	**Is there a clear focus on the guideline topic?** Yes. Focus is individuals with Down's syndrome and dementia. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Family carers and professionals. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Family homes, residential care and supported living. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Information, advice, training and support.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
	Are the findings convincing? Convincing. The themes are presented with verbatim quotes. **Are the conclusions adequate?** Adequate.	**Are the study outcomes relevant to the guideline?** Yes. Satisfaction with services use of services. **Are the views and experiences reported relevant to the guideline?** Yes. The views of family carers and practitioners are reported. **Does the study have a UK perspective?** Yes.	

2. Janicki MP, Zendell A, DeHaven K (2010) Coping with dementia and older families of adults with Down syndrome. Dementia 9: 391–407

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'The authors studied a group of older carers of aging adults with Down syndrome (DS) to ascertain what effects such care giving may have on them given the presence or possibility of age-associated decline or dementia. The study also examined the comparative levels of care provided, key signs noted when decline was beginning, the subjective burden experienced, and what were the key associated health factors when carers faced a changed level of care' (p391). **Methodology:** Qualitative study. 'Modified Caregiver Strain Index, Caregiver Burden Survey, Caregiver Concern Survey, Family Health Status Inventory, and the Caregiver Activity Survey-Intellectual Disabilities (CAS-ID)' (p395).	**How well was the data collection carried out?** Not sure/inadequately reported. Data collection procedure is not well described. We only learn that the sample were 'assisted' in completing the instruments and forms. **Is the context clearly described?** Clear. The characteristics of the respondents and their caring circumstances are well described. **Was the sampling carried out in an appropriate way?** Not sure. The study uses a convenience sample gained via word of mouth or internet solicitation. **Were the methods reliable?** Not sure. The methods of data collection are not well described we are not given key details about who assisted	**Does the study's research question match the review question?** Partly. Only some of the findings from this study are relevant to the review question. The findings from the study are more generally about the effect of care giving on carers and their care practices. The study does have some findings about sources of advice support and training. **Has the study dealt appropriately with any ethical concerns?** No. Not mentioned. **Were service users involved in the study?** No.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Is a qualitative approach appropriate? Somewhat appropriate. The approach and instruments are well described but do not gain rich qualitative data as they were a combination of survey-type instruments, which gave mainly Likert or tick-box style responses. **Is the study clear in what it seeks to do?** Clear. The study clearly outlines its intension to gain information on the effects of care giving, levels of care giver burden and the factors that influenced changing levels and sources of care. **How defensible/rigorous is the research design/methodology?** Defensible. The study describes its approach in detail including the function of each instrument in turn.	with the forms and when and where the collection was carried out. **Are the data 'rich'?** Poor. Data is not rich, we are given few verbatim quotes, and most of the findings are expressed in percentages with some thematic description. **Is the analysis reliable?** Not sure/not reported. Analysis methods are reported. We are not provided tables with findings from survey instruments. **Are the findings convincing?** Somewhat convincing. The findings are convincing given the description of the instruments used, but the quality is let down by a lack of description around data collection and analysis.	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Older people with Down's syndrome and dementia. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Family home. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Information, advice, training and support are mentioned but are not the focus of the paper.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Are the conclusions adequate? Somewhat adequate. The themes are not always internally coherent, with findings that so not necessarily correspond with the heading theme being included in some sections. At times the finding are not backed up by percentages from the relevant instrument, making it hard to know where they originate.	**Are the views and experiences reported relevant to the guideline?** Yes. The views are relevant in the sections in which information, support and advice are mentioned. **Does the study have a UK perspective?** No. USA.	

3. McLaughlin K, Jones A (2011) 'It's all changed': carers' experiences of caring for adults who have Down's syndrome and dementia. British Journal of Learning Disabilities 39: 57–63

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'This study aims to add to the current knowledge base by describing the information and support needs of carers who are caring for adults who have Down's syndrome and dementia. As a result of this study, more will be known	**How well was the data collection carried out?** Appropriately. The sampling was purposive, the sample size very small. We do not learn about the development of a	**Does the study's research question match the review question?** Yes. The study explicitly seeks views and experiences about information and support needs.	**Overall assessment of internal validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
about how information needs change as the dementia progresses as well as discussing the information needs of carers before dementia is diagnosed' (p58). **Methodology:** Qualitative study. **Is a qualitative approach appropriate?** Appropriate. Appropriate for gathering views and experiences. **Is the study clear in what it seeks to do?** Clear. Aims and objectives are clearly described. **How defensible/rigorous is the research design/methodology?** Defensible. The study describes its interviews as in-depth, and took place in carers' homes or workplaces. All the carers had to have been caring for	discussion guide but the interviews are describes as 'unstructured'. **Is the context clearly described?** Unclear. The context is not well described, we do not learn much about the characteristics of the carers or those they were caring for. Bias or the influence of the researchers is not discussed. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Purposive sampling. But we learn little of the context or how representative the sample may be. **Were the methods reliable?** Somewhat reliable. Data is only collected via one method and the sample is very small.	**Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. The ages of the people with Down's syndrome and dementia are not given, but the review team felt it reasonable to assume they were middle aged or older, given the dementia diagnosis. **Is the study setting the same as at least 1 of the settings**	**Overall assessment of external validity:** ++

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
a person with Down's syndrome and dementia for 6 months or more.	**Are the data 'rich'?** Mixed. Some of the themes are backed up with verbatim quotes, but some of the points are not and the results read more like the 'impressions' of the researcher than solid findings. The themes are a little muddled, but there are some valuable findings around the progress of carers information needs as dementia progresses. **Is the analysis reliable?** Not sure/not reported. We do not learn about the transcription or analysis methods. These are not described. The study only reports on peer review at the end of the process. **Are the findings convincing?** Somewhat convincing. There are issues with the quality of describing	**covered by the guideline?** Yes. Community setting and supported living or group homes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Information, support and advice. **Are the views and experiences reported relevant to the guideline?** Yes. The views and experiences of carers (paid and unpaid). **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	the methods and a lack of detail around participant characteristics. **Are the conclusions adequate?** Somewhat adequate. There seems to be some issues with the interpretation of findings and conclusions. In places the findings are not well organised.		

4. Tozer R, Atkin K (2015) 'Recognized, valued and supported'? The experiences of adult siblings of people with autism plus learning disability. Journal of Applied Research in Intellectual Disabilities 28: 341–51

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The study aimed to explore the potential of adult siblings to offer support to their brother or sister with autism and a learning disability. **Methodology:** Qualitative interviews.	**How well was the data collection carried out?** Appropriately. Data collection methods are clearly described and data collection and record keeping are systematic. The only obvious shortcoming was that siblings were always present during the interviews with their learning	**Does the study's research question match the review question?** Partly. The research touches on the need for advice and support among siblings. **Has the study dealt appropriately with any ethical**	**Overall assessment of internal validity:** + **Overall assessment of external**

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Is a qualitative approach appropriate? Appropriate. Because the research seeks to understand the subjective experiences of siblings of adults with learning disabilities and their feelings and opinions about current and future support. **Is the study clear in what it seeks to do?** Mixed. The purpose of the study is discussed in broad terms but there are no sections describing aims and objectives and no specific research question. There is no clear discussion about an underlying theory. There is however adequate and appropriate reference to the literature. **How defensible/rigorous is the research design/methodology?** Defensible. There are clear accounts	disabled brother or sister. Although the advantages of this are clear it does introduce the possibility that the responses of the learning disabled adults would be influenced by the presence of their sibling. However, given that only the data gathered from the sibling interviews are reviewed here, this issue does not undermine the validity of data collection. **Is the context clearly described?** Unclear. The characteristics of the participants and settings are not clearly defined – all we know is the ages of participants and their siblings. Data was only gathered in one situation and no observations were made that would have provided the opportunity for triangulation. The influence of the researcher was not explicitly was considered but to their credit, the team did employ visual and	**concerns?** Partly. Ethical approval was obtained from the university ethics committee. Consent was gained from all interviewees – for adults with a learning disability, their sibling helped to facilitate the consent/assent process. However, there is no mention of the transcripts being anonymised and or stored safely and in line with the principles of the data protection act. **Were service users involved in the study?** Yes. As participants plus 3 siblings were members of the project advisory group, which contributed to the drafting of the interview topic guide.	**validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
of sampling and the justification, namely that no representative sampling frame exists, which is why convenience sampling was the appropriate method. Respondents were self-selecting in response to adverts via national networks. Sampling of practitioners was via the non-disabled siblings, which introduces a risk of bias if there are particular reasons for some – and not other – practitioners being nominated. There is a clear rationale for the data collection and methods of analysis. Notably the analysis involved debate and the identification of themes among the whole research team plus feedback sessions with over half the sibling respondents to test the researchers' interpretation.	other techniques to help facilitate discussions and improve engagement with the learning disabled adult. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Recruitment of siblings was conducted appropriately – via convenience sampling (no representative sampling frame exists in the UK). Sampling of practitioners was a little less robust in that they were identified by the participating siblings who may have had specific reasons for choosing the professionals - and indeed, not choosing others. **Were the methods reliable?** Somewhat reliable. Data were only gathered via one method (interviews) and without observations or other collection methods, there is no	**Is there a clear focus on the guideline topic?** Partly. Relevant to the broad topic of care and support for older people with learning disabilities but in terms of the review question, the research wasn't entirely relevant. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The age range of the adults with autism and a learning disability is 24 to 65 years so some but not all could be described as 'older'. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	opportunity for triangulation. They do nevertheless investigate what they claim to. **Are the data 'rich'?** Mixed. How well are the contexts of the data are not described in a lot of detail – we know whether participants have brothers or sisters and we know their ages but little else. In particular, for our purposes it would have been illuminating to have responses compared by age group of the learning disabled sibling, but they were not. In addition, there is little by way of conflicting data or contrasting findings presented. **Is the analysis reliable?** Reliable. More than one researcher was involved in the data analysis and to their credit, the team conducted a	**Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Partly. Not all are the views of older people with learning disabilities or siblings of older people with learning disabilities (age range of adults with LD is 24–65 years). **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
	feedback session with participants in order to aid interpretation. **Are the findings convincing?** Convincing. The findings are clearly presented and supported by extracts from the original data. The data are also clear and coherent and organised according to themes for clarity. **Are the conclusions adequate?** Adequate. There are clear links between data, interpretation and conclusions and the conclusions seem to be plausible and coherent. They are discussed in the context of existing research on the topic and they do enhance understanding of the needs of siblings who wish to be involved in supporting their learning disabled brother or sister in adulthood. One drawback is that there		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	is no discussion about the limitations of the research design except to say that the sampling method meant that only siblings who wanted a role in their brother's or sister's lives were likely to self-select for participation.		

Review question 5. Access and referral to health, social care and housing support services:

a. What is the effectiveness and cost effectiveness of interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?

Review question 5b. What are the views and experiences of older people with learning disabilities and their carers about interventions or approaches to improve access and referral to health, social care and housing support services?

Review question 5c. What are the views and experiences of health, social care and other practitioners about interventions or approaches to improve access and referral to health, social care and housing support services for older people with learning disabilities?

Review question 5 – findings tables – the views and experiences of people using services, their families and carers

1. MacGiolla Phadraig C, Burke E, McCallion P et al. (2014) Dental attendance among older adults with intellectual disabilities in Ireland. Special care in dentistry: official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry 34: 265–72

Research aims.	**PICO (population, intervention, comparison, outcomes)**	**Findings.**	**Overall validity rating.**
Study aim: From the abstract, "To	**Participants:** Service users and their families, partners and carers.	**Quantitative findings** (note that no effect size data was provided)	**Overall assessment of**

investigate dental attendance patterns and reasons for nonattendance among older adults with intellectual disabilities (ID) in Ireland." (p265) **Methodology:** Mixed methods study. A cross-sectional survey of quantitative data and text analysis of qualitative data drawn from a nationally representative sample of 753 people with ID over 40 years of age in Ireland. **Country:** Republic of Ireland.	People with intellectual disability over 40 years of age was randomly selected from the National Intellectual Disability Database. **Sample size:** 727 **Intervention** • Intervention category - Access to health care • Describe intervention - Dental visits • Delivered by - Dentists or dental hygienists • Delivered to - Adults with learning disabilities • Duration, frequency, intensity, etc. – Varied • Key components and objectives of intervention - Not applicable • Content/session titles - Not applicable	These figures describe dental attendance by demographic characteristic: (Irregular attendee = not attended within last 2 years Regular attendee = attended within last 2 years) TOTAL 727 (100%) Irregular attendee, 98 (13.5%) Regular attendee 629 (86.5%) GENDER >.05 MALE 330 (45.4%) Irregular attendee, 45 (13.5%) Regular attendee 285 (86.4%) FEMALE 397 (54.6%) Irregular attendee, 53 (13.4%) Regular attendee 344 (86.6%) AGE <.01 40-49, 268 (36.9%) Irregular attendee, 28 (10.4%) Regular attendee 240 (89.6%) 50-64, 328 (45.2%) Irregular attendee, 40 (12.2%) Regular attendee 288 (87.8%) 65+ 130 (17.9%) Irregular attendee, 30 (23.1%) Regular attendee 100 (76.9%) TYPE OF RESIDENCE <.01 Independent/ family 125 (17.2%) Irregular attendee, 27 (21.6%) Regular attendee 98 (78.4%) Community group home 261 (35.9%) Irregular	**internal validity (qualitative):** + **Overall assessment of external validity (quantitative):** ++

Source of funding: Not stated.	• Location/place of delivery - Details not provided • Describe comparison intervention - Not applicable **Outcomes measured** • Service user related outcomes - Factors affecting frequency of dentist visits • Service outcomes - Dental attendance **Follow-up:** None. **Costs?** No.	attendee, 23 (8.8%) Regular attendee 238 (91.2%) Residential care 341 (46.9%) Irregular attendee, 48 (14.1%) Regular attendee 293 (85.9%) LEVEL OF INTELLECTUAL DISABILITY >.05 Mild 158 (23.6%) Irregular attendee, 26 (16.5%) Regular attendee 132 (83.5%) Moderate 315 (47.0%) Irregular attendee, 36 (11.4%) Regular attendee 279 (88.6%) Severe/ profound 197 (29.4%) Irregular attendee, 24 (12.2%) Regular attendee 173 (87.6%) **Qualitative findings** Note that gender and level of disability were not associated with frequency of attendance but age and type of residence were. The older the adult, the less likely they were to be regular attendees. Type of residence ($p < .01$): the proportion of regular attendees was lowest among people living independently (78.4%), compared with those in residential settings (85.9%) and highest among those in community group homes (91.2%). There was a similar pattern with attendance in the last year: 76/125 (60.8%) of people living independently reportedly attended the dentist in the last year, compared to 253/341	

		(74.2%) in residential settings and 197/261 (75.5%) in community group homes. Reasons for not attending: LACK OF PERCEIVED NEED - Edentulism 48 responses within category (6.4% of total sample and 31.0% of those included in text analysis) - Unnecessary 38 responses within category (5% of total sample and 24.5% of those included in text analysis) - Lack of pain/ problems 32 responses within category (4.2% of total sample and 20.6% of those included in text analysis) ABILITY AND PERSONAL CHOICE - Preference 10 responses within category (1.3% of total sample and 7.7% of those included in text analysis) - Cooperation/ ability 7 responses within category (.9% of total sample and 4.5% of those included in text analysis) ACCESS AND AVAILABILITY	

		- Access to services 6/153 responses within category (.8% of total sample and 3.9% of those included in text analysis) EXCLUDED Reason not known 12 (1.6% of total sample and 7.7% of those included in text analysis) Lack of perceived need - "I have no teeth and I have no problems with my mouth". (p268) So there is a misperception about the need for dental care - even if someone has no teeth, they should still attend dental checks where, for example, the early signs of mouth cancers can be identified. Ability and personal preference - included mobility problems preventing a person physically accessing the dentist. Also fear, when people were scared of the dentist they won't access it, "I am terrified of a dentist - I had a terrible experience when I was a child..." (p268) Access and availability - e.g. barriers arising from interactions between dental and disability services, "Currently there is no dental service available within the (disability) service, however, when the (disability) service	

		moves into the community...which is in operation at the moment...there will be a (dental) service available.” (p268) Also a lack of general anaesthetic facilities - one person used to have her teeth cleaned under GA but due to funding cuts this is no longer available so she hasn't had them cleaned for 3 years. From discussions; residential setting was an important factor in determining access to dental services, "three quarters of those in community group homes and residential centres reported dental attendance within the last year." (p269) Unsurprising since dentists generally visit selected residential services annually and people outside the residential system aren't so easily targeted. Age - irregular attendance was associated with increasing age, "rising from 10% of 40–49 year olds to 23% of those 65+ year olds." (p269) This trend is reflected in the general population and suggests that the proportion of people failing to access dental services will increase as the LD population ages. In other research barriers to access are emphasized more than in this study, which found that irregular attendance was more attributable	

		to personal choice.	

2. Swaine JG, Dababnah S, Parish SL et al. (2013) Family caregivers' perspectives on barriers and facilitators of cervical and breast cancer screening for women with intellectual disability. Intellectual and developmental disabilities 51: 62–73

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'The present study addressed the following research questions: (a) What are family caregivers' perspectives on why women with intellectual disability do not receive cervical and breast cancer screening? (b) What are family caregivers' perspectives on the comfort women with intellectual disability have with respect to cervical	**Participants:** Service users and their families, partners and carers – 32 female familial caregivers of women with intellectual disabilities. Of these 25 (78%) were mothers, 3 (9%) were grandmothers, 3 (9%) were sisters, and 1 (3%) was an aunt. **Sample size:** Total 32 completed responders out of initial sample of 50. **Follow-up:** None. **Costs:** Not reported.	**Clinical Breast exam** (p66) In 83% of cases the women with intellectual disability had received clinical breast exams, and nearly 80% had had 1 within the past year. Many of the women had reportedly been comfortable with the exam, and family caregivers offered 3 main reasons: first, the doctor and/or family caregiver explained the procedure. Second, the doctor's gender was female. Finally, the woman with intellectual disability was familiar with the doctor. Some caregivers emphasised the importance of being in the room with the participant during the exam, and several stated they would not allow an exam outside of their presence. Some reasons were given why some women with intellectual disabilities had felt uncomfortable. Many were generally shy or embarrassed about being touched. A minority of the women hadn't received a breast exam. The most common reason was the caregiver's belief that the exams were unnecessary. One caregiver noted her sister had a history of sexual abuse and so felt uncomfortable with the exam.	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
and breast cancer screening? (c) What do family caregivers feel are the best ways to facilitate screening for women with intellectual disability? (d) Do family caregivers feel that their women family members with intellectual disability receive adequate health care? (e) Are family caregivers knowledgeable about the need for cervical and breast cancer screening among women with intellectual disability?' (p63).		**Mammogram** Eight women with intellectual disability were aged 40 or over at the time of data collection and 75% of these had received a mammogram. More than half had been in within the past year. In most cases the participants had been comfortable with the procedure, and this had been because the relative had been preparing the women for the exam in advanced. However, 2 of the women had been uncomfortable with the exam because the procedure was unexpected and they believed it was painful. Of the 2 that hadn't had a mammogram, one mentioned the discomfort of the exam and the other had yet to schedule the exam. **Pap tests and pelvic exam** About 3/4 of participants had received pap/pelvic exams, but only half of those had had an exam in the past year. The most common reason for not getting an exam was that the person was not sexually active. Several didn't feel it was necessary, and stated they hadn't been recommended to by their doctor. Other care givers stated they had received hysterectomies and so didn't need further tests. For those that did, many had found the experience quite uncomfortable due to general shyness and unusualness of such contact. Some had found the procedure painful, others actively fought against receiving the procedure. One	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Methodology: Qualitative study. Semi-structured qualitative interviews. **Country:** USA. **Source of funding:** Not reported.		of the biggest comforters had been when the procedure was explained to the person beforehand. The presence of the relative also helped, and some used calming words and techniques during the procedure. In 2 cases the women had had to receive anti-anxiety medication. **Healthcare** Most family caregivers (87%) reported that their family members with learning disabilities received adequate healthcare. One of the most common reasons identified for this was that they themselves championed this and pushed for proper care. In return they needed medical professionals to make sure appointments were convenient and available to them. Medical knowledge, competence and facilitation with learning disabilities were also identified as very helpful where it existed. For those who said healthcare received was inadequate, the most common issue was Medicare coverage where several types of referral services aren't covered. Also issues with transportation cost were mentioned. **Family member's own knowledge of screening** 'For clinical breast exams, 50% of family caregivers correctly answered that a woman should typically receive a clinical breast exam yearly. Similarly, 75% of family caregivers of women aged 40 and older correctly reported	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		an annual mammography screening. Finally, 64% of respondents correctly reported guidelines of Pap tests every one to three years depending on age and health history' (p70).	

3. Wark S, Canon-Vanry M, Ryan P et al. (2015) Ageing-related experiences of adults with learning disability resident in rural areas: one Australian perspective. British Journal of Learning Disabilities 43: 293–301

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'The specific aims were to examine select issues of ageing when residing within rural areas, ascertain facilitators and barriers to services, and identify practices that may enhance supports for adults living outside metropolitan	**Participants:** Service users and their families, partners and carers. **Sample size:** Total 17 older adults and 17 carers. **Outcomes measured:** Service user related outcomes, experiences of accessing services. Family or caregiver related outcomes, experiences of accessing services to support older family	Analysis of the interviews identified a number of key thematic areas, not all of which are relevant to this review question. The relevant areas are as follows. **1. Access to health services** Access to health care, especially specialist services, was deemed to be a key aspect of having a 'good life'. Participants were happy with the support from their local doctor. 'He knows Dennis really well. He's got a good rapport with Dennis. And he takes on board whatever the staff are telling him as well' (support worker, p297). The smaller population in rural areas was sometimes seen as a benefit in terms of being able to access local doctors but on the other hand some people reported long waits for	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
locales' (p294). **Methodology:** Qualitative study. Face-to-face interviews with older people with learning disabilities and nominated carers (family members). **Country:** Australia, the states of New South Wales and Queensland. **Source of funding:** Not reported.	members with learning disabilities. **Follow-up:** None. **Costs:** Not reported	appointments and that the only option would be to go to the emergency department (and wait for hours). The big issue seems to have been accessing specialist services. As the person with the learning disability ages they need to see a gerontologist and the chances of this are low since 'We can't even get a GP to some age care facilities it is so hard' (carer for Stephen, age 79, own home) (p298). Distance seems to be the biggest barrier in rural Australia: 'the tyranny of distance'. 'While there were allied health practitioners with knowledge or specific interests in learning disability and specialist services nominally available, the individuals were required to travel often considerable distances to attend these appointments' (p298). Ken, aged 57, living in a group home, had to travel a 700km round trip to see his health specialist. Also Graeme, aged 54, living in own home, had to get his prescription medication from the next town; 100km away. **2. Limited choices and limited options** Carers identified a clear lack of options for adults ageing with a learning disability. Issue is a lack of services and a lack of choice in provision of services. Even if there are services, there's only one so the person has no choice	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		about which to use. 'That's basically only one option for them at the moment, especially in [this town] and even the rural areas. They won't have anywhere for those people to go, the only option is nursing homes and I don't believe a nursing home is a place for them' (Brenda, a support worker for Dennis, age 55, supported unit) (p298). If the person isn't happy with the services of a particular place, as they grow older (e.g. a supported unit) the only alternative option was a mainstream residential aged care provider. The authors observe that the right of the individual to make meaningful choices in their life is irrelevant as a philosophy if there are not options from which to select.	

Review question 5 – findings tables – health, social care and other practitioners' views and experiences

1. Benbow SM, Kingston P, Bhaumik S (2011) The interface between learning disability and old age psychiatry: two specialties travelling alone or travelling together? Mental Health Review Journal 16: 25–35

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The	**Participants:**	Respondents left many comments concerning problems	**Overall**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
overall aims of the interface group authoring the paper included 'to look at what services were needed and how they should be accessed'. With regards to this, the survey aimed to 'establish an overview of current service operation and provision' (p26.) **Methodology:** Survey. Postal questionnaire, with open questions. **Country:** UK. **Source of funding:** Not reported.	Professionals/practitioners. Professionals (primarily consultants) who were members of the Royal College of Psychiatrists, and working in the fields of Old Age Psychiatry or Learning Disability. **Sample size:** Total 444 surveys were returned out of 942 sent out (47%); 415 were from consultants, 15 by academics, 12 by associate specialists and 2 by others. **Follow-up:** No follow-up. **Costs:** Not reported.	in accessing LD and Old Age Psychiatry (OAPry) services for older people with LD and functional mental health problems. Each had trouble contacting and accessing each other, and sometimes there were disputes as to whose 'territory' the person fell into. Some specific areas were raised as hard to access – e.g. housing, residential care, and social services. With regards to older people with LD and dementia, many practitioners commented that there is a need for specific services in their areas but they don't currently exist to be accessed. Respondents commented on the problems accessing the other service (LD practitioners accessing OAPry services or vice-versa). In some cases LD practitioners commented that OAPry services don't take people with LD. Old age psych practitioners reported problems such as difficulty contacting LD services, or them being on a different site. It was concluded that when it came to access the service models that existed were highly variable. Some services had well established protocols for dealing with older people with LD. However for others there was 'no clarity on which service should meet the needs of this group' (p29).	**assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating

2. Coyle CE, Putman M, Kramer J et al. (2016) The role of aging and disability resource centers in serving adults aging with intellectual disabilities and their families: findings from seven states. Journal of Aging and Social Policy 28: 1–14

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To develop an understanding of how Aging and Disability Resource Centres (ADRCs) administer resources and support to adults ageing with intellectual and developmental disabilities (I/DD). There were 4 objectives: 1) to describe goals expressed by ADRCs with regards to serving the population of older adults with I/DD and	**Participants:** Professionals/practitioners – 7 state ADRC coordinators (8 were invited to participate) and 14 local ADRC programme staff. (Note that the sample characteristics given below are the characteristics of the aged care facility residents who had a learning disability.) **Sample size:** Total 21. **Intervention**	Findings are presented under 3 broad themes. **1. No explicit focus on adults ageing with LD and their families in the ADRC's work.** Across all states ADRC staff were aware of adults with LD as a population; however, they were not considered a specific focus population for their ADRC. Staff views fell into 3 main perspectives about how older people with LD fit into the work of ADRCs: i) adults with LD and their families do not have any special needs that would separate them from the broader service population or require a particular approach ii) adults with LD will be an important group to target in future but they're not being addressed in the current work of the ADRCs, 'we're always saying that ... this is an issue – as people are living longer and	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

their families. 2) to determine how older adults with I/DD are referred to both ageing and disability resources 3) to understand the range of programme activity geared toward serving older people and their families 4) to identify gaps in resources and services for older adults with I/DD and their families. **Methodology:** Qualitative study. Face-to-face interviews with program coordinators and project staff in 7 US states **Country:** USA. **Source of funding:** Not reported.	Intervention category – Information and referral services for adults ageing with a learning disability. Describe intervention – all 8 states (invited to participate in the study) had been awarded funds to implement the ADRC 'Enhanced Options Counselling (EOC)' programme by the Administration for Community Living. ADRC Options Counselling is an information and referral programme with a person centred focus. The idea behind EOC is to accelerate the development of mechanisms within existing programs to streamline the intake and eligibility determination processes for older adults with learning disabilities. (Also general background	parents pass away, but we haven't necessarily carved them out yet' (p5) iii) attempts are being made to unite services for older people with services for adults with LD so that the needs of the older LD population can be addressed – and these efforts will continue into the future. **2. Unique challenges in providing information and referral services result in complexities or gaps in service.** ADRC staff reported 'unique challenges related to accessing and providing information and referral services for the population of adults aging with ... [LD]' (p6). They identified 3 common challenges in providing adequate support to older people with LD: (i) adults with LD (or their families) often contact the ADRC in times of crisis because they're not already connected with formal services. This is hard for ADRC services because if contact is made (during crisis) it requires more time and resources to support them because they have no prior contact. Staff are therefore starting at the beginning with the person in terms of determining their eligibility and getting access to support for them. In these crisis situations it's also often the case that the ageing parent needs immediate support for example if the situation has arisen because they've been hospitalised.	

	re. ADRCs '... the intention of ADRCs is to facilitate the integration of information and referral services across the LTSS (long-term services and support) system, provide benefits and options counselling about LTSS to support informed decision making by consumers') (p2. Delivered by – the only detail given is 'local programme staff'. Delivered to – older people with learning disabilities (over 50 years of age), their families and carers. Duration, frequency, intensity, etc. – not reported. Location/place of delivery – Not reported although	(ii) ADRC community outreach doesn't necessarily resonate with the older LD population. ADRC in general doesn't necessarily resonate with the older LD population (or their families) – they don't necessarily identify as 'disabled' so it wouldn't occur to them that the ADRC could provide them with support. (iii) differences in needs for service delivery making the provision of information and referral services to older people with LD challenging to a system that's set up for providing support to older people (but not OPLD). Respondents doubted the capacity of staff in ageing services to provide support to this population but also felt that given the silo working (LD vs. OP services) it doesn't seem likely that these problems can be addressed. Another difference in the need for service delivery that makes it hard for ADRC staff to provide information and referral is that families are often the first point of contact for OPLD so coordinating between families, the OPLD and referral agencies makes it hard to streamline services across ageing and disability services, 'we place a very high priority on getting the primary guidance [from] the person with the disability. [For example] we cannot provide advocacy related to benefits ... unless we are talking directly with the person who has the disability or their legal representative. And so if you have a sibling or a	

	we assume the programme is delivered in the resource centre (the ADRC). **Follow-up:** No follow-up. **Costs?** No.	friend who isn't in that position of having the legal representation ... calling...we can't just dive straight into solving the problem. That could definitely be a barrier' (p8). Two other gaps in services highlighted: - eligibility requirements based on age mean that younger adults with LD (experiencing accelerated ageing) aren't eligible for the same information and direct services available to the general ageing population - a lack of services to meet the needs of the growing general population, let alone the growing population of adults with LD who are ageing. **3. Long-term services and supports (LTSS) needs of OPLD are seen in parallel with the needs of older people but there isn't appropriate tailoring/delivery models are lacking.** Staff reported that LTSS services aren't designed to include the OPLD population and in some cases, where the service could be appropriate it cannot be accessed because of eligibility criteria (sometimes tied to funding). One exception was housing and home adaptations where it's less challenging to meet the needs of OPLD with universal services. (Includes findings suitable housing and adapting current housing).	

		In the interviews, staff considered how to meet the needs of OPLD in future. Cross-training so that staff learn more about OPLD and their families, e.g., 'the physical, cognitive, and mental/social changes that they're going through because they age like everyone else but they age a lot faster. They don't have the same social networking that an average older adult has. And I think [knowing] how to approach that as a professional, how to connect them to resources and navigate the system – that would be important in a training' (p9). Staff said that in future they want to develop services specifically for OPLD. At the moment they sometimes expand older people's services to include adults ageing with LD but the LD adults often don't want to participate with the older people.	

3. Dodd P, Guerin S, Mulvany et al. (2009) Assessment and characteristics of older adults with intellectual disabilities who are not accessing specialist intellectual disability services. Journal of Applied Research in Intellectual Disabilities 22: 87–95

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: Part 1 of the study used the National Intellectual Disability Database (Ireland) to identify a representative sample of older individuals with ID who were outside of services. For the purposes of this review we will be looking at part 2 of the study – how key workers responded to a questionnaire on the assessment and support practices of service providers for older people with ID who have been identified as	**Participants:** Professionals/practitioners. Key workers of older individuals over 30 with ID who are outside of services. **Sample size:** Sample comprised 43 cases. **Follow-up:** No follow-up. **Costs:** Not reported.	Key workers contact with target individual/families. **Individuals** The mean time since the key workers contact with the target individual was 5.3 months. There were 4 cases where no information was given 10 cases: no contact with the individual 6 cases: last contact was 12 months or more. **Families** The mean time since the key-worker had any contact with the family was 5.2 months 11 cases: no contact with the family 7 cases: last contact was 12 months or more before the time of data collection. **Key-workers' opinion** Individual had no current service needs 60% agreed 28% disagreed. 12% missing data or comments that no opinion could be given. Key workers said they agreed with decisions when they felt that the family provided satisfactory care. 'His sister involves him in the working of the farm as well as going	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
being outside services. **Methodology:** Survey. **Country:** Ireland. **Source of funding:** Not reported.		to social activities with family members. The person appears very happy with the current situation' (p92). 'Very supportive family. Four adult sisters care for him and they say that between them they will always look after him' (p92). Some key workers has not personally assessed the individual but the family had said that the person did not need services. Key workers that disagreed with the decision usually did no on the basis that the individual may benefit from social activity. Some said that the individual themselves has said that they did not want help from services. **Key worker perceptions of service use** Individuals ceasing to use services: exploitation (4.7%); work too strenuous (6.9%); unknown (9.3%). Families not using services: most said that individual was happy at home, or happy with current services used, family were not offered services or appropriate services were not available. 'The cultural influences of being Jamaican (mother's ethnicity) is possibly a factor here. Both mother and son enjoy a good relationship and have established a way of coping that excludes	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		services' (p92). 'Family are elderly. Have coped without intervention for years. Feel that they can continue to manage independently. Lack of knowledge of services has caused apprehension. Fear of split of family unit' (p92). 'Mother considers her son as not being appropriate for a day service and thinks that he wouldn't be happy in a service' (p92). Eleven key workers said that in most cases families were not encouraged to engage in services (25.6%). Others said they encouraged families to engage and would inform them if more suitable services were created.	

4. McIlfatrick S, Taggart L, Truesdale-Kennedy M (2011) Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. European Journal of Cancer Care 20: 412–20

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'The overall aim of this study was to ascertain the healthcare	**Participants:** Professionals/practitioners. Healthcare professionals. **Sample size:** Total 18 professionals 9 primary care:	**Knowledge and awareness of breast cancer and breast screening** Practitioners felt that is was important that women with intellectual difficulties were screened for breast cancer. The reason for this was for early intervention and	**Overall assessment of internal validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
professional's perspective on their role in supporting women with intellectual disability to access breast cancer screening. Specific objectives included exploring healthcare professionals': 1) Knowledge and awareness of breast cancer and breast screening; 2) Role and experiences of supporting women with intellectual disability to access breast screening services; 3) Perceptions of the barriers and solutions as to	4 general practitioners, 2 practice nurses, 1 nurse practitioner, 1 primary healthcare advisor, 1 specialist registrar in public health, 9 hospital breast screening: 2 superintendent radiographers, 5 breast screening nurses, 1 clinical coordinator, 1 director of the breast screening programme. **Follow-up:** No follow-up. **Costs:** Not reported.	prevention. 'Well they [women with ID] shouldn't be left out of the group. It's part of health screening ... Why should they be discriminated against?' (p415). Practitioners appeared will informed about the particular risks of women with ID, associated with breast cancer. Practitioners identified risks associated with limited cognitive function, ability to self-examine, lack of knowledge of breast cancer, literacy skills and difficulty dealing with correspondence and attending appointments. 'Some of the difficulties would be that perhaps their [women with ID] ability to examine themselves. Examination may be a problem whether that be because perhaps they would be unable to do it or they wouldn't understand the importance of it or what they would be looking for' (p415). Other risks identified in the interviews: poor diet, medical history and hormone medications, not having children. **Role in supporting women with intellectual disability access screening services.** Health professionals tried to encourage women with ID to	**Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
why women with intellectual disability access breast screening services or not' (p413). **Methodology:** Qualitative Study. Focus groups and telephone interviews. **Country:** UK. **Source of funding:** Not reported.		attend breast screening. Their key roles were 'health promotion and providing education and support' (p415). Health Promotion: GPs used routine visits to promote breast screening, and liaison with family or community disability teams. 'We tend to see people with intellectual disabilities opportunistically mostly … and I think that could be used as an opportunity to check with themselves and their carers that they have actually accessed screening, not only breast but also cervical' (p415). Professionals who worked in screening units had a role in explaining the procedure to people and then offering health advice before and after, also involving carers. If there was a diagnosis, they referred them on to other services. 'My role as a clinical nurse specialist is to educate the ladies, to be a support aid, to provide information about each step of the process' (p415). **Barriers to women with intellectual disability accessing breast screening services** The barriers associated with women with intellectual	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		disabilities were linked to their cognitive abilities, communication issues and issues with understanding. 'If they have intellectual disabilities and something comes in the post and they are not able to read, they may not even be aware that they have been invited to breast screening' (p416). 'Also a lack of understanding of the procedure or of the purpose of the mammogram may be a barrier to the patient in that they really don't understand why they should be coming and don't realise the importance of it' (p416). **Some women may also have limited mobility and poor physical health** The issue of consent was also a concern, if women were felt to be unable to consent to the procedure and possible treatment: 'some patients because of their learning disability will not be able to consent and I think that is an issue' (p416) and other patients may say that they do not want the screening to be done. **Barriers attributed to carers** It was felt that carers were helpful in supporting women in	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		screening and so those without support were at a disadvantage. 'I don't think they [women with ID] would have ever gone through with any of the screening unless that they had the support of someone to communicate on their level and to advocate for them' (p416). Another view was that carer attitudes can be a barrier. For example, when carers made the decision not to do the screening. 'The decision could be taken for them [women with ID] by carers and relatives may feel that it's not what they need, that it might cause them distress. So the decision may not necessarily be taken by the patient themselves' (p416). **Practical barriers** There were other barriers to women attending screening, factors like the time of appointments and transport links were cited. 'So a transport practicality may prevent them from coming'; 'Maybe timing of appointments because a lot of these women need care in the morning' (p416).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Barriers attributed to healthcare professionals Barriers included attitudes, awareness levels, experience of LD and training. The study states that there may be a need for more training. Some participants said that health practitioner had a lack of awareness of older people with LD and did not consider how their needs may be a barrier to breast screening. 'I think the main barrier really is health promotion wise, I think we let them down by not being aware of the ladies within your population who have intellectual disabilities' (p416). The focus groups described GPs as gatekeepers for women to access breast screening. **Solutions to women with intellectual disability accessing breast screening** The groups discussed solutions to assist women to access breast screening. - Awareness around the needs of older women with learning disabilities. - Promote interdisciplinary working. - Promote integrated working. - Links with GPs.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'Having a multi-disciplinary approach from primary care, the radiography staff, you know, learning disability and identify what their learning needs are' (p416).	

Review question 5 – critical appraisal tables – the views and experiences of people using services, their families and carers

1. MacGiolla Phadraig C, Burke E, McCallion P et al. (2014) Dental attendance among older adults with intellectual disabilities in Ireland. Special care in dentistry: official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry 34: 265–72

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
Study aim: From the abstract, 'To investigate dental attendance patterns and reasons for nonattendance among older adults with intellectual disabilities (ID) in Ireland' (p265). **Methodology:** Mixed methods study. A cross-sectional survey of quantitative data and text analysis of qualitative data drawn from a nationally representative sample of 753 people with ID over 40 years of age	**Quantitative comp A:** Analysis of cross sectional quantitative data. **Are participants (organisations) recruited in a way that minimises selection bias?** Unclear. The paper states that a 'nationally representative sample of 753 people with intellectual disability over 40 years of age was randomly selected from the National	**Does the study's research question match the review question?** Partly. Because the study partly looks at patterns	**Overall assessment of internal validity (qualitative):** + **Overall assessment of external validity**

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
in Ireland. **Qualitative comp 1:** Open-ended question posed to irregular dentist attendees via survey method. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Partly. Reasons for irregular dentist attendance could have been explored in more depth had the researchers conducted interview with those individuals. The paper mentions that interviews were conducted but there is no account of them in the findings section (only answers from the open-ended survey question). **Is the process for analysing qualitative data relevant to address the research question?**	Intellectual Disability database' (p66). However, there is no description about how this randomisation was conducted and the demographic details are not presented within the context of the wider population of adults with LD. **Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?** Partly. The questions in the survey seem clear and appropriate to the aims of the study. The dental items are taken from the longitudinal study so the original is clear but there is no description about how they have been previously validated. The classification of regular or irregular attendees is based on previous published work, cited in the paper.	of attendance and partly at reasons for those patterns, so it's not entirely focussed on access issues. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was gained from the Faculty of Health Sciences research ethics committee in Trinity College Dublin and all	**(quantitative): ++**

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
Yes. The methods of data collection and analysis are clear and appropriate to the aims of the study. **Is appropriate consideration given to how findings relate to the context, such as the setting in which the data were collected?** N/A. Findings unlikely to be affected by context in this study. **Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants?** Partly. The researchers don't consider how their role could influence the research although it is difficult to see how it could. They do however explore reasons why the study findings are at variance with other research in this area (in the discussion) and presumably their own expectations about the findings.	**In the groups being compared (exposed versus non-exposed; with intervention versus without; cases versus controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?** N/A. There are no comparison and intervention groups. **Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?** No. RR was 46%. **Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question?** Yes. The rationale for mixing quant and qual	participating services. **Were service users involved in the study?** Yes. The researchers report that people with learning disabilities were involved in the design and implementation of the study although NB. It is unclear whether this refers to the design of the IDS-TILDA or specifically to this study, in	

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
	methods is clear – the researchers sought to identify the pattern of dental attendance and also the reasons behind that pattern. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Partly. No consideration of the limitations of integrating quant and qual data but the authors do describe the limitations of the methodology, including the self-report dental attendance patterns and the fact they did not ask people why they DO attend the dentist.	which analyses of data from the main data set were conducted. **Is there a clear focus on the guideline topic?** Yes. Access to health (dental) services for OPLD. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the**	

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
		same as at least 1 of the settings covered by the guideline? Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes.	

Internal validity – qualitative components	**Internal validity – quantitative components**	**External validity**	**Overall validity rating**
		Does the study have a UK perspective? No. Republic of Ireland.	

2. Swaine JG, Dababnah S, Parish SL et al. (2013) Family caregivers' perspectives on barriers and facilitators of cervical and breast cancer screening for women with intellectual disability. Intellectual and developmental disabilities 51: 62–73

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Study aim: 'the present study addressed the following research questions: (a) What are family caregivers' perspectives on why women with intellectual disability do not receive cervical and breast cancer screening? (b) What are family caregivers' perspectives on the comfort women with intellectual disability have with respect to cervical and breast cancer screening? (c) What do family caregivers feel are the	**How well was the data collection carried out?** Appropriately. Phone calls allow a small team to reach a big sample and can flexibly arrange times to talk that are convenient and don't require the participant to travel. The transcription process and double coding are sufficiently described.	**Does the study's research question match the review question?** Yes. Views and experiences of improving access to health services. **Has the study dealt appropriately with any ethical concerns?** Yes. 'The research protocol was approved by the team's university institutional review	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
best ways to facilitate screening for women with intellectual disability? (d) Do family caregivers feel that their women family members with intellectual disability receive adequate health care? (e) Are family caregivers knowledgeable about the need for cervical and breast cancer screening among women with intellectual disability?' (p63). **Methodology:** Qualitative study. Semi-structured qualitative interviews. **Is a qualitative approach appropriate?** Appropriate. Obtains views and experiences. **Is the study clear in what it seeks to do?** Clear. Use 'semi-structured qualitative interviews to assess barriers to	**Is the context clearly described?** Clear. The varying characteristics and contexts of the participants and their relatives are well described in Tables 1 and 2. Their geographic location is given, and the reader is referred to the original study for any further details on recruitment. Generalisability is discussed in the conclusion section. **Was the sampling carried out in an appropriate way?** Appropriate. The sampling was carried out well for a study that draws on an existing sample from another study. There were efforts to obtain an even range participants by race and economic status. Some were lost to follow-up, but the paper describes their	board' (p63). 'Study procedures to obtain consent and assent from women with intellectual disability to enrol in the larger study are described elsewhere (Swaine et al. 2011).' 'We sought consent from the women before inviting their caregivers to participate in the study' (p 64). **Were service users involved in the study?** No, but were involved in other aspects of the wider study. This part had a specific focus. **Is there a clear focus on the guideline topic?** Partly. This paper concerns views and experiences	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
care from the perspective of female familial caregivers' (p62). **How defensible/rigorous is the research design/methodology?** Defensible. Well described and justified in the methods section and then critically considered in the conclusions.	attempts to re-contact them. As a result of the sample being taken from another study, the sample is limited by only including participants that were already known to services – but this is considered in the discussion. **Were the methods reliable?** Somewhat reliable. No methods of triangulation are used, such as talking with the older people with learning disabilities themselves or seeking medical records. But the work is discussed in the context of other studies – particularly the agreement around barriers as described by health professionals and service users themselves. **Are the data 'rich'?** Rich. Mostly rich – lots of comparison between coded groupings and quotes to reinforce findings. Could also use	around enablers to healthcare access, but may be better in the topic question concerning health – some overlap. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. The female carers of older females with learning disabilities. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Private home as care setting. **Does the study relate to at least 1 of the activities covered by the guideline?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	some comparison across demographics. **Is the analysis reliable?** Reliable. Range of themes and diversity of responses well discussed and reinforced with quotes. One aspect missing is comparisons by groups/demographics. **Are the findings convincing?** Convincing. Coding and processes are well described and logical, and extracts from the original are laced throughout. The study question is addressed and put into the context of other research. **Are the conclusions adequate?** Adequate. Conclusions are detailed, and their own critical appraisal is thorough. The implications are well discussed.	Yes. Access to proper healthcare. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Barriers and enablers and feedback to efforts to promote health screenings. **Does the study have a UK perspective?** No. USA.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating

3. Wark S, Canon-Vanry M, Ryan P et al. (2015) Ageing-related experiences of adults with learning disability resident in rural areas: one Australian perspective. British Journal of Learning Disabilities 43: 293–301

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'The specific aims were to examine select issues of ageing when residing within rural areas, ascertain facilitators and barriers to services, and identify practices that may enhance supports for adults living outside metropolitan locales' (p294). **Methodology:** Qualitative study. Face-to-face interviews with older people with learning disabilities and nominated carers (family members). **Is a qualitative approach appropriate?** Appropriate. Because the research seeks to	**How well was the data collection carried out?** Appropriately. Data collection methods are clearly described (interviews were recorded and transcribed verbatim). Although not explicitly stated, data appear to have been collected systematically but there is no mention at all about systems for record-keeping. **Is the context clearly described?** Clear. The characteristics of the participants and settings are	**Does the study's research question match the review question?** Yes. The study examines experiences relating to accessing care and support for OPLD but specifically in rural areas. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval for this research was granted by the University of New England's Human Research Ethics Committee, with individual consent obtained from all	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
illuminate subjective experiences and views. **Is the study clear in what it seeks to do?** Clear. The purpose of the study is discussed in terms of aims/objectives and clearly defined research question. There is appropriate reference to the literature and theory which are discussed at the beginning and then at the end of the paper. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. The design is appropriate to the research question and there is a clear rationale for using a qualitative approach. The sampling is the key methodological weakness (not	clearly defined and linked with the original data. **Was the sampling carried out in an appropriate way?** Not sure. The authors provide very little detail about sampling, saying only that it was impractical to randomly select participants. Information sessions were held in the 2 selected locations and expressions of interest were invited. With participants being self-selecting it is therefore possible that only those with particularly negative experiences, keen to share them, were included in the study. **Were the methods reliable?** Somewhat reliable. The methods do investigate what they claim to and it is a positive that interviews were conducted both with OPLD	participants and/or their person responsible (p295). **Were service users involved in the study?** Yes. The research team established an advisory group composed of people with learning disabilities, carers and representatives from 4 non-government organisations. The advisory group provided ongoing feedback and support through reviewing the materials, suggesting representative locations and facilitating access to participants (p295). The only weakness is that older people with learning disabilities themselves were not involved as co-	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
random and not geographically widespread) although this is discussed and justified by the authors. The authors do not disclose how many people were invited to participate in interviews, 'expressions of interest were sought from potential participants ...' (p295). Data collection and data analysis techniques are clearly described and justifiable.	and nominated carers (potential triangulation) although it is unclear whether the interviews were conducted together or separately. Data collection was however limited to the 1 method of interviews and we do not benefit from hearing the views of practitioners, e.g. about the difficulties in ensuring access to care and support in rural areas. **Are the data 'rich'?** Rich. The contexts of the data are clearly described and some diverse perspectives have been explored. Supporting original data is provided and findings are organised under clear themes. **Is the analysis reliable?** Reliable. Analysis was in 2 stages, 'The first stage of the analysis had five members of the research	researchers. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Participants lived in a number of settings, all of which are covered by the	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	team read the transcripts. At a group meeting, an initial coding structure based on preliminary thematic areas was established. The five researchers then individually coded the transcripts' (p296). In the second stage the research team discussed emerging themes and established a coding structure. Finally, 'The interviews were jointly analysed by the research team in line with the coding structure and collaboratively refined into thematic areas' (p296). A process was established for addressing any disagreements about thematic areas but this wasn't needed. **Are the findings convincing?** Convincing. The findings are clearly presented in thematic areas and extracts from the original data are included. The	guideline. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Accessing care and support for OPLD. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views and experiences of older people with learning disabilities and their families/carers. **Does the study have a UK perspective?** No. Australia.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	data are appropriately referenced and the overall, the reporting is clear and coherent. **Are the conclusions adequate?** Adequate. The findings are relevant to the aims of the study demonstrated by clear links between data, interpretation and conclusions. The conclusions add weight to existing research about access difficulties in rural areas but it also shed light on some positive aspects of growing old with a learning disability in rural areas. The authors discuss the study limitations, which include its small-scale nature.		

Review question 5 – critical appraisal tables – health, social care and other practitioners' views and experiences

1. Benbow SM, Kingston P, Bhaumik S (2011) The interface between learning disability and old age psychiatry: two specialties travelling alone or travelling together? Mental Health Review Journal 16: 25–35

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The overall aims of the interface group authoring the paper included 'to look at what services were needed and how they should be accessed'. With regards to this, the survey aimed to 'establish an overview of current service operation and provision' (p26). **Methodology:** Survey. Postal questionnaire, with open questions. **Research design clearly specified and appropriate?** Yes. **Objectives of the study**	**Clear description of context?** Yes. There is a detailed outline of who the survey was sent to, and explaining the need, social and political context of why this group was seeking answers to these questions. **Survey population and sample frame clearly described?** Yes. All practitioners from their membership list in the 2 fields of LD and old age psychiatry. **Describes what was measured, how it was measured and the results?** Yes. Clearly outlines the open-ended questions asked, and makes them the headings for the	**Does the study's research question match the review question?** Partly. It is in the right population area, but not specifically about improving access – that comes up incidentally. **Has the study dealt appropriately with any ethical concerns?** Partly. No information is given. However it does not study any vulnerable groups directly and the anonymity of respondents is protected so ethical concerns aren't too high.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
clearly stated? Yes. The objectives of the working group behind the research was explained, and then it was outlined that this study sought to understand 'current service operation and provision' (p26) as a part of this.	results section – with answers divided into sub topics and the proportions of responses are given for each theme. **Measurements valid?** Yes. Very broad and open ended questions. The topics covered and wording used is fairly unambiguous, but it is not clearly described how these were chosen or tested. **Measurements reliable?** Partly. Open-ended questions based on experience – but may well be affected by any recent experiences. **Basic data adequately described?** Yes. Each section gives the results for each question, describing the themes, with typical examples and proportions of the responses that came under that category.	**Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Partly. It is in the right population area, but not specifically about improving access – that comes up incidentally. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Relates to practitioners and their experiences with the specific group outlined. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Yes, in mental healthcare settings.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Results presented clearly, objectively and in enough detail for readers to make personal judgements? Partly. It's a large dataset, with many varying responses, so there is some degree of interpretation and trust that the themes they have picked are the most useful. There is not a lot of detail for each theme either – could be longer. But mostly adequate. **Results internally consistent?** Yes. No obvious anomalies or missing data. **Clear description of data collection methods and analysis?** Yes. Details the analysis run in NVivo, and the themes and proportions for responses are clearly given. **Methods appropriate for the data?**	**Does the study relate to at least 1 of the activities covered by the guideline?** Partly. Relates to those accessing and using mental health services. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Not specific, but relates to the overall experience of practitioners with this group, which includes a bit on access, and obstacles to it. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Yes. **Results can be generalised?** Yes. A large sample that covers much of the UK, and can give a good idea of the varying experiences. **Conclusions justified?** Yes. Suitable to the responses, that combine the findings and themes with the broader context, and considers implications.		

2. Coyle CE, Putman M, Kramer J et al. (2016) The role of aging and disability resource centers in serving adults aging with intellectual disabilities and their families: findings from seven states. Journal of Aging and Social Policy 28: 1–14

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To develop an understanding of how Aging and Disability Resource Centres (ADRCs) administer resources and support to adults ageing with intellectual and developmental disabilities (I/DD). There were 4 objectives:	**How well was the data collection carried out?** Appropriately. Despite the questionable sampling technique, and the fact that no interviews were conducted with older people with learning disabilities or their families, the data were collected	**Does the study's research question match the review question?** Yes. The study's question focuses on how well OPLD can access the services provided by ADRCs.	**Overall assessment of internal validity:** + **Overall assessment of external validity:**

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
1) to describe goals expressed by ADRCs with regards to serving the population of older adults with I/DD and their families. 2) to determine how older adults with I/DD are referred to both ageing and disability resources 3) to understand the range of programme activity geared toward serving older people and their families 4) to identify gaps in resources and services for older adults with I/DD and their families. **Methodology:** Qualitative study. Face-to-face interviews with programme coordinators and project staff in 7 US states. **Is a qualitative approach appropriate?** Appropriate.	appropriately. **Is the context clearly described?** Unclear. Apart from knowing that respondents are either ADRC coordinators or ADRC programme staff, the characteristics of the participants and settings are not clearly defined. Data collection was via interviews leaving little opportunity for triangulation of findings. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. Sample was created through purposive approach. State ADRC programme coordinators were recruited by email from the 8 states who had been awarded funds in 2012 to implement the ADRC Enhanced Option Counselling (EOC) Program by Administration for Community Living (ACL). Options Counselling is an ADRC information and	**Has the study dealt appropriately with any ethical concerns?** Yes. All parts of the procedure were reviewed and approved by the Institutional Review Board at the University of Massachusetts Boston and Simmons College. Note that 'Due to the public position these ADRCs play in their states and communities, study participants were informed in the consent process that their confidentiality could not be ensured' (p4). However, data were aggregated across all states and individual state-level analysis was not reported – this was a means of providing some level of protection against direct linkage of interview data to staff.	+

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Is the study clear in what it seeks to do? Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. The qualitative design is appropriate to the research question although the authors do not provide their own rationale for their methodology. Sampling of the ADRC coordinators is clear and rational but the programme staff were identified by being 'recommended' by the coordinators. There is no rationale for taking this approach which does introduce a risk of bias into the sampling because the coordinators may have had particular reasons for recommending those programme staff and not others.	referral programme with a person-centred focus. The recruited programme coordinators then nominated a total of 21 local ADRC contacts to be interviewed (14 of which agreed). Recruitment of programme staff in this way does introduce a risk of bias as we do not know why they were chosen or why others were not. **Were the methods reliable?** Somewhat reliable. Apart from interviewing coordinators and programme staff, there is little opportunity for triangulation through observation or interviews with OPLD or their families. This is a clear weakness. **Are the data 'rich'?** Mixed. There are some supporting quotes and a fairly in-depth description of findings. **Is the analysis reliable?** Reliable. Two researchers	**Were service users involved in the study?** No. Neither as interviewees nor co-researchers. **Is there a clear focus on the guideline topic?** Partly. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes – the provision of information and services to	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	conducted primary coding. Final coding structure and excerpts of sample data presented to the full research team to reach agreement on analysis. After corroboration of codes the researchers carried out a more refined analysis of sub themes. **Are the findings convincing?** Convincing. The findings clearly presented and internally coherent. Extracts from the original data are included and appropriately referenced. **Are the conclusions adequate?** Adequate. There are clear links between data, interpretation and conclusions and the conclusions are plausible and coherent. The authors discuss the limitations of the research design.	support OPLD. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. And the Guideline Committee should consider the applicability of data about ADRCs to the UK context.	

3. Dodd P, Guerin S, Mulvany et al. (2009) Assessment and characteristics of older adults with intellectual disabilities who are not accessing specialist intellectual disability services. Journal of Applied Research in Intellectual Disabilities 22: 87–95

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: Part 1 of the study used the National Intellectual Disability Database (Ireland) to identify a representative sample of older individuals with ID who were outside of services. For the purposes of this review we will be looking at part 2 of the study – how key workers responded to a questionnaire on the assessment and support practices of service providers for older people with ID who have been identified as being outside services. **Methodology:** Survey. **Research design clearly specified and appropriate?** Partly. The survey design does not seem like the best way to gain detail around why families	**Clear description of context?** Yes. **Survey population and sample frame clearly described?** Yes. Population and sample clearly described. **Describes what was measured, how it was measured and the results?** Partly. The measurement and analysis are very poorly described. **Measurements valid?** Partly. The study used a questionnaire designed specifically. Most results are expressed as means. **Measurements reliable?** Partly. Description of the analysis is sparse but we are given a table with the frequency of reasons for	**Does the study's research question match the review question?** Partly. Only the second part of this 2-part review is relevant to this question. The second part does look at the assessment procedure for people who were seen has having no service needs. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval gained. **Were service users involved in the study?** No. Not directly. **Is there a clear focus on the guideline topic?**	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
were assessed as not having a need for services. **Objectives of the study clearly stated?** Yes.	assessment. **Basic data adequately described?** Yes. Basic data described in a table. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Partly. Results are presented thematically, but we are not given details of the analysis so it is hard to say how objective they are. **Results internally consistent?** Partly. As methods are poorly described it is hard to say. Themes appear to match table data. **Clear description of data collection methods and analysis?** Partly. Methods are described, but not analysis.	Partly. The mean age of the sample is 47.9, but did include people over 60, so the population does not exactly match our criteria. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. The guideline covers all older people with learning disabilities irrespective of whether they are known to services). **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community services. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Assessment of health	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Methods appropriate for the data? Partly. **Results can be generalised?** No. The reporting on data analysis is unclear and the questionnaire was designed specifically for this context. **Conclusions justified?** Partly. The conclusions are set out in detail, but die to issues with reporting it is unclear whether they are justified, but themes appear to match table data.	and social care needs. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Practitioner views on assessment of needs. **Does the study have a UK perspective?** No. Ireland.	

4. McIlfatrick S, Taggart L, Truesdale-Kennedy M (2011) Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. European Journal of Cancer Care 20: 412–20

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'The overall aim of this study was to ascertain the healthcare professional's perspective on their role in	**How well was the data collection carried out?** Appropriately. Data was collected via interviews and a focus group,	**Does the study's research question match the review question?** Yes. The focus of the study is on the levels	**Overall assessment of internal validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
supporting women with intellectual disability to access breast cancer screening. Specific objectives included exploring healthcare professionals': 1 Knowledge and awareness of breast cancer and breast screening; 2 Role and experiences of supporting women with intellectual disability access breast screening services; and 3 Perceptions of the barriers and solutions as to why women with intellectual disability access breast screening services or not' (p413). **Methodology:** Qualitative study. Focus groups and telephone interviews. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear.	both were recorded, transcribed and thematically analysed by more than 1 researcher. **Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate. Sample was taken from 3 breast cancer screening units. **Were the methods reliable?** Reliable. **Are the data 'rich'?** Rich. A good deal of verbatim quotes are included. **Is the analysis reliable?** Reliable. Thematic analysis was carried out using NVivo. **Are the findings convincing?** Somewhat convincing. The	of access to breast screening services, and the barriers and facilitators to screening. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was obtained. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Partly. The population is not strictly older people, but we can assume that the women would be of a certain age if they were eligible for breast screening. **Is the study population the same as at least 1 of the groups covered by the**	**Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
How defensible/rigorous is the research design/methodology? Defensible. Methods are well described and appear rigorous.	sample size is relatively small. But the aims of the study are to identify the issues around access for women with ID to breast screening. We learn about some of the barriers and facilitators, but less about the experiences of professionals working with women with ID. **Are the conclusions adequate?** Adequate. Findings are detailed and the themes seem appropriate.	**guideline?** Partly. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Health setting. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Assessment and review of health needs. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views of health practitioners. **Does the study have a UK perspective?** Yes.	

Review question 6. Volunteering, social and leisure activities, transport and technology and maintaining relationships:

a. What is the effectiveness and cost effectiveness of care planning and support for older people with learning disabilities to access volunteering, social and leisure activities, transport and technology and maintain relationships with family, friends and within their local community?

b. What are the views and experiences of older people and their carers in relation to support for developing and maintaining relationships with family, friends and the local community?

c. What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities to develop and maintain relationships with family, friends and the local community?

Review question 6 – findings tables – effectiveness

1. Brooker K, van Dooren K, McPherson L et al. (2014) A systematic review of interventions aiming to improve involvement in physical activity among adults with intellectual disability. Journal of Physical Activity and Health 12: 434–44

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: A systematic review of interventions aiming to improve PA levels of adults with intellectual disability.	**Participants:** Service users and their families, partners and carers adults with intellectual disability residing in the community, and their proxies.	**Effect sizes** Objective and subjective measures to PA frequency and duration using:	**Overall assessment of internal validity: +**

Methodology: Systematic review. **Country:** USA and UK. **Source of funding:** Not reported.	**Sample characteristics:** • Age – ranged from 18 to 71 years, mean age 38 to 48 years**.** • Gender – 40% male, 60% female. • Ethnicity – not reported. • Religion/belief – not reported. • Disability – level of intellectual disability ranged from mild to severe; 4 studies only included adults with mild to moderate intellectual disability. • Long-term health condition – 2 studies included only overweight or obese people. • Sexual orientation – not reported. • Socioeconomic position – not reported. **Sample size:** Systematic reviews: number of studies 6 studies (total participants 856, range 42 to 432). **Intervention:** Physical activity programmes. **Description:**	1. Accelerometers to measure minutes per day spent in PA and sedentary time. 2. International Physical Activity Questionnaire short form questionnaire (IPAQ-S), completed by caregivers and participants together. 3. Data collected from 5 days, 7 days including 2 weekend days (full data were only available for 59% of the participants). A. PA frequency and duration (Table 2, p 440–1). Mean frequency/week, using self-reported PA interviewer administrated questionnaire A significant increase in PA group exercise sessions pre: 3.2 times; post: 3.9 times (P =.01) mean minutes/week of self-reported PA: pre: 133 mins; post: 206.4 mins (p=.002) (Bazzano 2009, n=44, p440).	**Overall assessment of external validity:** **+**

	1. Most interventions set in the community with sessions implemented through support organisations and in a group format (pp436–7). 2. Offered optional home visits to participants to develop a home exercise programme (including exploring suitable walking routes in their community) and grocery visits to help identify healthy food choices (2 studies). 3. Individualised intervention within participants' homes (1 study). **Delivered by:** Health educators/professionals and peer mentors (all received training and support from research team on nutrition and weight loss). **Delivered to:** Adults with intellectual disability. **Duration, frequency, intensity, etc.:** **Intervention frequency**: ranged from once every 2 to 3 weeks to twice weekly. The length of each session: ranged from 30 to 120 minutes.	B. Mean time spent in moderate to vigorous PA (mins/day) using accelerometers (Table 2, pp440–1). No significant increase in PA pre: .00; post: 7.71 (p=.41)(Bodde 2012, n=42, p440). C. Exercise yes/no (%), using Self-reported PA interviewer administrated questionnaire (Table 2) No significant increase in PA in people with intellectual disability Participants with intellectual disability: pre: 75; post: 70 (p=.33) Participants without intellectual disability: pre: 58.8; post: 74 (p=.013) (Ewing 2004, an RCT, n=189) (Table 2, p440). D. Mean frequency/week, using Self-reported PA interviewer administrated questionnaire (Table 2). A significant increase in PA pre: 3.24 times; post: 4.62 times (p ≤.001)(Mann 2006, n=192).	

	Duration: Over 8 weeks (4 studies); 6 to 7 months (2 studies). **Key components and objectives of intervention:** Main components and focus: 1. Education about PA and the other health behaviours of interest, using interactive lessons to convey their information (3 studies), providing information on the benefits of exercise and information about PA guidelines (4 studies). 2. Participation in PA (e.g., offer of optional brisk walks after the sessions; incorporated 1 hour of exercise in the sessions and visited local parks and fitness facilities etc; or demonstration and practising exercises and stretches in the sessions) (p437). 3. Discussions with participants about their current PA behaviour and strategies (goal-setting) they could apply to increase their PA (e.g., replacing sedentary behaviours at home with gardening); also provided participants and their support person with details of local clubs and facilities with accessible groups.	E. % of participants with increased PA at 12 months, using accelerometers (Table 2). No significant increase in PA Intervention: 52.46% control (group hygiene and safety classes): 50.88% (p=.864)(McDermott 2012, n=432). F. % mean time spent in PA, using accelerometers (Table 2, pp440–1). a. PA in light intensity PA (min/day). A significant increase pre: 10.4; post: 12.3 (p=.027). b. PA in moderate to vigorous intensity (min/day). No significant increase pre: 2.1; post: 2.7 (p=.072). c. % mean time spent in sedentary behaviour (min). A significant decrease pre: 87.5; post: 84.9 (p=.012). IPAQ-S: no change, suggesting no change between baseline and follow-up measures (Melville 2011, n=54, p441).	

	4. Formally involve caregivers to support participants in the intervention (1 study) (p437). 5. Peer mentors created an exercise video for participants and were available to participants for support. **Content/session titles:** Physical activity. **Location/place of delivery:** Community or home settings. **Comparison intervention:** One study compared the outcomes of the PA programme (the Health Education Learning Program (HELP)) between adults with intellectual disability and adults without intellectual disability (Ewing 2004). One study compared the outcomes of the PA programme with a control group (receiving group hygiene and safety classes same time and venue as PA class) (McDermott 2012). Other 4 studies were of before-and-after design. **Outcomes measured – service user related:** Mean frequency and duration of PA per week. **Follow-up:** No follow-up data.	Three of the 6 included studies reported a significant increase in PA and three did not. PA interventions have the potential to improve the health and wellbeing of people with intellectual disability. However, these results are based upon a small number of studies mostly of a pre-post design with small sample sizes. None of the measures used in the studies reviewed have been demonstrated to be valid or reliable in people with intellectual disability and findings lacked follow-up data to determine the impact of interventions in the long term.	

	Costs Not reported.		

2. Carmeli E, Orbach I, Zinger-Vaknin T et al. (2008) Physical training and well-being in older adults with mild intellectual disability: a residential care study. Journal of Applied Research in Intellectual Disabilities 21: 457–65

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: The aim of this study was to investigate the effect of physical training on general wellbeing and self-image in older people with intellectual disability. **Methodology:** Comparative study The control group, which was age- and sex- matched, did not receive any physical intervention.	**Participants:** Older adults with intellectual disability living in a protected residential care setting**.** **Sample characteristics:** • Age – the exercise group included 23 women and 8 men, ranging from 47 to 67 years of age (mean age 56.5 years). The control group, was age and sex matched. • Gender – the exercise group included 23 women and 8 men, control group was matched for gender. • Ethnicity – not mentioned. • Religion/belief – Not mentioned • Disability – the study population required mild assistance for most of the daily activities.	**Effect sizes** An analysis of variance show a significant difference in groups in two specific domains. Social acceptance F (2,57) = 8.79, p<0.05 - Physical appearance F (2,57) = 3.15, p= 0.05. Physical exercise resulted in significant positive changes in relation to three basic dimensions of NHP: Mean post training results (%) Control group (n=31) Experimental group (n=29)	**Overall assessment of internal validity:+** **Overall assessment of external validity: +**

Country: Not UK. Israel (OECD country). **Source of funding:** Not reported.	- Long-term health condition – intellectual disability, required mild assistance for most of the daily activities. - Sexual orientation – Not reported - Socioeconomic position – participants were living in residential care centres. **Sample size:** Total 62 were enrolled, 31 experimental group and 31 control group. **Intervention:** The intervention, exercise programme will support older people with learning disabilities to improve health and wellbeing. **Description:** The prescribed exercise programme conformed to the guidelines set by the American College of Sports Medicine. **Delivered by:** Physical therapist and physical education teacher, who were familiar with the participants conducted the exercise, alternately. **Delivered to:** Experimental group trained as a group and not on an individual basis.	Energy – control group (22.73 +/- 4.3) Experimental group (51.46 +/-12.3) p=0.001*. Social isolation – control group (12.55 +/- 2.2) Experimental group (29.89 +/- 3.2) p=0.001*. Physical mobility – control group (11.92 +/- 1.9) Experimental group (34.76 +/-4.7) p=0.001*. The BMI results showed no significant change between T1, T2 and T3.	

	Duration, frequency, intensity, etc.: The training programme session of 40–45 min each was performed 3 days a week for 10 consecutive months. **Key components and objectives of intervention:** To investigate if physical training programmes could be considered valuable for enhancing the wellbeing of individuals with intellectual disability. **Content/session titles:** The programme included warming-up movements followed by large body movements in sitting and standing for stability and flexibility, dynamic balance exercise and general strength training using light hand weights and elastic bands. Balls, balloons, bands, sticks, bean bags and scarves were used for general activities, such as pushing, pulling, lifting, throwing, squeezing and pressing. In each session the participants were advised to 'listen' to their body, to pay attention to the exercise rhythm and to keep eye contact with the moveable limb. **Location/place of delivery:** Not specified. **Comparison intervention:** Subjects in the control group were introduced to a new vocational activity, i.e. packing skills.		

	Outcomes measured – service user-related: There were 3 main outcome measures: body mass index (BMI), self-perception profile of wellbeing and Nottingham Health Profile (NHP). **Follow-up:** There were 2 follow ups, 5 months after the training and at the end of the training programme. **Costs:** Not reported.		

3. Stancliffe RJ, Bigby C, Balandin S et al. (2015) Transition to retirement and participation in mainstream community groups using active mentoring: a feasibility and outcomes evaluation with a matched comparison group. Journal of Intellectual Disability Research 59: 703–18

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To examine the feasibility of supporting older adults with disability to attend a mainstream community group as a transition to retirement. This paper examines (1)	**Participants:** Service users and their families, partners and carers. Adults with long-term disability and whose work/day programme circumstances suggested that they might benefit from the programme. Also their proxies. **Sample characteristics:**	**Effect sizes** **Outcomes of intervention group** 1.Community group participation Intervention participants' weekly hours of participation in mainstream community groups increased from an average of 2.18 (sd=3.08) hours at pre-test to 5.35 (sd=3.83) hours at post-test, t=(1,25)=-7.87, p<0.001, d=1.54.	**Overall assessment of internal validity: +** **Overall assessment of external validity:** +

the feasibility of supporting older adults with disability to attend a mainstream community group; (2) the types of mainstream community groups or volunteering groups that participants joined; (3) the duration of participants' weekly attendance at their group; and (4) changes in outcomes experienced by participants that included loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts and work hours.	Age – the 58 participants' age averaged 55.6 years (sd=6.6, range 44.1 to 72.2 years). Mean age: Int (57.4 yrs); control (53.8 yrs); t (56)=2.16, p=.035. • Gender – males Int: 18 (62%); Con: 24 (83%); Females Int: 11 (38%); con: 5 (17%). • Ethnicity – not reported. • Religion/belief – not reported. • Disability – all have mild or moderate ID. All but 4 participants (2 interventions, 2 comparisons) could speak and answer simple questions. • Long-term health condition – 20 participants in each group has a primary intellectual disability diagnosis, 9 in each group have health issues such as mental health, vision, hearing, and acquired brain injury. • Sexual orientation – not reported. • Socioeconomic position F/T work Int: 9 (31%); con: 7 (24%) ; χ2 (2, n=58)=0.42, p=.81 P/T work Int: 17 (59%); Con: 18 (62%); Day programme only Int: 3 (10%); Con: 4 (14%) Living arrangements Independent Int: 4 (14%); Con: 1 (3%); χ2 (3, n=58)=3.89, p=.27	2. Social contacts Time spent with new social contacts increased from 0.03 (sd=0.13) hours per week at pre-test to 3.30 (sd=1.64) hours at post-test, t(1,24)=-9.94, p<0.001, d= 1.98. 3. Change in work hours. Overall, the participants reduced their weekly work hours from an average of 26.64 (sd=9.77) hours to 22.54 h, a significant reduction, t(1,25)=3.44, p=0.002, d=0.67. **Outcome comparisons between intervention and comparison group participants** 1. Self-report variables 1.1 Depression (n=47), F(1,44)=0.03, p=0.86, d=0.28. 1.2 Aloneness (n=45), F(1,42)=1.40, p=0.24, d=-0.15. 1.3 Social satisfaction (n=46), F(1,43)=10.61, p=0.002, d=0.78.	

Methodology: Comparative study with matched controls. Each intervention-comparison pair was matched as closely as possible on work/day programme placement, full-time or part-time work status or day programme attendance, living arrangements, gender and age group. **Country:** Not UK, Australia. **Source of funding:** Not reported.	Group home Int: 12 (41%); Con: 14 (48%) Hostel Int: 9 (31%); Con: 6 (21%) Family Int: 4 (14%); Con: 8 (28%). **Sample size:** Total 58 (intervention group,29 and control group, 29). **Intervention:** Intervention to support older people with learning disabilities to participate in mainstream community activities. **Description:** While attending their individual mainstream community group 1 day per week, intervention group participants received support from community group members trained as mentors. **Delivered by:** Trained mentors were existing members of the community groups who volunteered to receive training and to support the participant when he/she was attending their group. There were 73 mentors (38 women,35 men) for 26 intervention group participants. **Delivered to:** Intervention participants were invited to join the project if they	1.4 Loneliness (n=20), F(1,17)=1.72, p=0.21, d =-0.28. 1.5. Quality of life (physical) (n=34), F(1,31)=0.55, p=0.47, d=0.21. 1.6. Quality of life (mental) (n=34), F(1,31)=0.37, p=0.55, d =-0.36 2.Proxy report variables 2.1. GDS Depression (n=36), F(1,33)=2.98, p=0.095, d=-0.51 2.2. Mini PAS-ADD Depression (n=42), F(1,33)=2.76, p=0.105, d =-0.36. 2.3.Mini PAS-ADD Life events (n=42), F(1,39)=0.14, p=0.71, d=0.03. • **Narrative findings – effectiveness** Outcomes for the intervention group. Attending community groups success rate, attrition and ongoing attendance. Overall, 27 (93%) of the 29 intervention participants joined a community group and attended for at least 3 months, with 25 (86%) attending for a full 6 months. Hours: participants attended their group	

	were aged 45 years or older and their work/day programme circumstances (e.g. part-time attendance, frequent absences, lack of engagement with work, age-related health problems or acquired disabilities) suggested that they might benefit from reduced work/day programme attendance. **Duration, frequency, intensity, etc.:** Disability interaction training of mentors were 1–1.5 hours. Participants attended their group during the day on a weekday for 1–6h (average 3.6h, n=27). Several extended their involvement in community groups. Overall,27 (93%) of the 29 intervention participants joined a community group and attended for at least 3 months, with 25 (86 %) attending for a full 6 months. **Key components and objectives of intervention:** Transition to retirement program a) Individual retirement planning meeting. A planning meeting was held for each intervention participant to discuss the details of dropping a day at work/day programme to attend a community group on that	during the day on a weekday for 1–6h (average 3.6h, n=27). Ongoing attendance: individual attendance ranged from 3 to 24 months Mean =12.4, n=27.	

	day. b) Locating a community group or volunteering opportunity. c) Attending the group. d) Training mentors. Mentor training consisted of two phases (1) disability interaction training and (2) hands-on training. e) Activity restructuring with assistance from mentors. This approach was to identify appropriate activities, often with a joint decision to reserve the activity as the responsibility of the participant. f) Monitoring and ongoing support. Content/session titles: Transition to retirement programme a) Individual retirement planning meeting b) Locating a community group or volunteering opportunity. c) Attending the group. d) Training mentors. Mentor training consisted of two phases (1) disability interaction training and (2) hands-on training. e) Activity restructuring. f) Monitoring and ongoing support. **Location/place of delivery:** Individual retirement planning meetings were held at the participant's home. Intervention participants each attended a different community/volunteer group,		

	according to individual interest. Where multiple individuals attended the same group type, each person attended a separate group in a separate location. **Comparison intervention:** Comparison group members received no intervention and continued to attend work as usual. **Outcomes measured – service user-related:** Study assessed participants' loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts and work hours before and 6 months after joining a community group. **Follow-up:** Follow-up was up to 6 months after intervention. **Costs:** Not reported.		

Review question 6 – findings tables – the views and experiences of people using services, their families and carers

1. McCarron M, McCallion P, Carroll R et al. (2014) The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDSTILDA). Advancing Years, Different Challenges: Wave 2 IDS-TILDA. Findings on the ageing of people with an intellectual disability. University of Dublin, Trinity College

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To document the changes over time of people with intellectual disability (ID) since Wave 1 (ID-TILDA [The Irish Longitudinal Study on Ageing]) in relation to social participation and connectedness. **Methodology:** Survey. Pre-interview questionnaires and extensive face-to-face computer assisted personal interview. This study is part of a longitudinal study (Wave 2) conducted to	**Participants:** Service users and their families, partners and carers. Adults with intellectual disability. **Sample characteristics:** • Age – age range: 40–65+ years. • Gender – males: 44.5%; females 55.5%. • Ethnicity – not reported. • Religion/belief – not reported. • Disability – level of ID: Mild - 24% Moderate - 46.5% Severe/profound - 29.5%. • Long-term health condition – not reported.	**Narrative findings** Social participation for older adults with intellectual disability (quantitative data). **A. Social connection for people with ID** 1. Social connection with family (Table 2.1, p35). a. Older people with ID most likely to be reliant on siblings and extended families – sisters (77%); brothers (70.4%); niece/nephews (53,2%); cousins (25%); mothers (24%). b. 8% of older people aged over 65 years likely to have no family at all. c. Social connectedness – proximity of family members: majority of family members lived outside the participant's neighbourhood (Table 2.2, p36).	**Overall assessment of internal validity: +** **Overall assessment of external validity: ++**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
document the changes over time of people with intellectual disability (ID) since Wave 1 (ID-TILDA [The Irish Longitudinal Study on Ageing] in 2008) in relation to social participation and connectedness. **Country:** Ireland. **Source of funding:** Government. Health Research Board and Department of Health.	- Sexual orientation – not reported. - Socioeconomic position – not specified, 'full range of residential circumstances' (p164). **Sample size:** N=708. **Outcomes measured:** Service user-related: family- or caregiver-related outcomes. Social participation for older adults with intellectual disability. **Follow-up:** This survey was conducted as Wave 2 (2013) after Wave 1 (2008). **Costs:** Not reported.	d. Face-to-face contact with family members (52%); telephone contact (47%); written contact (4%) (p36). **2. Social connection with friends** a. No friends at all outside own home (43%); for people with severe ID (34%). b. For those living in independent/family residences (87%); those living in community group homes (60%); in institutional settings (41%). c. About 70% of respondents participated in social activities with staff (Table 2.4, p39). **3. Self-reported feelings of social inclusion/exclusion** a. Feeling lonely – women more likely to feel lonely than men (53% vs. 34%); left out (28% vs. 24%); having difficulty making friends (28% vs. 27%). Similar levels in those who lived in community group homes and institutional residences.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		b. Paid staff most likely to be confidantes of respondents with ID (73%), ahead of siblings (26%) and friends (11%) (Table 2.5, p42). c. People with ID living in independent/family residences more likely to receive/give help than those living in community homes and institutional settings (Fig 2.6, p44). **B. Community engagement in social life** People with ID living in independent/family residences more likely to vote and own a mobile phone than those living in community group homes and institutional settings. Those in community setting more likely to have a hobby and go on a holiday (Fig 2.7, p47). 1. Internet and mobile phones. In people with ID, internet use (11%, general population 77%); mobile phone ownership (24%, 120% nationally). 2. Membership of clubs, organisations and societies. Overall involvement in voluntary clubs, organisations and societies 43%; men more likely not to be involved than women (59% vs.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		55%); those with profound ID (75%); those in institutional setting (71%); those over 65 years old (66%)(Fi. 2.8, pp47–8). 3. Participation in social activities. Relatively high engagement – participating in social activities (eating out/coffee, shopping, visit to hairdressers, going to church, cinema or visiting friends). Lowest activity rate in those aged over 65 years, those with severe ID, and those living in institutional settings (Fig 2.9, p49). **C. Facilitators and barriers of/to social participation** 1. Participating in social activities outside homes a. 52% experienced difficulties participating in social activities outside homes; more in women than men (55% vs. 49%); more in those aged over 65 years than those under 50 (59% vs. 50%). Those with severe ID experienced these difficulties the most (78% vs. 30% in those with mild ID). Those in institutional settings (68%), in family homes (27%) and those in community group homes (48%) (Fig. 2.10, p50).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		b. Most frequently reported difficulties – needing someone's assistance (70%); health considerations and physically unable (41%) (Fig 2.11, p51). 2. Difficulties getting around the community. a. 64% experienced difficulties and did not travel around the community, more men than women (36% vs. 31%), and those in institutional residences (41%) (Fig 2.12, p52). D. Employment changes. a. 6.5% in regular paid employment; 12% attending sheltered workshops; 80% attending day services.(p52). E. Day service attendance 80% attended day services (art, crafts and music most popular); 19% reported rarely or never chose their activities (p53). F. Education and lifelong learning. Not engaged currently in further education (86%), 12% expressed interest in attending courses such as reading/writing and computer classes; 14% attending FE (FETEC level course and literacy classes) (p54).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		G. Identified difficulties engaging in further education. Issues of numeracy and literacy – difficulties with writing (83%), with reading (82%); with number identification (81%) and understanding money (78%) (Fig 2.15, p55). H. Access and engagement with technology. Less than a quarter own a mobile phone; less than 1 in 20 can send a text; 36% had access to computer; 28% had access to the internet. (Fig 2.16, p56). In summary, this survey found: 1. Older people with learning disabilities were reliant on siblings and extended families to provide family network and support. 2. Older people with learning disabilities lived in different neighbourhoods than their families/relations – difficulty in maintaining connection. 3. Older people with learning disabilities had reduced regular contact with family members and close friends.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		4. Other social partners such as paid staff were more important as confidantes in the lives of older people with ID. 5. Women with ID were more likely to feel excluded socially than men. Those in community group homes and institutional residences more likely to feel social exclusion than those in independent family residences. 6. Purposeful contact with families, friends and neighbours was greatly impacted by level of ID, types of residence and age. 7. Engagement in social activities declined, especially for men and those with profound ID, for those aged over 65 and who lived in institutional residences. These groups were also likely to be at greater risk of being unable to travel around in their own local community. 8. Employment status remained poor – exacerbated by issues of numeracy, literacy and money management. 9. Few benefit currently from access to information technologies. To support greater level of genuine integration, renewed efforts needed.	

2. McCarron M, Swinburne J, Burke E et al. (2011) Growing older with an intellectual disability in Ireland 2011. First results from the intellectual disability supplement to the Irish Longitudinal Study on Ageing. Dublin: School of Nursing and Midwifery, Trinity College Dublin

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: 1. To identify the principal influences on successful ageing in persons with intellectual disability, and then determine if they are the same or different from the influences for the general population. 2. A second aim is to develop a first wave baseline picture of ageing among persons with intellectual disability and a cohort of subjects that may then be followed longitudinally.	**Participants:** Service users and their families, partners and carers. **Sample characteristics:** • Age The age of respondents ranged from 41–90 years, with an average age of 54.7 years. Similar to the general population the biggest proportion of participants (46%) fell within the 50–64 age group, with 36% falling within the 40–49 age group. • Sex Total 45% were male and 55% were female. • Ethnicity Not mentioned. • Religion/belief	**Narrative findings** 1. Adults with an Intellectual Disability Ageing in Ireland as Members of their Families and Communities : People with an intellectual disability (ID) living in community settings participated in their local communities more than people living in residential centres. However, regardless of residential circumstances, adults with an ID in Ireland were not actively engaged with their communities and community presence was not actually equated with 'living' in the community. Given that those currently living in community settings tend to be younger, this does not bode well for community participation as they age and experience health decline. **1.1. Social networks** **a. Family members**	**Overall assessment of internal validity: + +** **Overall assessment of external validity: + +**

Objectives: 1. To understand the health characteristics and status of persons with intellectual disability as they age. 2. To examine the service needs and health service utilisation of older persons with intellectual disability as compared to the general population. 3. To identify disparities in the health status of older persons with intellectual disability as compared to findings yielded by TILDA for the general population.	Most adults with ID reported having a religion with the majority 57% attending religious service at least once a week. Most participants were Roman Catholic (96%), with 15 participants identified as Church of Ireland/Anglican, Methodist or Presbyterian. Ten participants responded as ‘other’ here and 8 participants stated they had no religion. • Disability All levels of ID were represented in the sample, with the highest number of participants (44%) falling within the moderate range of ID. • Long-term health condition Many in the IDS-TILDA sample, particularly those in the younger age cohorts, reported experiencing good health but there were significant concerns in terms of cardiac issues (including	The majority of adults had some level of contact with at least 1 family member. However, approximately 1 in 4 adults reported meeting their family once a year or less (27.7%) or less and 8% reported that they never meet family members. Persons with a mild to moderate ID (53%) tended to meet their family on a more regular basis (3 to 4 times per week, weekly or monthly) than those with a severe to profound ID (40.8%). Over 3/4 of adults (75%) with an ID reported that they never wrote, texted, emailed or used social media tools such as Facebook to contact their family or friends. Moreover, less than 60% used the telephone to make such contacts. A large number of respondents (42.5%) had no phone contact with their family, with 9% of this group indicating that this question was not relevant. **b. Meeting friends** Of great concern was the finding that 37% of adults with an ID in Ireland reported never meeting their friends; among this sub group, 50% were within the mild to moderate ID levels. Contact also varied by residential circumstances: 72% (n=42) of those without contact lived in a residential setting, 22% (n=13) in a community setting and 6% (n=3) were living independently or with their family. The majority of participants indicated that they never	

4. In preparation for longitudinal follow-up, to determine potential - Risk factors for ill health - Facilitators of good health and longevity - Biological and environmental components of successful ageing. **Methodology:** Survey. The study was a nationally representative survey. **Country:** Republic of Ireland. **Source of funding:** Government. Health Research Board and Department of Health.	risk factors), epilepsy, constipation, arthritis, osteoporosis, urinary incontinence, falls, cancer and thyroid disease. • Sexual orientation Unlike the general population the majority of adults with intellectual disability (ID) were not married/partnered and did not have children. • Socioeconomic position A third had no formal education, approximately half completed some or all of their primary education and only 3 respondents reported having completed secondary level education. Most participants lived in out-of-home placements; those living with families and in the community tended to be younger, with a mild/moderate range of intellectual disability; those living in residential type accommodation tended to be	spoke on the telephone (58%,n=432) or wrote (73%, n=548) to their friends. **1.2. Loneliness and inclusion** Of those who reported loneliness, 15% (n=29) reported feeling lonely most of the time, a majority of 74% (n=142) felt lonely sometimes, and a further 10% (n=20) said they occasionally felt lonely. Those living in community-based settings including group homes, independent living and with families were more likely to report experiencing at least some loneliness. This was particularly the case among those in the younger age groups. **Experience of inclusion** Self-reporting participants were asked if they ever felt left out, and approximately 1/3 34% (n=140) reported experiences of feeling left out most of the time (12%; n=16) sometimes (74%; n=103) and rarely (14%; n=19). Making friends – participants were asked if they found it difficult to make friends and 1 in 3 (32%; n=132) reported such difficulty. **1.3. Social engagement** **a. Voting**	

	older with more severe to profound levels of ID. Overall, 6.6% (n=50) of Irish adults with an ID were in paid employment. It was reported that 37.6% (n=283) were unable to work due to permanent disability or sickness and 6.1% (n=46) were retired. **Sample size:** Total 753 people with ID. **Outcomes measured – service user-related** Relationship with family and communities. Employment, retirement, day services and lifelong learning. **Follow-up:** The longitudinal study is planned to have follow-up – Wave 2 and Wave 3. **Costs –** Not reported.	Approximately 70% of adults with an ID in Ireland did not vote in the last general election. Those living at home or independently were more likely to vote than those living in a community group home, or in a residential centre, at 61.2%, 41.4% and 12.1% respectively. **b. Holidays** Three quarters of adults with an ID reported going on a holiday last year, with 17% going abroad on holiday. People with a more severe ID were less likely to go on holiday and more often went on day trips. With regards holidays, 53% reported that they went on holidays in Ireland in the last year and 17% reported they went abroad. People living in a community group home (66%, n=177) were more likely to holiday in Ireland than those living independently (57.4%, n=74) or within a residential centre (41.9%, n=149). However, people who lived independently or with their family (36.4%, n=47) were more likely to go on a foreign holiday than those living in a community setting (23.5%, n=63) or in a residential centre (5.3%, n=19). **c. Internet access** Overall, 7.3% (n=55) reported that they had used the internet in the last year and of those who had,	

		the majority (n=48) were within the mild to moderate range. In addition, 23% (n=172) of people mainly mild to moderate ID reported that they owned their own mobile phone. **d. Hobbies and activities** Most adults with an ID (61%) had a hobby, engaged in daytime activity and leisure pursuits on a regular basis, and had social contacts with others. Watching television 81.5% of adults with an ID watched TV at least once a week. **1.4. Engaging in community life** **a. Neighbours and community inclusion** In this study, 14.7% (n=111) received help from their neighbour over the past 2 years. Of those who received help, 40.5% (n=45) lived at home or independently, 31.5% (n=35) lived in a community setting and 27.9% (n=31) were in a residential centre. A total of 13.1% (n=97) gave help to their neighbours. Among this group, 44.3% (n=43) lived at home or independently, 33% (n=32) lived in a community setting and 22.7% (n=22) lived in a residential setting. **b. Member of an organisation or club**	

		Respondents were asked to identify, from a list of options, the clubs, societies or organisations to which they belonged. Special Olympics ranked the highest, reported by 19% (n=145). Advocacy groups were next at 12% (n=92), followed by church/religious groups at 11% (n=81). Respondents were less likely to report engaging in education/music or evening classes (10%, n=75), or retirement clubs (4.2%, n=32) with very few (2.3%, n=17) reporting they were members of tenants or residents associations. A number of respondents (4.1%, n=31) reported being a member of the Arch Club, 11 were members of a charitable association and 3 were members of a political party. It is evident that age group, level of ID and living circumstances all have some influence on the person's engagement in leisure activities. People aged between 50–64 years were more likely to eat out (90%), go for coffee (88%) or go to the pub (70%), whereas for people aged 40-49 years, going shopping (86%) was the most commonly engaged in activity. For people aged 65 years and over, going to church (80.6%) and to the hairdressers (81.3%) were the most popular activities. The majority of respondents (79%) identified their key worker/support staff as the main person with whom they engaged in leisure activities. In addition, a further 57% reported	

		engaging in these activities with friends within their house, and 34% reported engaging in these activities with their family. Overall, only 30% reported engaging in these activities with friends outside the house. Overall, respondents reported quite regular engagement, with 80.8% reporting going out to the cinema every few months or more, 52.1% going shopping at least once a week and 46.2% going to the pub for a drink once a week or less. Over 60% expressed a wish to do more activities, particularly gardening, boating, bowling or keeping fit. **c. Difficulties participating in social activities outside the home** Over 50% of adults with an ID reported having difficulty in participating in social activities outside their home, with greatest difficulties being the need to have someone's assistance (44.2%) and health considerations (26%). Generally, people living independently/with their family (30.4%) or in a community setting (43.3%) reported less difficulty than those living in a residential centre (65.3%). **d. Difficulties getting around the community** Although a sizable proportion of respondents (42.1%, n=313), reported they did not experience	

		any difficulty getting around their community, almost 60% did; 38.2% (n=284) reported a lot of difficulty here and a further 19.7% (n=147) reported that this was not applicable to them, because they did not travel around their community. Further examination identified that those living in a community setting experienced the greatest level of difficulty; with 22.3% (n=25) having difficulty due to a lack of street crossings, 33% (n=37) had problems with signage, and a further 29.5% (n=33) felt unsafe. In contrast 30.6% (n=53) of people living in a residential setting had difficulty with footpath design and surfaces. Finally, 14.3% (n=4) people living independently experienced the greatest level of difficulty in accessing recreational areas. **e) Transportation** People were asked to identify the means of transport they utilised within the past year. The majority of people (90%, n=678) identified being driven as a passenger by service staff as the means of transport they used most often. In total, 20.6% (n=155) reported using the public bus, and 2.8% (n=21) used the public bus in rural settings. Interestingly, 37.7% (n=244) of participants reported a lack of transportation within their community. The majority of adults with an ID were	

		dependent upon others for transportation and other assistance to access community options. Participants reported that their need for such assistance was the greatest barrier to successfully participating in social activities. **f) Voluntary work** Numbers volunteering (7.7%; n=58) were smaller for adults with an ID, with the majority (63.2%, n=36) doing so twice a month or more. Reasons why people with an ID volunteered included enjoyment (8.5%, n=35), contributing something useful (7.9%, n=33), meeting other people (6.0%, n=25) and a sense of achievement and feeling needed (4.1%; n=17). **2. Employment, retirement, day services and lifelong learning** Overall, 6.6% (n=50) of Irish adults with an intellectual disability (ID) were in paid employment. Of those in paid employment, 44% (n=22) received less than the minimum wage. Over half of respondents did not know how much money they received on a weekly/monthly basis. The majority of adults with an ID (79.4%) attended a day service, with 43.5% reporting they had choices in their activities there and 32.7% reporting that they rarely	

		or never had such choices. Just over 1/3 (66.8%) reported that they received assistance going to and from their day service. A total of 15.6%, most of whom were aged 40–49 years, indicated that they were currently engaged in further education. For those who expressed a desire to engage in further education, computer and literacy classes were most frequently cited courses. **a. Employment status** Only 23.1% (n=174) of the population surveyed described themselves as being in employment and 6.1% (n=46) reported being retired. A large number of respondents reported their day service or sheltered workshop as a place of employment; 33.3% (n=58) who described themselves as employed actually attended a day service or other kind of service and a further 37.9% (n=66) attended a sheltered workshop. In total, almost 3/4 (71.1%) of respondents reported their participation in some form of sheltered workshop or day service as employment. **b. Day services** Overall, 79.4% (n=597) of respondents reported attending a day service, where the most popular activities were arts and crafts (76.7%), music	

		(69%), and multisensory and other health therapies such as massage or occupational therapy (59.8%). In total, 43.5% (n=256) reported that they were usually able to choose the activities they engaged in, and a further 23.8% (n=140) reported that they got this opportunity sometimes. However, not everyone was happy with their day service. Almost a third (32.7%) reported that they rarely or never had the opportunity to choose activities. **c. Lifelong learning** The majority (84.5%) of adults with an ID were not engaged in further education, with only 15.4% (n=116) reporting that they had or were currently attending courses. Of those engaging in further education, 26.1% reported that their course was organised by the Vocational Education Committee (VEC), 11.3% by a training centre, and 7.8% by a local community programme. **d. Retirement** Forty-six participants, most of whom were over 65 years, reported they were retired. The average preferred age of retirement was 62 years. Three quarters (75.4%) of those attending a day service reported they did not plan to retire from it at all and a further 12.2% of the total sample reported that	

		they had already retired. Some respondents indicated they had no choice but to retire; as one participant reported, 'when 50 you automatically retire from the day service' (p141). A large number of adults with an ID indicated that they did not want to retire. Positive social consequences, including retaining contact with staff and friends and having somewhere to go during the day, are likely to be serious considerations in people's decision not to retire.	

3. Judge J, Walley R, Anderson B et al. (2010) Activity, aging, and retirement: the views of a group of Scottish people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7: 295–301

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To understand the views of older adults with learning disabilities in relation to their current daytime activity (which was not necessarily part of a day centre) and their hopes and	**Participants:** Service users and their families, partners and carers. Older adults with learning disabilities. **Sample characteristics** • Age Range from 41 to 64 years. • Sex Total 11 female and 5 male. • Ethnicity	**Narrative findings** Five major themes emerged from the analysis. **1. The importance of being active** Most participants were clear about the importance of their activities both now and in the future. Being occupied was really important, giving	**Overall assessment of internal validity: +** **Overall assessment of external validity:** +

dreams about future daytime activity. **Methodology:** Qualitative study. Interpretive phenomenological analysis. **Country:** UK, Scotland. **Source of funding:** Study was undertaken as part of the first author's doctorate, funding source not reported.	Not reported. • Religion/belief Not reported. • Disability Case records indicated that participants had a 'mild to moderate range' (p296) of learning disabilities. • Long-term health condition Not reported. • Sexual orientation Not reported. • Socioeconomic position All participants attended day centres. Two were married to each other, the others were single. Three lived in own accommodation with visiting support. Three lived with and were supported by family members. Ten lived in 24-hour supported accommodations. **Sample size:** Total 16.	them enjoyment and confidence. They felt strongly that they wanted this to continue and would even like to be doing more than they currently are, 'They always tell me, you have to slow down when you get older, but I can't see myself doing that ... I can't see myself doing that because I just like to be on the move all the time ...' (p297). The participants often said their activity shouldn't be limited to the day centre. They especially liked activities which have a purpose, for example voluntary work or work representing other service users. It gave them great confidence and a sense of achievement. So whereas participants were generally happy to be active they were especially happy when the activity had meaning and purpose. For example, one woman enjoyed knitting, but only when she was making something for other people. **2. The day centre as a social hub**	

		Many recognised that the day centre was really important in facilitating the activities that they felt were so important. The day centre was also a community in its own right, ‘you can mix in with people and you get new friends and all of that. You know ... community’ (p297). Many had been attending the centre for years and built up strong friendships including with staff. The sense of community and friendship were described by many as the most important aspect of daytime activity. Participants were clearly worried that they would lose contact with friends when they are no longer allowed to attend the day centre, ‘if I wasn’t coming here I would be just staying in my bed, or just staying in my own home’ (p298). **3. Confusion concerning ‘retirement’** In Scotland, common practice is that adults with learning disabilities can attend day centres until they are aged 65, which is considered	

		‘retirement’ age. Participants were asked about their perceptions of ‘retirement’ and how they felt at the prospect. Some were confused by the concept. Others understood what it meant in terms of day centre policy – but they were confused about the implications. For example, one respondent thought that although she wouldn’t be able to attend after she turned 65, she could still visit, and another thought they would at least be able to have lunch at the day centre. For those who fully grasped the implications, their displeasure was evident, ‘No, no. Want to keep on coming I think ... I think I like to meet and mix with people ... talking to people’ (p298). One of the participants reflected the fact that they have no choice in the matter or leaving the day centre and he commented, ‘it means you can’t go there any more ... so they’ll probably find you something else to do’ (p298) (researcher’s observation). Since adults with a learning disability get no choice about whether to retire (e.g. cease	

		attending the day centre) it seems to be an upsetting experience since friendships, activities and opportunities are taken away. With retirement comes a loss of connectedness. **4. Desire for continuity** The general message was that participants didn't want to stop their day centre attendance when they reached 'retirement'. People wanted to keep going the way they are now – not least because they recognised the importance of continued activity and involvement as they age. When asked whether he would want to stop attending the day centre, one man said 'No, all the time I want to come here' (p298). Essentially all the participants were happy with their current routine and wanted to continue with the day centre and staying busy even when they reach 65. **5. The value of independence**	

		In the context of ageing, respondents valued their independence and wanted it to continue. Some were determined to ensure this, e.g. 1 woman continuing to cook for herself (a skill she learned after her mother passed away). However others were less optimistic about maintaining independence in their older age, 'I hope I can stay in my own home ... I hope so ... I don't want to go into a home if I can help it' (p299).	

4. Newberry G, Martin C, Robbins L (2015) How do people with learning disabilities experience and make sense of the ageing process? British Journal of Learning Disabilities 43(4): 285–92

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To explore how people with learning disabilities experience and make sense of the ageing process and old age.	**Participants:** Service users and their families, partners and carers. **Sample characteristics** • Age Three women and 4 men, aged 60–81. • Sex	**Narrative findings** The master themes arising from the group analysis were as follows. **1. Quality of relationships is central to enjoyment of life, including sub themes on the importance of affection and companionship,**	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Methodology: Qualitative study. Analysis was carried out using interpretative phenomenological analysis (IPA). **Country:** UK. **Source of funding:** Not reported.	Three women and 4 men. • Ethnicity Not reported. • Religion/belief Not reported. • Disability Mild learning disability. • Long-term health condition Mild learning disabilities. • Socioeconomic position Employment was reported – college, voluntary work, day centre voluntary work. **Sample size:** Total 7 participants.	**distress at lack of closeness and anxiety about ability to satisfy others** • Some experienced care and good treatment in friendship, and relationships were valued as sources of support and comfort during times of need. • Many participants had a strong attachment to 1 key person. • Some participants were distressed at the lack of close affectionate relationships, expressing grief, sadness or anger. • Some participants in this study found relationships difficult, even mystifying, and had always done so. • Some participants described increasing anxieties about satisfying others' expectations;	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		becoming forgetful, e.g., made it even more difficult for them. **2. Needing a sense of purpose** • Participants wanted to continue working, learning and participating in activities, maintaining voluntary work, attending day services or doing housework. • Most participants talked with pride about experiences of feeling needed at work or having a useful role. • Overall, the meaning of purposeful activity was tied to the concepts of work and retirement, and as varied as it might be in the general older population. **3. Powerlessness which includes restricted autonomy, frustrated by dependency**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		- Several participants described experiences of powerlessness and restricted autonomy. There were differing levels of satisfaction with the amount of autonomy participants could exercise; some were happy with new found autonomy and independence, others felt constrained. - Some examples of restricted autonomy were mentioned in passing. Some participants seemed to accept them unquestioningly. Others seemed frustrated by their dependence on staff. One participant explicitly acknowledged her sense of powerlessness, speaking with anger. She described feeling unheard. **4. Making sense of getting older, including sub themes on reactions**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		to changes with age, life review and looking to the future • Six participants had some awareness of ageing. Their attitudes and beliefs were largely negative, generally focused on stereotypical physical changes, e.g. greying and forgetfulness. Several participants used ideas about what is ‘normal’ to help them make sense of the changes they experienced. Two participants spoke of becoming less mobile. • Several participants seemed to be reviewing their past, as might be expected of older people in general. They seemed to be negotiating a relationship with past experiences and making sense of how their past has influenced current experience.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		- Some participants had come to terms with past difficulties and contrasted these with current contentment. Three participants talked with strong feelings of sadness or anger about experiences of betrayal or abuse earlier in life, placing these experiences firmly in the past and reporting that their lives had improved. - Several participants seemed to make an association between old age and death, talking about the deaths of friends and family members in old age. Two participants talked about their own death.	

5. Randell M and Cumella S (2009) People with an intellectual disability living in an intentional community. Journal of intellectual Disability Research 53: 716–26

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To explore the experiences of people living in an intentional community, and to understand what the idea of 'community' means to them as individuals. **Methodology:** Qualitative study. **Country:** UK. **Source of funding:** Not reported.	**Participants:** Service users and their families, partners and carers. People with ID. **Sample characteristics:** • Age Ranging between 38 and 78 years (median =50 years). • Sex Ten men and 5 women. • Ethnicity Not reported. • Religion/belief Six of the 15 respondents regularly attended church (Christian belief). • Disability All respondents had ID. • Long-term health condition Not reported. • Socioeconomic position All 15 respondents had been in full-time employment in Botton Village (2 worked part time, and 1 was fully retired from work – animal husbandry, cooking, cleaning, administration, shop assistant, making wooden toys and restoring furniture, weaving workshop, etc.).	**Narrative findings** Views of people with ID on living in an intentional community. **1. Living with other families in households** a. Some had lived with same families for many years and had watched their co-workers' children grow up. They particularly valued these relationships. 'I like that it is a big house, there is always someone to talk to' (p720). b. Felt able to contribute towards household by taking on tasks such as collecting the milk, getting the post, helping cook lunch and helping tidy up after meals. c. The common concerns were a lack of space, privacy and cold weather: 'I don't like it when people argue, but other than that I like it here very much.' 'I don't like the winter very much. I get worried about it being icy' (p720).	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	Sample size: Total 15. **Intervention:** Intentional community. **Describe intervention** Botton Village is an intentional community organised as a new form of community living based on the philosophical ideas of Karl König and Rudolf Steiner. The community will accept the individual, integral personality in such a way that the developmental otherness becomes variety instead of abnormality, that diversity rather than uniformity becomes the foundation of healthy social life. (Weihs 1988, p19) (p719). 'The village has 300 community members (members with disabilities and co-workers) in over 30 households. Households provide an extended family setting comprising co-workers (often a family with children) who live alongside the members with disabilities and provide support as required. Members	d. Felt 'listened to': 'Yes I do, I feel I can talk to people or my house parents if I need to.' 'They do listen. If you want something you go to the houseparents and they will sort it out' (p720). **2. Employment** a. Work formed an important part which enabled them to fully participate and contribute to the life of the village. 'I enjoy looking after the animals and making sure they are cleaned out properly.' 'I like the work, all the work I do' (p720). b. Main reason given for enjoying their job was that they met people: 'Mainly it's the people. The people are nice' (p720). c. Most common complaint was that sometimes they felt bossed about: 'Sometimes I don't like being demanded to do things that's all, and	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	and co-workers of the village have a working role to help in meeting the shared and individual needs of the community. Employment is provided by: five biodynamic farms providing the meat, milk and vegetables for the community; a creamery, bakery, food centre and meat store; and various craft workshops that generate income for the village. Amenities in the village include a store, post office, bookshop and gift shop, recycling workshop and a coffee bar' (p719). The smallest current household had 5 people in it while the largest household was made up of 17 people including a family with young children (p720). Intentional communities (Konig 1956) create a life for those unable to find a place in the outside competitive world, but can avoid becoming an asylum in which people led passive and regulated lives if men and women whose intelligence is according to test standards supposed to be inferior, will live and work with others of normal intelligence but will not regard this as a barrier between them.	sometimes that can make me a bit cross, but I do like work' (p720). d. Felt listened to at work, and knew who to talk to if they had problems: 'Yes I talk to the workgroup if I have a problem.' 'I am trying to decide which place is better to work, Charles listened to me and helped me to find a new place to work' (p720). **3. Leisure** a. Respondents enjoyed leisure activities at home (such as reading, watching TV, music, knitting) and away from home (such as visiting friends' houses, going out for dinner, walks, swimming, playing games with friends and, most commonly, going to the coffee bar). 'I enjoy my own company' or that 'it's nice to relax'. 'I like the coffee bar because my friends always come here. It's nice to talk to people.' 'I usually meet my friends there and we have a nice time together' (p722).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	• Delivered to: People with ID. **• Key components and objectives of intervention:** Key aims of the village to achieve these objectives by providing a full life for its members, comprising: '1 A Cultural Life in which education and learning, appreciation of the arts and music, concern for the land and the environment and the fostering of mutual understanding combine to offer the possibility for all members of the community to realise their potential; 2 A Community Life in which the recognition of the special qualities of every individual and the celebration of the Christian festivals through the year form the basis for daily life, which brings together each person as an equal in a common purpose; 3 An Economic Life in which there is a separation of work and money, whereby work is carried out according to the need of the community and the ability of each person, while people's	b. Participation in formal community-based activities (such as choir singing taking part in plays, involved in the Advent fairy tale) 'I enjoy socialising with the village at Christmas. 'I like sharing these times with other people in the village' (p722). c. Experienced less incidences of victimisation and verbal abuse than other people living in more community-integrated environments: 'Here we are very lucky. We can all go out. We are able to go to the neighbours like we do. It is safe here' (p722). **4. Friendships** a. Most respondents enjoyed a wide network of friendships and the company of other people with whom they could share things. 'Friends are very important yes, you know, to spend time with people and things.' 'Yes I have masses of friends in the	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	financial needs are met on an individual and cooperative basis irrespective of the work done' (p719). • **Content/session titles:** Botton Village (intentional community). • **Location/place of delivery:** Intentional community: domestic-style housing in urban settings. • **Describe comparison intervention:** None. **Outcomes measured:** • Satisfaction with services Views on living with other families in households, employment prospects, leisure, friendship, religion and identity. • **Follow-up:** Not reported. **Costs:** Not reported.	village. I have close friends in lots of different houses.' 'I can tell a lot of things to my friends that I wouldn't tell other people that I know.' 'Friends play an important part in my life, you know, it is nice to know that people really like you, it's nice to have friends to talk to and keep you company and not to feel secluded' (p722). b. At times, friendships could be strained; 'One minute we are friends and the next minute you find that we are shouting at each other and then we are all friends again' (p723). **5. Religion** a. Six of the 15 respondents regularly attended church and regarded attendance an important part of their lives: 'I enjoy attending church with my friends, it is both spiritual side and social side that is important.' b. Remaining respondents all attended church on festivals, such as	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		Easter and Christmas, weddings between co-workers and christenings of their children. **6. A community identity** a. Respondents felt a sense of inclusion determined mainly by taking part in shared activities: 'I like to be noticed not unnoticed. I don't mean showing off, but I like people to know that I am here. I don't want to feel separate from everything.' 'The work I do is important to the village, helping to clean all the houses and everything' (p723). b. Had a positive experience of being listened to and how they feel able to influence decisions: 'I do feel included yes, because I can join in neighbourhood meetings and talk about what I think should happen in the village.' 'Well if you have a point to make you raise it at the	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		neighbourhood meetings. It works all right, yeah' (p732). c. Intensity of social relationships could have disadvantages, too much arguing or knew too much of each other's lives: 'Sometimes it can be a little fraught, but mostly it is good and you work your differences out and when you have sorted those out then you are on top. It is nice that way we get on well together most times' (p732). d. Living in the village of central importance to the respondents: 'It is my home and always will be. Its good here, it is my home. I enjoy everything. The family I live with and the work that I do' (p732). In summary, people with ID said they liked living in the village because of having a job within the community; socialising with friends and knowing a lot of people; living in the countryside; knowing your neighbours; living with	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		people who are supportive and caring; having the coffee bar; and living alongside families. The spiritual needs were also catered for and they felt safe in the intentional community setting. However, the intensity of social relationships could have disadvantages.	

Review question 6 – findings tables – health, social care and other practitioners' views and experiences

1. Zakrajsek AG, Hammel J, Scazzero JA (2014) Supporting people with intellectual and developmental disabilities to participate in their communities through support staff pilot intervention. Journal of Applied Research in Intellectual Disabilities 27: 154–62

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: The main aims of the project were to (i) use the needs identified by community agency staff and administrators to develop resources and strategies for supporting full participation, (ii) develop and implement a pilot intervention specifically for staff members to increase their confidence in supporting choice and control of people with I/DD and (iii) complete a formative evaluation of the pilot intervention.	**Participants:** Professionals/practitioners, staff and administrators. **Sample characteristics:** • Age Not specified. • Sex Not specified. • Ethnicity Not mentioned. • Religion/belief Not mentioned. • Disability Not mentioned. • Long-term health condition Not mentioned. • Sexual orientation Not available. • Socioeconomic position Not available. **Sample size:** A group of 36 participants.	**Narrative findings – effectiveness** The results of the pre/post-test scores on the confidence surveys indicated a general trend towards participants scoring their confidence higher on the post-test than the pre-test. For all outcome measures except 1, the sign test indicated that the intervention had a significant positive effect at $p<0.001$*. • **Narrative findings – qualitative and views and experiences** Participants felt the intervention had an impact on supporting them to plan (more systematic, better prepared, tools to plan) community participation opportunities. Participants also stated that the intervention positively influenced their relationship with clients when supporting community participation in terms of being more aware of options to support and ideas of how to go about encouraging people. Results also indicated that agencies may want to think about	**Overall assessment of internal validity:** **+** **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Methodology: Mixed methods. The evaluation Contained 2 main components: (i) quantitative pre/post-confidence measurements of the confidence of intervention participants and (ii) qualitative feedback participants shared about the intervention. **Country:** USA. **Source of funding:** Government. This project was sponsored in part with funding from the National Institute of Disability and Rehabilitation	**Follow-up:** Not reported. **Costs:** Not reported. **Intervention:** • **Intervention category** Intervention to increase confidence of staff/practitioners to support older people with learning disabilities to participate in their communities. **Describe intervention:** • **Delivered by:** Not reported. • **Delivered to:** Forty-one study participants underwent intervention, but only 36 were involved in evaluation. • **Duration, frequency, intensity, etc.:** It was held in the form of a 2-hour workshop hosted by 2 community agencies in 3 occurrences.	offering continued opportunities such as refresher course to explore community participation strategies and resources in formal or informal ways. Qualitative data indicated that some changes could be made such as more time to practise skills, role playing, to the intervention to make it more effective. Finally, the results indicated that more time during the intervention should be devoted to participants being able to share their backgrounds with one another.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Research, within the Rehabilitation Research and Training Center on Aging and Developmental Disabilities (H133B031134) and the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function (H133B080009).	**• Key components and objectives of intervention:** The aims of the intervention were to (i) share the findings of a needs assessment with staff members and administrators to identify factors driving community participation programming and consumer-directed choice and control, (ii) provide a forum where staff members could learn from each other's experiences, (iii) offer resources and strategies to the staff on increasing community participation and (iv) increase staff members confidence in how to support community participation with people with I/DD. **• Content/session titles:** Intervention activities – Presentation of preliminary results from the Community Participation Project – Brainstorm of community participation opportunities as a large group – Reflection on the who, what, when, where, how and why of a community activity with step-by-step planning worksheet in small groups – Provision of resources on cognitively		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	accessible transportation planning and low/no-cost community participation opportunities – Group discussion of using planning worksheet to 'do' participation and additional worksheet to guide reflection of people with I/DD on the status of achievement of participation goals – Small group work using documentation (i.e. worksheets and pictures from community participation activity) to identify supports and barriers to participation – Individual and paired work to identify system-level barriers within community agency, develop a goal for change and strategise issues, opportunities, options and progress towards goal with use of worksheet. • **Location/place of delivery:** It was held in the form of a 2-hour workshop hosted by 2 community agencies in 3 occurrences. • **Describe comparison intervention:** Not applicable. **Outcomes measured:**		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	• Service user-related outcomes The evaluation contained 2 main components: (i) quantitative pre/post-confidence measurements of the confidence of intervention participants and (ii) qualitative feedback participants shared about the intervention. **• Follow-up:** Not reported. **Costs:** Not reported.		

Research question 6 – critical appraisal tables – effectiveness

1. Brooker K, van Dooren K, McPherson L et al. (2014) A systematic review of interventions aiming to improve involvement in physical activity among adults with intellectual disability. Journal of Physical Activity and Health 12: 434–44

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Study aim: A systematic review of interventions aiming to improve physical activity (PA) levels of adults with intellectual disability. **Methodology:** Systematic review. **Appropriate and clearly focused question?** Unclear. **Inclusion of relevant individual studies?** Somewhat relevant. **Rigorous literature search?** Partly rigorous.	**Study quality assessed and reported?** Yes. **Adequate description of methodology?** Yes. **Do conclusions match findings?** Yes.	**Does the study's research question match the review question?** Partly. To identify the strengths and weaknesses of PA interventions for people with intellectual disability that aim to measure changes in PA levels, which could improve wellbeing. Engagement and participation in physical exercise. **Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the design of the study?** No. **Is there a clear focus on the guideline topic?** Partly. Participation in PA can have mental health benefits. Some of the interventions involved/included family members, or provided details of local clubs and facilities. **Is the study population the same as at least 1 of the groups covered by the guideline?**	**Overall assessment of internal validity: +** **Overall assessment of external validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
		Yes. Adults with intellectual disability. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community settings. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Engagement with physical activities. **Are the study outcomes relevant to the guideline?** Yes. PA frequency (as indicators of achieving wellbeing?). **Was the study conducted in the UK?** No. Systematic review of 6 studies – 5 from USA and 1 from UK.	

2. Carmeli E, Orbach I, Zinger-Vaknin T et al. (2008) Physical training and well-being in older adults with mild intellectual disability: A residential care study. Journal of Applied Research in Intellectual Disabilities 21: 457–65

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Study aim: The aim of this study was to investigate the effect of physical training on general wellbeing and self-image in older people with intellectual disability. **Methodology:** Comparative study The control group, which was age- and sex-matched, did not receive any physical intervention. **Description of theoretical approach?** No. **How was selection bias minimised?** Participants were not randomised, but matched for age and gender. **Was the allocation method concealed?** No.	**Was the exposure to the intervention and comparison as intended?** Yes. Compliance with the programme, computed from attendance records, was 91.5%. The dropout frequency throughout the programme was 2 individuals for the control group (1 female and 1 male) because of medical reasons (respiratory distress/dyspnoea and general fatigue). **Was contamination acceptably low?** • Not reported. **Did either group receive additional interventions or have services provided in a different manner?** Partly. Study authors reported 'it is possible that members of the experimental group received more attention,	**Does the study's research question match the review question?** Partly. The study is about an exercise programme which is effective in improving the wellbeing of older people with learning disabilities. Note that it does not take into account the main outcomes such as maintaining relationships with family, friends and local communities and improving access to volunteering, employment and adult learning, social and leisure activities, transport and technology. **Has the study dealt appropriately with any ethical concerns?** Yes. The study was performed in accordance with the Helsinki declaration and approved by the IRB of Tel Aviv University and the ethics committee of the residential care centres. Verbal consent was obtained from each participant, as well as written consent from their guardians. **Were service users involved in the design of the study?**	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Were participants blinded? No. **Were providers blinded?** No. **Were investigators, outcome assessors, researchers, etc. blinded?** Yes. The interviewers were blind to the condition experienced by each participant. **Did participants represent the target group?** Partly. Participants volunteered to participate in the study. **Were all participants accounted for at study conclusion?** Yes.	praise and approval for participating in the exercise than the control group'. **Were outcomes relevant?** Partly. Three main outcome measures: body mass index (BMI), self-perception profile of well-being and Nottingham Health Profile (NHP) which are partly relevant. **Were outcome measures reliable?** Yes. Authors used valid and reliable measures such as BMI, standardised NHP. Authors modified Harter's self-perception profile to measure self-perceived well-being and established reliability and validity of the modified tool. **Were all outcome measurements complete?**	No. Not mentioned specifically about study, but there is a description about study population that the residential care centre environment is characterised by self-direction and sharing needs, concerns and expectations of the residents. The residents take part in the decision-making process that affects their life (vocational duties, recreational activities, etc). **Is there a clear focus on the guide-line topic?** Partly. The study is about an exercise programme which is effective in improving the wellbeing of older people with learning disabilities. Note that it does not take into account the main outcomes such as maintaining relationships with family, friends and local communities and improving access to volunteering, employment and adult learning, social and leisure activities, transport and technology. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	Yes. **Were all important outcomes assessed?** Partly. Could have assessed procedural integrity. The effects of the exercise programme in terms of wellbeing (enhancing interest in exercise, voluntary enrolment in other physical activities, and greater awareness and interest in healthy diet) were not objectively measured. **Were there similar follow-up times in exposure and comparison groups?** Yes: 5 months and 10 months following intervention. **Was follow-up time meaningful?**	Study is about older people with learning disabilities. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Residential care centres. **Does the study relate to at least 1 of the activities covered by the guideline?** Partly. The study is about an exercise programme which is effective in improving the wellbeing of older people with learning disabilities. **Are the study outcomes relevant to the guideline?** Partly. The study is about an exercise programme which is effective in improving the wellbeing of older people with learning disabilities. Note that it does not take into account the main outcomes such as maintaining relationships with family, friends and local communities and improving access to volunteering, employment	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	Partly. Could have a long-term follow-up. **Were the analytical methods appropriate?** Partly. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Yes. Matched for age and gender and also authors mentioned that analysis of variance of regression showed no significant differences between the two groups. **Was intention to treat (ITT) analysis conducted?** No. **Was the study sufficiently powered to detect an**	and adult learning, social and leisure activities, transport and technology. **Was the study conducted in the UK?** • No. Israel.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
	intervention effect (if it exists)? Not reported. Sample size calculation not provided. **Were the estimates of effect size given or calculable?** Yes. **Was the precision of intervention effects given or calculable? Were they meaningful?** Partly. **Do conclusions match findings?** Yes.		

3. Stancliffe RJ, Bigby C, Balandin S et al. (2015) Transition to retirement and participation in mainstream community groups using active mentoring: a feasibility and outcomes evaluation with a matched comparison group. Journal of Intellectual Disability Research 59: 703–18

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Study aim: To examine the feasibility of supporting older adults with disability to attend a mainstream community group as a transition to retirement. This paper examines (1) the feasibility of supporting older adults with disability to attend a mainstream community group; (2) the types of mainstream community groups or volunteering groups that participants joined; (3) the duration of participants' weekly attendance at their group; and (4) changes in outcomes experienced by participants that included loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts and work hours.	**Was the exposure to the intervention and comparison as intended?** Not reported. **Was contamination acceptably low?** Not reported. **Did either group receive additional interventions or have services provided in a different manner?** Not reported. **Were outcomes relevant?** Yes. **Were outcome measures reliable?** Yes. Using validated instruments for depression, health-related quality of life, loneliness, life events checklist, social satisfaction and logs.	**Does the study's research question match the review question?** Yes. Reports on the feasibility and outcomes of a transition to retirement programme for older adults with disability. **Has the study dealt appropriately with any ethical concerns?** Yes. Approved by the Human Research Ethics Committees at the University of Sydney and La Trobe University. Informed written consent obtained from all participants, or given by a family member or guardian. **Were service users involved in the design of the study?** No. Only as participants. **Is there a clear focus on the guideline topic?** yes.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Methodology: Comparative study with matched controls. Each intervention-comparison pair was matched as closely as possible on work/day programme placement, full-time or part-time work status or day programme attendance, living arrangements, gender and age group. **Description of theoretical approach?** No. **How was selection bias minimised?** Matched control: 'individual with similar characteristics was recruited to serve in a comparison group' (p705).	**Were all outcome measurements complete?** Partly. Missing data reported, also for some pre- and post-test comparisons, only data from the intervention group were available (p715). **Were all important outcomes assessed?** Partly. Some data missing/unavailable. **Were there similar follow-up times in exposure and comparison groups?** Yes. **Was follow-up time meaningful?** Yes.	**Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Older adults with long-term disability. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community setting. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Social participation and community support. **Are the study outcomes relevant to the guideline?** Yes. Social participation and satisfaction, quality of life, loneliness, depression. **Was the study conducted in the UK?** No. Sydney, Australia.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Was the allocation method concealed? Not reported. **Were participants blinded?** Not reported. **Were providers blinded?** Not reported. **Were investigators, outcome assessors, researchers, etc., blinded?** Not reported. **Did participants represent the target group?** Yes. **Were all participants accounted for at study conclusion?** Yes. Intervention group: n=29 at baseline, 27 (93%) attended	**Were the analytical methods appropriate?** Yes. Analysis of covariance and descriptive statistics. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Partly. matched controls **Was intention to treat (ITT) analysis conducted?** Not reported. **Was the study sufficiently powered to detect an intervention effect (if it exists)?** No. Author stated that 'the small sample size limited statistical power and made errors more likely' (p713).		

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
for 3 months, 25 (86%) attended for 6 months (at conclusion). Control group: not reported.	**Were the estimates of effect size given or calculable?** Partly. Due to missing data. **Was the precision of intervention effects given or calculable? Were they meaningful?** Partly. Due to missing data. **Do conclusions match findings?** Partly.		

Review question 6 – critical appraisal tables – the views and experiences of people using services, their families and carers

1. McCarron M, McCallion P, Carroll R et al. (2014) The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDSTILDA). Advancing Years, Different Challenges: Wave 2 IDS-TILDA. Findings on the ageing of people with an intellectual disability. University of Dublin, Trinity College

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Study aim: To document the changes over time of people with intellectual disability (ID) since Wave 1 (ID-TILDA [The Irish Longitudinal Study on Ageing]) in relation to social participation and connectedness. **Methodology:** Survey. Pre-interview questionnaires and extensive face-to-face computer assisted personal interview. This study is part of a longitudinal study (Wave 2) conducted to document the changes over time of people with intellectual disability (ID) since Wave 1 (ID-TILDA [The Irish Longitudinal Study on Ageing] in 2008) in relation to social participation and connectedness.	**Describes what was measured, how it was measured and the results?** Yes. Using data obtained from face-to-face computer assisted personal interview (CAPI). **Measurements valid?** Yes. Used previously at Wave 1. **Measurements reliable?** Yes. **Measurements reproducible?** Yes. **Basic data adequately described?** Yes. **Results presented clearly, objectively and in enough**	**Does the study's research question match the review question?** Yes. Social participation, social and community engagement, social connection of people with intellectual disability. **Has the study dealt appropriately with any ethical concerns?** Partly. Participants consented to take part in study (Fig 1.2, p19). **Were service users involved in the study?** No. Only as participants. **Is there a clear focus on the guideline topic?** Yes. Survey data on older people with ID and their experiences of relationships with family, friends,	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Objectives of the study clearly stated? Yes. To document the changes over time of people with intellectual disability (ID) since Wave 1 (ID-TILDA [The Irish Longitudinal Study on Ageing]) in relation to social participation and connectedness. One of the questions addressed by the survey on Social participation for older adults with intellectual disability. **Design measures for contacting non-responders?** Unknown. **Research design clearly specified and appropriate?** Yes. Pre-interview questionnaires and extensive face-to-face	**detail for readers to make personal judgements?** Yes. **Results internally consistent?** Yes. **Data suitable for analysis?** Yes. Descriptive analyses. **Clear description of data collection methods and analysis?** Yes. **Methods appropriate for the data?** Yes. **Statistics correctly performed and interpreted?** Yes.	access to social activities and participation, information technologies, barriers and facilitators to social engagement, social exclusion etc. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. People with an intellectual disability. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Social participation and connectedness.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
computer assisted personal interview. **Clear description of context?** Yes. **References made to original work if existing tool used?** Yes. **Reliability and validity of new tool reported?** Yes. **Survey population and sample frame clearly described?** Yes. At Wave 1, the National Intellectual Disability Database (NIDD) provided the sampling frame for the study and a nationally representative group of 753 respondents with an ID over the age of 40 years were	**Response rate calculation provided?** Yes. **Methods for handling missing data described?** Unclear. **Difference between non-respondents and respondents described?** Yes. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Yes. **Results can be generalised?** No.	**(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. Republic of Ireland.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
successfully enrolled in the study. At Wave 2, all living Wave 1 respondents were invited to participate. **Representativeness of sample is described?** Yes. The National Intellectual Disability Database (NIDD) provided the sampling frame for the study and a nationally representative group **Subject of study represents full spectrum of population of interest?** Yes. **Study large enough to achieve its objectives, sample size estimates performed?** Yes. Over 700 participants.	Generalisable to the population sampled, but not generalisable to the population with ID in Ireland. **Appropriate attempts made to establish ‘reliability’ and ‘validity’ of analysis?** Partly. **Conclusions justified?** Yes.		

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
All subjects accounted for? Yes. **All appropriate outcomes considered?** Yes. **Response rate** Attrition at Wave 2 (~6%): 45 (Deceased [34] and refusal [11] from 708 participants). **Measures for contacting non-responders?** Not reported			

2. McCarron M, Swinburne J, Burke E et al. (2011) Growing older with an intellectual disability in Ireland 2011. First results from the intellectual disability supplement to the Irish Longitudinal Study on Ageing. Dublin: School of Nursing and Midwifery, Trinity College Dublin

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim 1. To identify the principal influences on successful ageing in persons with intellectual disability, and then determine if they are the same or different from the influences for the general population. 2. A second aim is to develop a first wave baseline picture of ageing among persons with intellectual disability and a cohort of subjects that may then be followed longitudinally. **Methodology:** Survey. The study was a nationally representative survey. **Objectives of the study clearly stated?** Yes.	**Describes what was measured, how it was measured and the results?** Each participant completed, or was assisted to complete a pre-interview questionnaire, and then took part in a face-to-face interview. A carers' questionnaire was left to complete and return, where applicable. A pre-interview questionnaire (PIQ) was sent to the participant approximately 7 days prior to the interview. The questionnaire covered demographic information, health status, healthcare utilisation and medication usage. Similar to TILDA the interview included: socio-demographic characteristics; physical health and behavioural health; mental and cognitive health, social participation and social connectedness, health care	**Does the study's research question match the review question?** Partly. Selected areas of report are in alignment with guideline topic of interest such as relationship with family and communities, volunteering, social and leisure activities, employment and retirement. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was sought from and granted by Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin The IDS-TILDA was granted full ethical approval for Wave One by Trinity College Dublin Faculty of Health Sciences Research Ethics Committee in 2009, following the completion of an extensive pilot (McCarron et al. 2010), which tested the survey instruments and fieldwork approach.	**Overall assessment of internal validity:** + + **Overall assessment of external validity:** + +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Research design clearly specified and appropriate? Yes. Nationally representative survey design. **Clear description of context?** Yes. The increased life expectancy of people with an intellectual disability is an incredible success story and to be celebrated, but it also poses tremendous challenges as we know little about this population group in Ireland or indeed internationally. The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), designed to better understand these challenges, is a large scale nationally representative study of people with an intellectual	utilisation, employment, income and lifelong learning. **Measurements valid?** Yes. Methodology report says the survey used valid instruments. **Measurements reliable?** Yes. Methodology report says the survey used reliable instruments. **Measurements reproducible?** Yes. **Basic data adequately described?** Yes. Baseline characteristics of participants which include age, gender, living accommodation, level of ID, BMI, and geographical distribution mentioned.	**Were service users involved in the study?** Yes. The input of 2 groups was critical to the design of the study, people with ID and an international scientific committee. In pursuit of inclusion and participation people with an ID were included in every stage of the development, design, implementation and evaluation of the pilot and Wave 1 of the study. Their input helped in the design of pictorial explications to complement all written material increasing the accessibility of the study's questionnaires. An international scientific committee with extensive experience working with people with intellectual disability advised on the development of all protocols and provided input on both ID-specific content and advised on the opportunities for comparability with international studies.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
disability aged 40 years and over in Ireland. This study is the first of its kind in Europe, and the only study with the potential of comparing the ageing of people with intellectual disability directly with the general ageing population. **References made to original work if existing tool used?** Yes. Study refers to similar published surveys, publications and existing data collection tools. **Reliability and validity of new tool reported?** Unclear. Study used several valid and reliable existing tools. Not clear from the documents available regarding the validity and reliability of new tools.	**Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes. **Results internally consistent?** Yes. **Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Yes. **Methods appropriate for the data?** Yes. It is acknowledged that the purpose of this report is to solely describe the current circumstances of the	**Is there a clear focus on the guideline topic?** Partly. Selected areas of report is in align with guideline topic of interest such as relationship with family and communities, volunteering, social and leisure activities, employment and retirement. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Study is about people with learning disability above 40 years. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Study took place in people's home, community homes and residential centre.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Survey population and sample frame clearly described? Yes. The National Intellectual Disability Database (NIDD) provided the sampling frame for the study and facilitated the random selection of people with intellectual disability aged 40 years and over. **Representativeness of sample is described?** Yes. The National Intellectual Disability Database (NIDD) provided the sampling frame for the study and facilitated the random selection of people with intellectual disability aged 40 years and over. IDS-TILDA successfully recruited a random sample of 753 participants across all the age	population; it does not explore causal relationships between factors nor are any differences described reported as statistically significant. **Statistics correctly performed and interpreted?** Yes. For the purposes of this report only descriptive data is reported and all analyses were conducted using SPSS version 18. **Response rate calculation provided?** Yes. **Methods for handling missing data described?** Yes. Other than the variables, level of ID and aetiology of ID there was a small amount of item level missing data and other	**Does the study relate to at least 1 of the activities covered by the guideline?** Yes. The study focussed on selected areas of report in alignment with guideline topic of interest such as relationship with family and communities, volunteering, social and leisure activities employment and retirement. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views related to relationship with family and communities, volunteering, social and leisure activities employment and retirement are relevant to the guideline. **Does the study have a UK perspective?** No. Republic of Ireland.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
groups, male and female, and includes all levels of intellectual disability and living arrangements. The sample of 753 people with ID aged 40 years and over who completed all interviews represented 8.9% of the total population 40 years and over registered on the 2008 NIDD database. **Subject of study represents full spectrum of population of interest?** Yes. IDS-TILDA successfully recruited a random sample of 753 participants across all the age groups, male and female, and includes all levels of intellectual disability and living arrangements. A total of 138 intellectual disability service providers throughout Ireland were involved in supporting	than those 2 variables little evidence that the small amount of missing data would result in differences in findings. This concern will be investigated further in subsequent analyses, including mechanisms to re-weight level of ID in particular. **Difference between non-respondents and respondents described?** No. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Yes. **Results can be generalised?** Yes.		

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
people with ID to take part in this study. **Study large enough to achieve its objectives, sample size estimates performed?** Yes. Supplementary material on methodology of survey shows the study is adequately powered and using randomised representative sampling 'The RANSAM system was eventually chosen because it provides a true probability sample, permits stratification and clustering, and gives an exact geocode for each selected address'. **All subjects accounted for?** Yes. **All appropriate outcomes considered?**	As it is a nationally representative study, this results can be generalised to similar populations to some extent. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** Yes. **Conclusions justified?** Yes.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Yes.			

3. Judge J, Walley R, Anderson B et al. (2010) Activity, aging, and retirement: the views of a group of Scottish people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 7: 295–301

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To understand the views of older adults with learning disabilities in relation to their current daytime activity (which was not necessarily part of a day centre) and their hopes and dreams about future daytime activity. **Methodology:** Qualitative study using interpretive phenomenological analysis. **Is a qualitative approach appropriate?**	**Is the context clearly described?** Unclear. The characteristics of the participants and settings are not very clearly defined; we're provided with an age range and gender characteristics and an overview of people's living circumstances but nothing more. Data were only collected via interviews with the individuals at one time point. Although the analytical approach (IPA) adopted by researchers does imply that the researcher is 'also a participant in the research' (p296) there is no reflection about	**Does the study's research question match the review question?** Partly. The study aimed to find out people's views about daytime activity but the findings do provide data about the role of the day centre facilitating the building of relationships and connections. **Has the study dealt appropriately with any ethical concerns?** Partly. It is unusual that research of this nature would not be submitted for full ethical approval. Informed consent was obtained from participants.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Appropriate. Because the study was attempting to understand the lived experience and the hopes and dreams of the participants. **Is the study clear in what it seeks to do?** Clear. The purpose/ aims of the study are discussed and there is appropriate reference to the literature around this topic. **How defensible/rigorous is the re-search design/methodology**? Somewhat defensible The study design is appropriate to the research question and a clear description of and rationale for the qualitative approach is	how the researchers may have influenced/affected the data collection and findings. **Was the sampling carried out in an appropriate way?** Inappropriate. There is a risk of bias or influence on the respondents due to the sampling method. They were recruited purely on the basis that service managers felt they could give consent and articulate their views. As the research seems to have been presented as a 'service evaluation' (hence no need for ethical approval - according to the researchers) there is every chance that only people who would be happy with their day centre (and the activities it facilitates) were suggested as participants. **Were the methods reliable?** Somewhat reliable.	**Were service users involved in the study?** No. Involved only as participants. **Is there a clear focus on the guide-line topic?** Yes. Active ageing among older people with learning disabilities. **Is the study population the same as at least one of the least 1 of the settings covered by the guide-line?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Day centres and people's own homes. **Are the views and experiences reported relevant to the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
given. There are also clear accounts of the rationale and justification for data collection and data analysis techniques. The sampling strategy is a little questionable and appears to have been based on practitioner views about which of their service users could give consent and articulate their experiences. Adults with more complex learning disabilities or with communication difficulties were, by implication, not included. **How well was the data collection carried out?** Appropriately. Data collection methods are clearly described and seem appropriate to address the research question. Data collection and record keeping were systematic.	The methods do investigate what they claim to but data were only collected via 1 method – though the authors do discuss their findings alongside the results of other studies (for triangulation). **Are the data 'rich'?** Poor. The contexts of the data described aren't described terribly clearly and most of the data are in agreement, with little diversity of perspective (although respondents may indeed have all been in agreement). Only a handful of quotations are provided, which doesn't provide a huge amount of detail. Responses are not compared/contrasted across the different day centres from which respondents were recruited. **Is the analysis reliable?** Unreliable.	**Does the study have a UK perspective?** Yes, Scotland.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	Although analysis may have been reliable and there is a good description of how it was conducted, there is nothing to suggest that more than 1 researcher themed and coded transcripts/data. Also, there is no suggestion that participants fed back on the transcripts/data. It is difficult to tell whether discrepant results were ignored or whether all participants generally shared the same views and attitudes (which is of course possible). **Are the findings convincing?** Somewhat convincing. The findings are internally coherent and fairly clearly presented although more clarification about the context of responses/respondents would be useful. Some extracts from the original data are included but it would have more convincing if more were presented. On the		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	whole the reporting is clear and coherent. **Are the conclusions adequate?** Adequate. The conclusions are plausible and coherent although alternative explanations haven't obviously been explored and discounted. However, research implications are clearly defined and the researchers seem to be aware about some of the study limitations.		

4. Newberry G, Martin C, Robbins L (2015) How do people with learning disabilities experience and make sense of the ageing process? British Journal of Learning Disabilities 43(4): 285–92

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To explore how people with learning disabilities experience and make sense	**Is the context clearly described?** Yes.	**Does the study's research question match the review question?** Yes.	**Overall assessment of internal validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
of the ageing process and old age. **Methodology:** Qualitative study. Analysis was carried out using interpretative phenomenological analysis (IPA). **Is a qualitative approach appropriate?** Appropriate. Study used interpretive phenomenological analysis. **Is the study clear in what it seeks to do?** Yes. **How defensible/rigorous is the research design/methodology**? Defensible. Analysis was carried out using interpretative	**Was the sampling carried out in an appropriate way?** Somewhat appropriate. Limitations of the study include the recruitment method: all participants accessed learning disability services within a single city. **Were the methods reliable?** Yes. **Are the data 'rich'?** Yes. **Is the analysis reliable?** Yes. **Are the findings convincing?** Yes. **Are the conclusions adequate?** Yes.	The study is about exploring the experience and making sense of aging in older people with learning disabilities, which is in line with the guideline. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was granted by Leeds Central Research Ethics Committee. Potential participants were given accessible information sheets. The researcher discussed the study and assessed capacity for informed consent with each participant, checking that participants were able to understand and retain information about the study, and use it to reach a decision. **Were service users involved in the study?** Yes. The researcher discussed the study and assessed capacity for informed consent	**Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
phenomenological analysis. Each transcript was analysed individually before the group analysis. The validity of interpretation was checked through discussion between the authors. **How well was the data collection carried out?** Appropriately. The interviews involved discussing potentially sensitive topics; the researcher monitored participants for signs of distress, and debriefed them. There were identified strategies to manage risk, including sources of support available for participant distress, and referral processes for the safeguarding team. No safeguarding action was necessary. The pace of the		with each participant, checking that participants were able to understand and retain information about the study, and use it to reach a decision. **Is there a clear focus on the guideline topic?** Yes. The study is about exploring the experience and making sense of aging in older people with learning disabilities, which is line with the guideline. **Is the study population the same as at least 1 of the least one of the settings covered by the guideline?** Yes. Study participants were older people with learning disabilities. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Experience of older people with learning disabilities and making sense of ageing.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
semi-structured interviews was adjusted to suit each individual, allowing participants to articulate their experiences as best they could. Questions were designed to be accessible; most participants understood and answered questions but some struggled.		**Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

5. Randell M, Cumella S (2009) People with an intellectual disability living in an intentional community. Journal of intellectual Disability Research 53: 716–26

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To explore the experiences of people living in an intentional community, and to understand what the idea of 'community' means to them as individuals. **Methodology:**	**Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate. 'Using an initial selective sample designed to identify respondents	**Does the study's research question match the review question?** Yes. Explores the perceptions of older people with learning disabilities living in an intentional community and the meaning of their community to them.	**Overall assessment of internal validity: +** **Overall assessment of external validity: ++**

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology**? Defensible. **How well was the data collection carried out?** Appropriately. Unstructured interviews using simple open-ended questions, and used Makaton and a range of pictures and symbols to aid communication where required.	who had lived in the village for different durations. The population was grouped into 5 cohorts according to numbers of decades of residence (i.e. from 0–10 years to 41–50 years). The sample was selected at random with equal numbers from each cohort, and sampling continued until additional respondents reported similar beliefs and experiences to those already sampled' (p718). **Were the methods reliable?** Reliable. **Are the data 'rich'?** Yes. **Is the analysis reliable?** Reliable. All interviews taped, transcribed and analysed in a hierarchy of categories and themes, following grounded theory procedures.	**Has the study dealt appropriately with any ethical concerns?** Yes. Approved by York Local Research Ethics Committee; consent procedures involved member of the sample and their main co-worker, and completion of the consent form. **Were service users involved in the study?** Yes. Interviews were piloted with two randomly selected members. **Is there a clear focus on the guideline topic?** Yes. Focus on opportunities for friendship and meaningful employment for people with ID. **Is the study population the same as at least 1 of the least one of the settings covered by the guideline?** Yes. Older people with learning disabilities. **Does the study relate to at least 1 of the activities covered by the guideline?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	‘The interviewer and analyst, a qualified learning disabilities nurse with experience of community-based supported living’. (p718) **Are the findings convincing?** Somewhat convincing. Some residents unable to participate because of insufficient communication and cognitive skills. Four members were excluded because of anxiety about changes to their routine or the introduction of new people. **Are the conclusions adequate?** Yes.	Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Birmingham.	

Review question 6 – critical appraisal tables – health, social care and other practitioners' views and experiences

1. Zakrajsek AG, Hammel J, Scazzero JA (2014) Supporting people with intellectual and developmental disabilities to participate in their communities through support staff pilot intervention. Journal of Applied Research in Intellectual Disabilities 27: 154–62

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: The main aims of the project were to (i) use the needs identified by community agency staff and administrators to develop resources and strategies for supporting full participation, (ii) develop and implement a pilot intervention specifically for staff members to increase their confidence in supporting choice and control of people with I/DD and (iii) complete a formative evaluation of the pilot intervention. **Methodology:** Mixed methods.	**Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question?** Partly. Both quantitative and qualitative methods were used superficially in the study. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Partly.	**Does the study's research question match the review question?** Yes. Though the intervention is for staff and administrators it helps to support the empowerment of older people with learning disabilities in community participation. **Has the study dealt appropriately with any ethical concerns?** Yes. All participants who decided to participate were consented with the University of Illinois at Chicago Institutional Review Board -approved consent process. **Were service users involved in the study?** No.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
The evaluation contained two main components: (i) quantitative pre/post-confidence measurements of the confidence of intervention participants and (ii) qualitative feedback participants shared about the intervention. **Qualitative comp 1** Participant feedback of the intervention was the only qualitative component. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. Qualitative feedback. Participants shared about the intervention.	Not fully integrated, qualitative components was mainly to obtain feedback of the intervention. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Unclear.	**Is there a clear focus on the guideline topic?** Yes. Guideline topic includes interventions to support older people with learning disabilities to maintain relationships with their local community. Though the intervention is for staff and administrators it helps to support the empowerment of older people with learning disabilities in community participation. **Is the study population the same as at least 1 of the least one of the settings covered by the guideline?** Yes. Staff and administrators from agencies who support people with learning disabilities. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Is the process for analysing qualitative data relevant to address the research question? Yes. Not followed a particular method to analyse qualitative data but the authors summarised and grouped similar responses into paragraphs like a descriptive summary. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes. The results from the qualitative data also indicated that agencies may want to think about offering continued opportunities to explore community participation		The main outcome reported is the increased confidence of staff (study participants) in supporting older people with learning disabilities to participate in their communities. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. USA.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
strategies and resources in formal or informal ways. **Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants?** Unclear. **Quantitative component** **Which quantitative component?** Pre- and post-confidence measurement of staff participants. **Are participants (organisations) recruited in a way that minimises selection bias?** Unclear.			

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes? Unclear. Used a questionnaire in which each of the confidence questions was rated on a 4-point Likert scale and matched with intervention objectives. **In the groups being compared (exposed versus non-exposed; with intervention versus without; cases versus controls), are the participants comparable, or do researchers take into account (control for) the**			

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
difference between these groups? N/A. The study had a single group. **Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?** Yes. Study had 41 participants and 36 participants completed evaluation.			

Review question 7. Care and support

a. What is the effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities?

b. What are the views and experiences of people using services and their carers in relation to care at home, in supported housing or accommodation with care and support for older people with learning disabilities?

c. What are the views and experiences of health, social care and other practitioners about care and support at home, in supported housing or accommodation with care and support for older people with learning disabilities?

Research question 7 – findings tables – effectiveness

1. Nambisan P, Lamkin D, DeLong C (2014) Feasibility, benefits and challenges of using telemonitoring for the aging with developmental disabilities (DD): an exploratory study. Online Journal of Public Health Informatics 6: e186

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The study stated its objective to 'Assess the feasibility, benefits and challenges of using	**Participants:** Service users and their families, partners and carers: older patients with learning disabilities and a medical problem that required monitoring.	**Quantitative findings – effects of intervention on quality of life** All indicators of quality of life had improved scores after, but only 2 were statistically significant. These were 'To what extent do you feel that physical pain prevents you from doing what you need to do?' which at pre-test had a mean of 4.45 (sd of .510) and mean for post-test was 3.90 (sd of	**Overall assessment of internal validity:** - **Overall assessment of**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
telemonitoring for aging patients with developmental disabilities' (p1). **Methodology:** Mixed methods. Quantitative survey and qualitative focus groups. **Country:** USA. **Source of funding:** Government. NYS Developmental Disabilities Planning Council.	**Professionals /practitioners** Nurses and care staff from the Centre for Disability Services (CFDS) at Albany, NY. **Sample size:** Total 21 patients participated in survey part of the study. A total of 6 patients participated in the focus group; 25 nurses and care staff participated in interviews. **Intervention:** The article explains that 'telemonitoring is defined as "an automated process for the transmission of data on a patient's health status from home to the respective health care setting." Telemonitoring differs from telemedicine in	.912; t (19) =2.604; p<.05). The mean for 'How healthy is your physical environment?' at pre-test was 3.77 (sd of .922) and the mean post-test was 4.23 (sd of 0.752; t(21)=-2.215, p<.05). **Narrative findings on effectiveness – medical records** With regard to the specific health outcomes, each individual's health record was carefully analysed by an RN for changes in their health conditions, number of hospital/doc visits, emergency room visits and for anything that could be attributed to the daily monitoring using the new technology. We did not find any major changes in health conditions or in number of hospital/doc/emergency room visits. **Narrative findings – views and experience** It is feasible and beneficial to use telemonitoring, at least for higher functioning patients. Patient interviewees expressed several times that they 'liked it'; at least 2 people mentioned the terms 'more independent' and the terms 'doing it myself/on my own'. It was indicated that telemonitoring helps to improve patient literacy/knowledge regarding own disease (e.g. 'When I exercise and eat better the reading is better next day'). This in turn could also explain the increased level of self-	**external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	that telemonitoring is limited to support provision for patients who need regular monitoring using various telecommunication technologies, whereas telemedicine is the provision of clinical care in the form of diagnosis, treatment and consultation by a provider using various telecommunication technologies. Telemonitoring allows providers to remotely monitor patient status for long periods of time' (p2). **Delivered to:** Patient participants – all older people with learning disabilities. The patients who had some level of functional independence were trained to use the telemonitoring device	confidence and self-efficacy as well as the greater motivation for self-care and prevention. At the same time, there are some challenges that we will need to address as practical measures for enhancing the effective use of this technology. Two people mentioned that 'sometimes it gets on my nerve' which points to some of the usability issues of the system. Overall, the caregiver focus group indicated a unanimous and strong support that the telemonitoring technology is useful and allowed more independent living for higher functioning patients, but that it was not so useful for low functioning patients. The main benefit from the caregivers' perspective was getting daily values on their patient. Caregivers found that this provided them with better understanding of the patient and more control on what is going on. An unanticipated problem was high turnover rate of the care giving staff. Future studies should focus on outcomes such as feeling of independence, empowerment, better understanding of their own disease and feelings of security.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	themselves. Patients with limited functional independence were assisted by professional caregivers from the Center for Disability Services (CFDS). **Place of delivery:** Within residential homes, independent living facilities and private homes, associated with the Center for Disability Services (CFDS) at Albany, NY. **Outcomes measured:** Service user-related outcomes: quality of life – on a validated 8-item scale. **Service outcomes:** Health data (e.g. blood pressure, glucose levels), health and service use outcomes.		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
	Follow-up: Pre-results were taken 6 months before installation, and post-results were taken up to 6 months after installation. **Costs?** No.		

Review question 7 – findings tables – the views and experiences of people using services, their families and carers

1. Forbat L (2008) Where should people with dementia live? Using the views of service users to inform models of care. British Journal of Learning Disabilities 36: 6–12

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The authors intended the study to collect 'qualitative data from people with a	**Participants:** Service users and their families, partners and carers. Included individual interviews, a service user	**Service user advisory forum – experiences of dementia in a group home setting** Member of the panel were all residents of the group home with learning difficulties, but they did not necessarily have dementia.	**Overall assessment of internal validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
learning disability who live with someone with dementia, to explore how their views on and understandings of dementia can inform the appropriate development of service provision and care models' (p7). **Methodology:** Qualitative study. **Country:** UK. **Source of funding:** Government. Community Fund Grant.	advisory forum, and ethnographic work in homes and workplaces. **Sample size:** Total 8 individuals were interviewed and observed. Data also included from service user advisory group (also 8 people). **Follow-up:** Unclear. Not mentioned, but the study was conducted over 3 years, so there may have been some form of follow-up. **Costs?** No.	Identified seven issues around dementia. These were: confusion, forgetfulness, wandering, health and safety, the effect of dementia on staff time, perceived special privileges and changes to the physical environment. The study found that residents had some knowledge of peers developing dementia and of the symptoms. 'Both two had problems they were wandering round the building, couldn't see what they were going to do' (p9). 'Patricia couldn't know how … couldn't explain how she, she fell over had a fit in the cottage that time and didn't remember it' (p9). **Staff time** The study reports on resident's comments about those who had dementia take up a lot of staff time. Residents commented that it could negatively impact their time. 'Some of us feel as if we … I know it's not right, but it makes some of us feel as though we need a few more staffing' (p9). 'Because of the way the one-to-one is on with Clare and er	**Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		"I'm sorry I am doing the one-to-one with Clare" and if they are doing the one-to-one, it's like they've got only so many different things to do' (p9). **Special privileges** Some participants commented that residents that were showing signed of dementia were given different treatment compared to other residents. 'Maybe because the other one, she sees the other one that's got dementia, gets away with sitting at the little coffee table ... getting her tea. And it makes her think "well if that one can get away with it, why can't I?" (p10). The need for some residents to be away from the group while having meals was not understood by some residents and seen and preferential treatment. **Changes to the environment** The facility where the participants lived was set to be changed into specialised housing for dementia sufferers. This news was not welcomed by current residents. 'I don't think Ronny, it's like I said, Ronny doesn't like to move' (p10).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		'That means my flat's going to get pulled down!' (p10). Residents were concerned about the changes to the physical environment, but the study does not link this concern to dementia, or residents who currently had dementia. **Residents with learning difficulties** The study spoke to 8 residents who had dementia. The findings focus on interviews with 2, neither of whom showed much awareness of the disease, apart from some mention of confusion and repeating themselves. However, neither interviewee knew what the drugs they took were for; 1 was only aware of taking medication for epilepsy. They showed some awareness of the ageing process and the need for some people to move to old people's homes or care homes, but were not positive in their opinions.	

Review question 7 – findings tables – health, social care and other practitioners' views and experiences

1. Bigby C, Webber R, Bowers B et al. (2008) A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. Journal of Intellectual Disability Research 52: 404–14

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The aim of this study (which is the first phase of a 4-year study) was to map the population of people with ID in residential aged care facilities in Victoria, asking care providers: '(1) how many and what are the characteristics of people with ID living in residential aged care in Victoria; (2) why do they move to residential aged care and where do they move from; (3) what type of support do they receive in residential aged	**Participants:** Professionals/practitioners. Providers of aged care facilities were the survey respondents. (Note that the sample characteristics given below are the characteristics of the aged care facility residents who had a learning disability.) **Sample size:** Detailed data available for 158 residents with learning disabilities. **Follow-up:** No follow-up. **Costs?** No.	**(1) How many and what are the characteristics of people with ID living in residential aged care in Victoria – 158 residents with learning disabilities.** Also note that prevalence of dementia was a lot lower than in the general population, 'Just over 10.0% of residents with ID (17) were reported as having dementia compared with an estimated 60.0% in the general resident population' (p408). Also, there was no difference in the mean age of residents in this study with and without dementia. Down's syndrome and dementia – residents with Down's syndrome were younger at 60 years than those without this condition at 66 years [t(148)=-1.87, p=0.06]. Residents with Down's syndrome and dementia were significantly younger, at 61, than residents with dementia without Down syndrome at 74 [t(15) = -3.91, p=0.001]. **(2) Why do they move to residential aged care and where do they move from?** Numbers and proportions moving to the aged care facility from the following accommodation: Community residential unit (group home) n=10 6.3% Other supported accommodation n=40 19.0% Living with family n=58 36.7%	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
care; and (4) what do residential aged care providers see as the issues in providing support for people with ID' (p406). Note that the fourth of these aims is the most relevant to our review question. **Methodology:** Survey. Postal survey sent to 826 residential aged care facilities in Victoria. **Country:** Australia. **Source of funding:** Not		Living alone or with unrelated others n=12 7.6% High-care aged care facility n=10 6.3% Low-care aged care facility n=11 7.0% Hospital n=14 8.9% Don't know n=3 1.9% Psychiatric hospital n=2 1.3% Total n=158 100% Main reason for moving into the aged care facility for people with a learning disability was the inability of the previous facility to provide adequate support. Main reason for people to be admitted from the family home was the death or ill health of the primary carer. People with Down's syndrome (with/without dementia) did not enter residential care at a significantly earlier age than other residents with LD. For 69% the move to residential care was the person's preferred option (not preferred, 9%) although note that this information was given by the residential care provider, not the individuals themselves. Respondents said that for many people residential care was the only option: 'It seems to me that families hit a crisis [when the person has to be hospitalised]. They don't know what to do so they decide on aged care as the only option but with good care the person often starts to feel better' (p409).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
reported.		**Key question of relevance to our review** How appropriate is it for people with LD to be in the aged care facility? This was explored in the study by establishing the (a) participation of residents in the local community and (b) the development of meaningful relationships. **(a) Participation of residents in activities** The majority of residents with LD (94%) took part in on-site activities at least weekly, with 73% participating daily. Authors note that there's no comparable data for rates of engagement for the general aged care population but that anecdotal evidence suggests that the rate is higher than this for both weekly and daily take-up. For residents who didn't participate, reasons given were: Their health, cognitive incapacity and emotional or behavioural difficulties. Respondents cited frailty, residents being asleep most of the day, poor motivation and chronic pain – also being disruptive and unable to concentrate. Some facilities had designed activities specifically for people with LD or encouraged them to get involved in the facility by doing jobs or taking on roles (collecting bread and mail, setting up rooms for activities). Just under 50% of adults with LD participated in activities off-	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		site at least once a week. These included disability day programmes or outings with staff or friends/ family. A total of 16% of residents (mostly <60 years) continued to use disability services after admission in order to maintain engagement in activities. For some the cooperation between aged care and disability services seems to work well. Respondents from some facilities did say that their resident with LD was unable to access LD services because this would be 'double dipping' – e.g. using funding from both aged and disability services. (NB in Australia there are no firm policies about concurrent access to residential aged and disability services). **(b) Development of meaningful relationships** Total 28% of residents were reported as having no positive relationships with other residents. Notably, in the 'exceptional facilities' (meaning they have large numbers of LD residents) only 5% of residents were reported as not having positive relationships (compared with 28.7% in smaller facilities). Residents in the 2 exceptional facilities were twice as likely to have a close friendship with another resident. It wasn't unusual for residents with LD to have friendships with staff rather than other residents.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Care providers' views about appropriateness of residential aged care for people with LD The survey included an open-ended question about issues that arose in providing care to adults with LD in residential aged care. Three quarters cited a range of difficulties. The most common issue was people with LD 'fitting in' with activities for other residents because of their younger age, different interests, 'difficult behaviours' or different care needs. Other issues: the need for individual attention (24%), social isolation (11%), negative attitudes of other residents (6%), lack of appropriate staff training (6%), shortages of resources to adapt to their needs (10%). 'The main issue is that most of the time, people are placed as they are usually younger than other residents. They have nothing in common with aged residents except that they can't look after themselves. It would be good if there were services outside for these people' (p411). Note that the remaining 24% did not cite problems – they said care for the LD group was not dissimilar to the older residents or that differences had been accommodated.	

2. Iacono T, Bigby C, Carling-Jenkins R et al. (2014) Taking each day as it comes: staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes. Journal of Intellectual Disability Research 58: 521–33

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The aim of this study was outlined as 'to report on the experiences of disability staff in group homes supporting residents with Down syndrome and Alzheimer's disease in relation to their under understanding of what was happening to these residents, their responses to them, and how they felt about their support role' (p521). **Methodology:** Qualitative study. Semi-structured	**Participants:** Professionals/practitioners. Disability support staff. **Sample size:** Total 15 staff interviewed, who together cared for a total of 9 older people with learning disabilities. **Follow-up:** Initial interview followed by a second conducted 6–12 months later. **Costs?** No.	Specific research questions addressed how staff (i) understand what is happening to residents with Down's syndrome and Alzheimer's disease, (ii) respond to these residents, and (iii) feel about providing support to them. It was found that they are: (i) Struggling to understand change (e.g. in memory and capacity, communication, personality, challenging behaviour or disinterest/apathy). Also struggled with understanding how these fluctuated or may be confounded by changes in medication or other factors. Staff shifted between differing explanations for similar behaviour. In some cases they felt residents' personality wasn't 'different' but rather 'more pronounced'. (ii) Taking each day as it comes. Staff found it difficult to project what would be needed, what changes to expect or when they would occur. When strategies were successful, staff reported attempts to ensure a consistent approach by all staff. There were staff who were critical of others, who were unaware of needs and best approaches. A recurring strategy was to provide comfort and reassurance to patients and finding what kept them calm and happy. (iii) Feeling 'he's got a disability and that's our job'. Staff	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
interviews analysed thematically. **Country:** Australia. **Source of funding:** Not reported.		saw it as their responsibility to continue to provide support to the resident, considering that they were the best people to do so. They feared that a move to residential aged care would be detrimental to residents' wellbeing, and thought aged care staff lacked disability-specific training. Despite their sense of responsibility, they were not confident about their skills, and were also resigned to the inevitability of a move to aged care sooner or later. This stemmed from their doubts their organisation's commitment to support residents to remain at home, reflecting a feeling of unwillingness and lack of resources. With varying degrees of success, staff had sought assistance from behaviour intervention services. They often had little confidence in the advice or assistance they did receive, and variously questioned its validity, suggested it did not go far enough or some-times ignored it.	

3. Kåhlin I, Kjellberg A, Hagberg J (2015) Ageing in people with intellectual disability as it is understood by group home staff. Journal of Intellectual and Developmental Disability 41(1): 1–10

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The paper stated its	**Participants:** Professionals/practitioners.	There were 3 overarching themes in the way that care staff discuss and understand ageing among people with ID, and	**Overall assessment of**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
aim as 'To explore how group home staff address issues of ageing and being old among people with ID' (p2). **Methodology:** Qualitative study. Interviews were conducted, and findings obtained using directed content analysis, where a theory or set of relevant research findings is used to guide the coding and analysis process. **Country:** Sweden. **Source of**	They were direct care staff from group homes for people with LD. They each had between 2 and 34 years' (mean=15) experience in supporting people with ID. **Sample size:** Total 12 staff were interviewed, from group homes with 7 to 9 residents each. They had between 2 and 34 years' (mean=15) experience in supporting people with ID. **Follow-up:** No follow-up. **Costs?** No.	how it influences their everyday work. **1) Silence of ageing** Both staff and residents rarely discussed aging and old age in everyday conversation. Residents rarely talk about ageing, and the staff felt this was because they tended not to think about it. Instead it was reported they live in the present and are happy for each day, perhaps in part due to difficulties perceiving time. Residents cared about identifying themselves as adults, but identifying as older didn't seem to matter to them. The staff themselves also tended not to talk to the residents about ageing. In part this was attributed to it being a social taboo generally, but mostly they referred to the residents' limited understanding of ageing as a phenomenon. Finally, staff only occasionally discussed ageing among each other. When they did it was mainly in relation to physical and mental aspects, as they affected their everyday work. Occasionally staff would also have training on ageing and ID and it would be discussed then. **2) Dual faces of ageing** Views and beliefs were often quite contradictory. In several ways the physical/medical sides of ageing for people with LD are shared with the general population, such as decreased mobility and senses, conditions like high blood	**internal validity:** ++ **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
funding: Not reported.		pressure and decreased memory and cognitive function. Dementia was considered a particularly important issue and came up frequently. On the other hand, there were aspects of ageing that distinguished people with ID. Staff believed that residents aged prematurely compared to the general population. Some practitioners mentioned that they felt the considerable use of medication through the life course may be a reason for this, and some mentioned that vulnerability and social exclusion experienced earlier in life may be a reason. Another difference was that physical conditions could be harder to identify because of their ID. Firstly because it was hard to know if any impairments were due to age-related changes or a part of the lifelong ID, secondly because the resident may lack awareness to notice changes in themselves, and thirdly because of trouble then communicating difficulties they're having. As a social phenomenon ageing was sometimes constructed like the retirement process, but rather than a regulated age it was described as a gradual winding down of activities based on the resident's abilities. Many described this 'tapering down' on an individual basis as the ideal retirement model. However, other staff advocated a regulated retirement age for people with ID, feeling that it was a question of equal opportunity. Some also reasoned that it was important to give room to younger people with ID. The staff were also conflicting about what should	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		happen to residents and made comparisons between them and regular residential services for ageing people. Mostly they felt they offered better resources and opportunities, and with a more favourable staff ratio and closer personal relationships with residents than they might expect in regular residential services. **3) Being in a state of readiness** As more residents aged, staff found themselves having to be constantly prepared for changes in residents' physical and psychological state. Although these changes tended to be slow and gradual rather than 'winding', they now had more frequent and closer contact with services, and needed to be better prepared for coping with death. Also they had to make more decisions for residents – which increased their power and many felt this contradicted their professional role as someone intended to promote autonomy. Although they were in a state of readiness, they did not feel they were ready to act. The greatest challenge was preparing for death – which required increased support and care to provide a dignified end. Being put into this state of readiness by ageing was considered a burden by some staff, and was considered emotionally stressful – although some said it became easier to handle as more residents reached old age. Some staff were proud of their role, while others felt it made the job less rewarding as their role had	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		become monotonous and more concerned with care, cleaning etc.	

4. Maes B, Puyenbroeck J (2008) Adaptation of Flemish services to accommodate and support the aging of people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 5: 245–52

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The 3 aims of the study were outlined as follows – '(1) To what extent and in which ways have services adapted their accommodations and their personnel to meet the needs of aging people with intellectual disability? (2) To what extent and in which ways have	**Participants:** Coordinating staff in facilities for older people with learning difficulties. **Sample size:** Staff from 66 of the 120 services in the region responded to the questionnaire request. **Follow-up:** No follow-up. **Costs?** No.	**Infrastructure and personnel** The study found that in 66% of the sample who offered residential care to individuals with learning difficulties felt that their infrastructure was adapted to the needs of elderly people with learning difficulties. The adaptations made most commonly included 'wall grips, adapted bathroom equipment, accessibility of rooms for wheelchairs, adapted beds, lifting apparatus, and better lighting' (p247) and also included 'a stair lift, adapted furniture, call-up systems, and automatic doors' (p247). Some 26% felt that they had adapted their services to the need of people with learning difficulties, but not specifically for older people. Total 6% said that they had not made adaptations for the needs for people with learning difficulties with or without learning difficulties.	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
services adapted their working methods to meet the needs of aging people with intellectual disability? (3) What are the views and attitudes of staff members with regard to successful aging of people with intellectual disability? Are these views in line with the different theoretical models on successful aging? To what degree do these views differ according to the type of setting?' (p246).		All the respondents to the questionnaire said that they had made adaptation in terms of employing qualified staff. There was a variety of professionals working in the facilities where older people with learning difficulties lived. Including 'psychologists, therapists, and medical staff. In more than half of the services, nurses (58%, n=37) and older age support workers (58%, n=37)' (p247). Facilities had also adapted staffing to meet the needs of older people – 39% reported that they had a higher staff-to-patient ratio for older patients. This was because old patients tended to have greater needs, medically (45%) and also that they had lost skills (41%) or had emotional needs (24%). Less common reasons included loss of mobility and additional day care needs; 58% of respondents said that staff levels were insufficient to respond to the needs of older people with learning difficulties. The study found that not many staff had received training in working with older people with learning difficulties. Only 20% reported specific training around older people with learning difficulties. **Working methods** Total 59% of the respondents reported adapting support	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Methodology: Survey. **Country:** Belgium. **Source of funding:** Not reported.		plans as people aged. Plans were most commonly revised every 2 years (40%) or yearly (35%), 25% were revised less than every 2 years. In 89% of cases it was reported that service users helped in the revision process. There were diverse responses to the question about whether age should inform how residents are grouped in care facilities – 45% said it was an important factor and 47% said that it was not (others did not respond to the question). For those who deemed age unimportant this was because the residents had lived together for a significant amount of time already. Few services had a specific programme for older residents. Most service users in the services questioned had their own activity programme. A large group of respondents felt that specific activities for the older people may be necessary (89%), but were unrealistic (44%). Some services did offer activities aimed at older residents such as: 'vintage games, reminiscence, visiting old friends'. These happened in 73% of services. Dementia was screened in 45% of the services, and more frequently among those suffering from Down's syndrome. Palliative care was also organised in some services (64%).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Staff views and attitudes The questionnaire asked staff to rate principles about supporting older people with learning difficulties. Staff rated the following 5 as the most important (highest mean scores): 1. Social relations remain important when growing older. 2. Extending and maintaining social networks is very important for older persons. 3. We give older persons the opportunity to be inactive. A quieter pace is indicated 4. We respect that older persons prefer to withdraw themselves especially towards younger persons. 6. It is important for older persons to remain independent, even when they lose certain functions like mobility, hearing, and sight. The lowest scores were attributed to: 1. With older persons, we should focus on their past and their memories. 2. We focus on the 'here and now,' so that older persons keep their orientation on the current situation. The study used exploratory factor analysis to identify solutions to the issues ranked at important in the view of care staff. The factors were organised into 3 overall factors.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		‘Activating and socialising’ 1. Stimulating older persons to remain physically and psychologically active. 1. Stimulating older persons to remain independent. 2. Giving older persons chances for new initiatives. 3. Stressing the importance of social relations. 4. Continuing the earlier pattern of activities. 2. Compensating aging problems with assistive devices. 5. Making plans for the future. 6. Stressing the importance of extending and maintaining social relations. ‘Disengagement’ 1. Not forcing persons to participate in activities. 2. Not forcing persons to do things that they do not want to. 7. Giving older persons chances for being inactive. 3. Respecting the choice of older persons. 4. Stressing the importance of cosiness and familiarity in the environment. ‘Methodical approach’ 1. Stimulating persons by means of (non-)verbal	

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Overall validity rating**
		instructions. 2. Focusing on the past and on memories. 3. Supporting orientation to current situation. 4. Stimulating reminiscence. 5. Respecting older persons' choice to participate or not in activities. 6. Compensating aging problems with assistive devices.	

5. Webber R, Bowers B, McKenzie-Green B (2010) Staff responses to age-related health changes in people with an intellectual disability in group homes. Disability and Society 25: 657–71

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The aim of this study was outlined as 'to explore how supervisors in group homes caring for people with intellectual disability responded to the development of age-related health changes in their residents' (p657). **Methodology:** Qualitative study. Interviews used dimensional analysis, a variant of grounded theory.	**Participants:** Professionals/practitioners. Supervisors of group homes for people with an ID. **Sample size:** Total 10 supervisors of group homes, each with up to 6 residents. **Follow-up:** No follow-up. **Costs?** No.	Group home supervisors consistently expressed the belief that, at some point, residents with serious health conditions may require more intensive or skilled care than they can provide. However, there was less consistency about the criteria that determine when a resident could no longer be accommodated. Supervisors' philosophy had a significant impact on whether a resident was able to stay 'home' following the development of health conditions, with supervisors tending to fall into those who believed that group homes are for physically active, physically healthy people with the primary purpose of supporting active engagement with the wider society, and those who believed that residents should be able to stay 'home' until it was no longer feasible. While direct care staff (and family members) had some input into the decision, supervisors were ultimately responsible for deciding which residents could stay and which should be considered for a move to residential aged care. In no cases did residents participate in the decision about whether or not they would be moved to aged care. There were three particular changes that influenced the likelihood of decisions to moving to residential care - these	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Country: Australia. **Source of funding:** Not reported.		were 'slowing down', 'physical conditions' and 'cognitive/behavioural changes'. Equipment and staffing were mentioned as the most important resources for maintaining people in group homes as they aged. Increased staffing was needed, but intermittent staffing levels created a particular challenge when caring for people with declining physical abilities who needed consistent supervision. Many group homes were not built to accommodate people with increasingly poor mobility – steps, narrow hallways, inaccessible bathrooms. Supervisors who were committed to the 'ageing in place' advocated strongly for equipment and house modifications. Supervisors, who adhered to the 'active engagement' philosophy, often rejected the idea of bringing in specialised equipment. Resident behaviour change or new evidence of confusion generally led to supervisors assuming that the resident had developed dementia – moving quickly to a decision that the resident must move to aged care. Other possible sources of confusion, such as medication side effects, underlying medical conditions or depression were rarely acknowledged of pursued. Several supervisors described their confusion over just what	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		service to enable staying at home residents were eligible for – where to obtain services, when and by whom and in what setting they could be used and how to find the answers to these questions. Several providers spoke of the lack of planning and coordination at a regional or national level with the result that ‘ageing in place’ was compromised. A major issue identified, regardless of philosophy, was the impact of age-related health changes on the lives of other residents (wake others up at night, have frequent visits to clinics, events and outings having to be cancelled). All supervisors were very aware of the waiting lists and the need to move people on so that new residents could be accommodated, however those with an ‘active engagement’ philosophy tended to give this greater consideration.	

Review question 7 – critical appraisal tables –effectiveness

1. Nambisan P, Lamkin D, DeLong C (2014) Feasibility, benefits and challenges of using telemonitoring for the aging with Developmental Disabilities (DD): An exploratory study. Online Journal of Public Health Informatics 6: e186

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
Study aim: The study stated its objective to 'Assess the feasibility, benefits and challenges of using telemonitoring for aging patients with developmental disabilities' (p1). **Methodology:** Mixed methods. Quantitative survey and qualitative focus groups. **Qualitative comp 1:** Patients' focus groups. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Partly. The question is on feasibility, benefits and challenges of this intervention, so seeking info from users directly is a valuable source. However it is acknowledged that the focus group was mostly with the	**Quantitative comp A:** Patients' questionnaire. **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** No. Opportunity sample, not obtained deliberately so no strict sampling strategy. **Is the sample representative of the population under study?** No. Opportunity sample, so although there is variation within the sample it is not engineered to be representative of any population. **Are measurements appropriate (clear origin, or validity known, or standard instrument)?**	**Does the study's research question match the review question?** Partly. It adds to ways of living at home, in supported accommodation or accommodation with care for this population while having a health condition that needs monitoring. **Has the study dealt appropriately with any ethical concerns?**	**Overall assessment of internal validity (qualitative):** + **Overall assessment of internal validity (quantitative):** - **Overall assessment of external validity:** +

Internal validity – qualitative components	**Internal validity – quantitative components**	**External validity**	**Overall validity rating**
higher functioning patients, as lower function patients are harder to engage in focus groups and so the results mostly apply to this specific sub group of the overall population. **Is the process for analysing qualitative data relevant to address the research question?** Yes. Methods are clear, well explained and well justified. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** No. The context/setting for the focus group isn't made clear. Sessions appear to have been run in the centre where the study was run from, which is a state-department sponsored institution so there are likely to be	Yes. The scale is given (CDC, which is a validated measure), and an indication of reliability for the sample they applied it to is given. **Is there an acceptable response rate (60% or above)?** Yes. All 21 answered the questionnaire. **Quantitative comp B:** Caregiver's questionnaire **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** No. Nothing deliberate – primarily opportunity.	No. No mention of ethics or approval boards. **Were service users involved in the study?** Yes. Also their carers. **Is there a clear focus on the guideline topic?** Partly. Combines/supplements places and ways of living with health monitoring needs for the concerned population. **Is the study population the**	

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
some environmental effects. Participants were not interviewed in the settings the intervention occurs, such as in peoples private homes (a subpart of the intended population) and this may have had influencing effects. **Is appropriate consideration given to how findings relate to researchers' influence; e.g., though their interactions with participants?** Partly. It was indicated that the consensus on the outcomes was made with the participants through 'in session summarising', which was then further agreed afterwards in consensus between the authors. The effects of the researchers and note takers upon the data obtained (e.g. demand characteristics etc) does not seem to have been considered.	**Is the sample representative of the population under study?** No. Not representative, although there is variation within the sample it is an opportunity sample. **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** No. Vaguely described measure of satisfaction, little info given. **Is there an acceptable response rate (60% or above)?** Unclear. Couldn't find clear results from it, it was seemingly merged into the qualitative findings.	**same as at least 1 of the groups covered by the guideline?** Yes. Participants are all older with learning disabilities, from a range of different levels of functioning. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Accommodation with care, and also some received intervention at home. **Does the study relate to at least 1**	

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
Qualitative comp 2: Caregivers' focus groups. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. The question is on feasibility, benefits and challenges of this intervention and so after asking the patients, asking the caregivers directly is arguably the best source. **Is the process for analysing qualitative data relevant to address the research question?** Yes. Methods are clear, well explained and justified.		**of the activities covered by the guideline?** Partly. Housing-related support including equipment, adaption and assistive technology. Although it relates to medical conditions, the focus is on person-focused, i.e. independence and control over daily life. **Are the study outcomes relevant to the guideline? (For effectiveness questions)** Partly. Although it relates to medical	

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected? No. The context/setting for the focus group isn't made especially clear, it seems it is in the centre where the study was run from, and given this is a state department sponsored institution there is likely to be some environmental effects. It is asking about the problems while not being in the settings they occur, such as in peoples private homes, which was a sub part of the intended population. **Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants?** Partly. It was indicated that the consensus on the outcomes was		conditions, the focus is largely on person-focused, i.e. independence and control over daily life. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Views and experiences of older people with learning disabilities and their carers, when using this technology. **Does the study have a UK perspective?** No.	

Internal validity – qualitative components	Internal validity – quantitative components	External validity	Overall validity rating
made with the participants through 'in session summarising', which was then further agreed afterwards in consensus between the authors. The effects of the researchers and note takers upon the data obtained (e.g. demand characteristics etc) does not seem to have been considered overall.			

Review question 7 – critical Appraisal tables – the views and experiences of people using services, their families and carers

1. Forbat L (2008) Where should people with dementia live? Using the views of service users to inform models of care. British Journal of Learning Disabilities 36: 6–12

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The authors intended the study to collect 'qualitative data from people with a learning disability who live with someone with dementia, to explore how their views on and understandings of dementia can inform the appropriate development of service provision and care models' (p7). **Methodology:** Qualitative study. **Is a qualitative approach appropriate?** Appropriate. Qualitative approach is useful for gaining views and experiences. **Is the study clear in what it seeks to do?**	**How well was the data collection carried out?** Somewhat appropriately. Given the issues with the level of detail about the study design, it is also hard to rate the data-gathering. It seems that interviews were recorded and semi-structured, but we do not learn how often people were interviewed or the duration of the interviews. **Is the context clearly described?** Unclear. We learn that the sample was taken from 6 residential centres in an area, but details are not given on the type of residential homes, the number of residents or	**Does the study's research question match the review question?** Partly. Focus on the views and experiences of people with learning difficulties. But the relevance to question 5 is less direct. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval obtained. **Were service users involved in the study?** Yes. Service users were interviewed and spoken to in a group setting.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. The study does not describe its methods that clearly, so it is difficult to accurately rate the design. We are not really told about the aims for the study design or the desired sample size. The study does not tell us in detail about participants (we only learn that they were a mixture of genders, ages and abilities), interview scripts or the number of interviews.	how many residents were suffering from dementia. **Was the sampling carried out in an appropriate way?** Not sure. **Were the methods reliable?** Not sure. It is difficult to gauge, due to the lack of detail around design, data collection and sample. **Are the data 'rich'?** Mixed. Some direct quotes are given and the views and experiences of residents are analysed. **Is the analysis reliable?**	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The age of the participants is not given. It is not 100% clear whether they can be classed at 'older people' or not. Although all the people spoken to appear to having learning difficulties of some sort. **Is the study setting the same as at least 1 of the settings covered by the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Somewhat reliable. We are given detail of the general themes extracted from the data, 8 themes are outlines. But they are not discussed in detail and it also seems that some assumptions are made about the meaning of some comments. The writer at times states what findings 'clearly' mean, but this statement is not qualified and we are not given a great deal of verbatim, interview data. However we are told that scripts were analysed, re analysed and that this work was done by 2 researchers. **Are the findings convincing?** Somewhat convincing. Given the small sample we would expect fairly sparse findings, but this paper is attached to a 3-year study. There is no sense of	**guideline?** Yes. Residential care. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. The study gathered views from people with learning difficulties, hence the findings are valuable. Given the dearth of this type of study available. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	changes over time or a diversity of views. The findings are divided into themes, but the quotes under each theme only come from 1 participant, lessening the credibility of the analysis. **Are the conclusions adequate?** Somewhat adequate. The conclusions seem reasonable, but the description of the methods and data collection is poor, so it is hard to say whether they are convincing one way or the other.		

Review question 7 – critical appraisal tables – health, social care and other practitioners' views and experiences

1. Bigby C, Webber R, Bowers B et al. (2008) A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. Journal of Intellectual Disability Research 52: 404–14

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The aim of this study (which is the first phase of a 4-year study) was to map the population of people with ID in residential aged care facilities in Victoria, asking care providers: '(1) how many and what are the characteristics of people with ID living in residential aged care in Victoria; (2) why do they move to residential aged care and where do they move from; (3) what type of support do they receive in residential aged care; and (4) what do residential aged care providers see as the issues in providing support for people with ID' (p406). Note that the fourth of these aims is the most relevant to our review question. **Methodology:** Survey. Postal survey sent to 826 residential aged care facilities in Victoria.	**Clear description of context?** Yes. **Survey population and sample frame clearly described?** Partly. The survey was sent to the Nursing Directors of all residential aged care facilities. **Describes what was measured, how it was measured and the results?** Yes. **Measurements valid?** Yes. **Measurements reliable?** Partly. Reasons for the residents' move to residential care and whether they were happy with the move were elicited via the survey with providers with no opportunity for triangulation with the views of residents themselves, nor their families. **Basic data adequately**	**Does the study's research question match the review question?** Partly. The survey is partly a mapping exercise for people living LD living in aged residential care in Victoria, Australia. This element does not contribute to answering our review question. However certain data relating to the appropriateness of placements and issues around supporting older adults with LD in aged residential care do contribute. **Has the study dealt appropriately with any ethical concerns?** Yes. Survey data about individual characteristics were anonymised and ethics approval was granted by Human Research Ethics Committees of the Australian Catholic University and La	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Research design clearly specified and appropriate? Yes. Survey methodology with follow-up phone calls for non-responders. **Objectives of the study clearly stated?** Yes.	**described?** Yes. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes. **Results internally consistent?** Unclear. **Clear description of data collection methods and analysis?** Yes. 'Data were analysed statistically with the aid of the Statistical Package for the Social Sciences. Answers to open-ended questions were analysed thematically by coding them into separate categories' (p406). **Methods appropriate for the data?** Yes. **Results can be generalised?** Unclear. The authors caution	Trobe University. **Were service users involved in the study?** No. They were neither involved as survey respondents nor as co-researchers or advisors. **Is there a clear focus on the guideline topic?** Partly. Some of the data contribute to answering our review questions, some do not. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Older adults with a learning disability living in residential aged care facilities. **Is the study setting the same as at least 1 of the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	against generalizing to all residential care facilities in Victoria but they seem to suggest that results might be applicable to the UK because of the similar resident profile. This is not clear. **Conclusions justified?** Yes.	**settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. Australia.	

2. Iacono T, Bigby C, Carling-Jenkins R et al. (2014) Taking each day as it comes: staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes. Journal of Intellectual Disability Research 58: 521–33

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The aim of this study was outlined as 'to report	**How well was the data collection carried out?**	**Does the study's research question match the review**	**Overall assessment of internal validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
on the experiences of disability staff in group homes supporting residents with Down syndrome and Alzheimer's disease in relation to their under understanding of what was happening to these residents, their responses to them, and how they felt about their support role' (p521). **Methodology:** Qualitative study. Semi-structured interviews analysed thematically. **Is a qualitative approach appropriate?** Appropriate. Specifically sought personal experiences within an area that has rarely been researched previously. **Is the study clear in what it seeks to do?** Clear. Sets out	Somewhat appropriately. Not entirely consistent in who conducted the interviews. Also didn't make use of blinding etc., but otherwise generally adequate and conducted by professional researchers. **Is the context clearly described?** Clear. It is only in a limited context, but this is clearly expressed in the study title. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. The sample was taken from opportunity, i.e. from another study. Although it may have been more ideal to recruit a (bigger) sample specifically for this question, this was a good use of something existing.	**question?** Yes. Directly captures the views and experiences of practitioners working in 'supported accommodation' for older people with learning disabilities. **Has the study dealt appropriately with any ethical concerns?** Yes. Consent for the primary participants was obtained from a next of kin, in line with the National Health and Medical Research Council. Didn't say if they asked participants themselves though. **Were service users involved in the study?** No.	**Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
3 aims, and gives answers within this format. **How defensible/rigorous is the research design/methodology?** Defensible. Sought a greater understanding of the experience of caring for adults with dementia in addition to ID, for which a qualitative approach is most suited. Outlines why it is useful – to address the divide between what might be considered good and actual practice The sample was taken from opportunity, i.e. from another study. Although it may have been more ideal to recruit a sample specifically, this was a good use of something existing.	**Were the methods reliable?** Somewhat reliable. Not especially sophisticated. Data collected and transcribed from interviews and then analysed by the interviewers. The 3 researchers/authors did consult each other and negotiate agreement about their conclusions, but no blinding. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Somewhat reliable. Good overall but with some room for improvement. Analysis was conducted in agreement between 3 authors, including 2 that had collected the data – it's reasonable but may add some bias. Methods are not described (although refers to other papers) intricately and it does not say if	**Is there a clear focus on the guideline topic?** Yes. Directly captures the views and experiences of practitioners working in 'supported accommodation' for older people with learning disabilities. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Directly captures the views and experiences of practitioners working in 'supported accommodation' for older people with learning disabilities. **Is the study setting the same as at least 1 of the settings covered by the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	their findings were verified with those who were interviewed. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Somewhat adequate. The conclusions aren't especially complex. They seem well grounded, but alternative explanations aren't well considered. They give very little critical appraisal of their own methods in the written paper.	**guideline?** Yes. In supported accommodation. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Service planning and organisation of appropriate accommodation, staff training etc. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Directly captures the views and experiences of practitioners working in 'supported accommodation' for OPLD. **Does the study have a UK perspective?** No. Australia. But does make comparison to UK services: 'Unlike countries, such as England	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
		and Ireland, whose ID nurses and other allied health specialists provide support to people living in residential settings, care staff in group homes rely on the mainstream system, in particular, general practitioners, for health care supports for residents' (p523).	

3. Kåhlin I, Kjellberg A, Hagberg J (2015) Ageing in people with intellectual disability as it is understood by group home staff. Journal of Intellectual and Developmental Disability 41(1): 1–10

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The paper stated its aim as 'To explore how group home staff address issues of ageing and being old among people with ID' (p2). **Methodology:** Qualitative study. Interviews run and	**How well was the data collection carried out?** Appropriately. Very well described and justified, a rigorous and systematic procedure. **Is the context clearly described?** Clear. Clear idea of who, where, how and when. Four group homes	**Does the study's research question match the review question?** Yes. Directly captures the views and experiences of practitioners working in group home	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
analysed using directed content analysis, where a theory or set of relevant research findings is used to guide the coding and analysis process. **Is a qualitative approach appropriate?** Appropriate. Sought views and experiences. **Is the study clear in what it seeks to do?** Clear. To explore how group-home staff address issues of ageing and being old among people with ID. **How defensible/rigorous is the research design/methodology?** Defensible. Well justified, and grounded in theory and an understanding of where and what information is needed.	in municipalities in Southern Sweden were selected based on the criterion of having older residents with ID. The homes had a small number of separate but linked flats located in ordinary housing areas. Each interview lasted between 1 and 2 hours, and was conducted in a private location at the informant's workplace. With permission, all interviews were tape-recorded. **Was the sampling carried out in an appropriate way?** Appropriate. A purposive sampling method was used to obtain an appropriate distribution in terms of age, gender and years of working experience. **Were the methods reliable?** Somewhat reliable. The authors do not use any other methods to triangulate their findings, but did discuss their findings alongside other results. The semi-structured procedure allowed some flexibility	including older people with learning disabilities. **Has the study dealt appropriately with any ethical concerns?** Yes. Details the approval by local ethics board in Linkoping, and the consent forms and processes for participants. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. Directly captures the views and experiences of practitioners working in group homes that house older people with learning disabilities.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	but meant the questions asked of each participant were reliably consistent. **Are the data 'rich'?** Rich. Lots of themes well described, and a reasonable (if not huge) use of quotes to back up the findings and give further richness. **Is the analysis reliable?** Somewhat reliable. **Are the findings convincing?** Convincing. Seems coherent and based in quotes. Perhaps could have shown their final themes to the participants to check they were endorsed by those who were interviewed. Their second theme 'dual faces' was a little bit incoherent in places. **Are the conclusions adequate?** Adequate. Well-grounded and gives detailed consideration to what was said, where the conclusions came	**Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Supported group home. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Service planning and organisation of appropriate accommodation, staff training etc. **Are the views and experiences reported relevant to the guideline?** Yes. Directly captures the	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	from and what the ramifications might be.	views and experiences of practitioners working in group homes that house older people with learning disabilities. **Does the study have a UK perspective?** No. A European OECD country with a state care system, perhaps slightly better resourced than in England.	

4. Maes B, Puyenbroeck J (2008) Adaptation of Flemish services to accommodate and support the aging of people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities 5: 245–52

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The 3 aims of the study were outlined as follows: '(1) To what extent and in which ways have services adapted their accommodations and their personnel to meet the needs of aging people with intellectual	**Clear description of context?** Yes. The questionnaire was given to facilities that provide support to older people with learning difficulties. **Survey population and sample**	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** No. Not	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
disability? (2) To what extent and in which ways have services adapted their working methods to meet the needs of aging people with intellectual disability? (3) What are the views and attitudes of staff members with regard to successful aging of people with intellectual disability? Are these views in line with the different theoretical models on successful aging? To what degree do these views differ according to the type of setting?' (p246). **Methodology:** Survey. **Research design clearly specified and appropriate?** Yes. Research design is clearly described; a more in-depth qualitative approach, rather than a questionnaire/survey design would have elicited richer data.	**frame clearly described?** Yes. The study identified all the services that matched the criteria in Flanders. Those that supported more than 6 individuals with a learning difficulty, and were aged over 40 (Down's syndrome) or over 55 for other groups. **Describes what was measured, how it was measured and the results?** Yes. The questionnaire asked about the adaptations made to the environment, workforce changes and the views of staff and practitioners. **Measurements valid?** Yes. The study uses descriptive statistics for the most part and analysed the 'factor structure' in the last section of the paper. They used LISREL 8.7 (Jöreskog and Sörbom 2004). This was an exploratory factor analysis. **Measurements reliable?** Yes.	reported. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Residential care. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Activities include: Assessment and review of care, some elements of care and care planning.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Objectives of the study clearly stated? Yes.	**Basic data adequately described?** Yes. The study uses table that clearly describe basic data. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes. **Results internally consistent?** Yes. **Clear description of data collection methods and analysis?** Yes. The questionnaire is well described, as is the analysis procedure. **Methods appropriate for the data?** Yes. Descriptive statistics are appropriate given the questionnaire format, as is the factor analysis. **Results can be generalised?** Unclear. The results relate to a	**Are the views and experiences reported relevant to the guideline?** Yes. The views of practitioners. **Does the study have a UK perspective?** No. Belgium.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	fairly small sample in a specific geographical region. But some general messages may be generalised. **Conclusions justified?** Yes.		

5. Webber R, Bowers B, McKenzie-Green B (2010) Staff responses to age-related health changes in people with an intellectual disability in group homes. Disability and Society 25: 657–71

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The aim of this study was outlined as 'to explore how supervisors in group homes caring for people with intellectual disability responded to the development of age-related health changes in their residents' (p657). **Methodology:** Qualitative study. Interviews run, analysed using dimensional analysis – a variant of grounded theory.	**How well was the data collection carried out?** Appropriately. Interviews carried out appropriately, and with continual refinements made to the interviewer's topic guide in accordance with the methodology. However little information is given on exactly who conducted them and where. **Is the context clearly described?** Unclear. The location	**Does the study's research question match the review question?** Yes. Experiences of group home supervisors as they respond to aging clients with ID. **Has the study dealt appropriately with any ethical concerns?** No. Ethics not discussed. But isn't directly interviewing or	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Is a qualitative approach appropriate? Appropriate. Uses interviews and dimensional analysis to elicit past experiences and also illuminate participant's core personal beliefs towards aging and ID. **Is the study clear in what it seeks to do?** Clear. Explores how supervisors in group homes caring for people with intellectual disability responded to the development of age-related health changes in their residents. Seeks to explore participants understand a particular phenomenon as well as the actions that result from those understandings.	and set-up for the interviews is not described. **Was the sampling carried out in an appropriate way?** Not sure. It's not clear how the sampling was done. With this type of methodology (grounded theory) it is not essential to have a sample that's representative of a bigger population but just enough that themes can be honed on sufficiently to be considered grounded. **Were the methods reliable?** Not sure. The goal of grounded theory means that the themes and findings were drawn from intensive refinement evolving across participants and responsive to variance. Provided we trust the researchers' processes and iterative	intervening with vulnerable people. **Were service users involved in the study?** No. Not directly, just interviewed supervisors of services. **Is there a clear focus on the guideline topic?** Yes. Experiences of group home supervisors as they respond to aging clients with ID. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Group home supervisors of aging clients with ID. **Is the study setting the same as at least 1 of the settings covered by the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
How defensible/rigorous is the research design/methodology? Somewhat defensible. The question justifies the methodological approach, and the approach justifies the size and nature of the sample. Does not discuss how the sample was recruited, or why these participants or this area were chosen over others.	developments then we can only presume the methods were reliable. **Are the data 'rich'?** Rich. Lots of details are given about the opinions and states of mind, and comparisons between who tended to feel what. **Is the analysis reliable?** Not sure/not reported. Provided we trust the researchers, we can assume it is a sensible and reliable account of this population and their views/experiences. But no follow-ups or similar studies in other regions are mentioned so there's little way of confirming how dependable/reliable these conclusions (and thus methods) are.	**guideline?** Yes. Group homes for people with ID. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Identification of care and support needs relating to aging. Age-appropriate service planning and configuration. Care and support planning for older people with LD within housing, housing-related support and support to maintain relationships and established social lives. **Are the views and experiences reported relevant to the guideline?** Yes. Experiences of group home supervisors as they	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	Are the findings convincing? Convincing. The details and subject's processes behind their actions and feelings are elaborated on in great depth. Seems convincing. **Are the conclusions adequate?** Adequate. The conclusions are grounded strongly in the findings and so are adequate in the way they describe the views/experiences of those interviewed. The implications are discussed well, however the limitations are not.	respond to ageing clients with ID. **Does the study have a UK perspective?** No. Australian	

Review question 8. End of life care

a) What interventions, tools, aids and approaches are effective and cost-effective in end of life care for older people with learning disabilities?

b) What are the views and experiences of older people with learning disabilities, carers and practitioners about end of life care?

Review question 8 – findings tables – the views and experiences of people using services, their families and carers

1. McLaughlin D, Barr O, McIlfatrick S et al. (2014a) Service user perspectives on palliative care education for health and social care professionals supporting people with learning disabilities. BMJ Supportive & Palliative Care 5: 531–7

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To develop a best practice model to guide and promote partnership practice between specialists palliative care and intellectual disability services by gathering quantitative and qualitative data from	**Participants:** Professionals/practitioners. Services and practitioners working in intellectual disability and palliative care services in primary and secondary care, who had provided end-of-life	**Phase 1 quantitative data** From 47 services of the 66 services approached (response rate: 71.2%). **A. Partnership working between intellectual disability and specialist palliative care services** 1. 8/10 intellectual disability services and 5/15 nursing homes reported previous contact with specialist palliative care for advice.	**Overall assessment of internal validity:** + + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
practitioners from these services. **Methodology:** Mixed methods. Phase 1 – survey using self-completed questionnaires with 8 quantitative questions and 4 open qualitative questions; Phase 2 – Phase 2: semi-structured interviews. **Country:** UK, Ulster, NI and Dublin **Source of funding:** HSC Research and Development Doctoral	care to adults with intellectual disabilities. **Sample characteristics:** • Age Phase 2 respondents: age range (30–59 years). • Sex Phase 2 respondents: 22 females; 8 males. • Ethnicity Not reported. • Religion/belief Not reported. • Disability Not reported. • Long-term health condition Not reported. • Sexual orientation Not reported. • Socioeconomic position Phase 2 respondents: all	2. 14/22 specialist palliative care services reported contact with their local intellectual disability service for advice. 3. A minority of services stating that they nearly always worked in partnership with specialist palliative care professionals. 4. 8/15 of nursing homes had never taken part in joint working with a specialist palliative care team. 5. 2/10 intellectual disability services and 4/15 nursing homes had not provided palliative and end of life care to adults with intellectual disabilities for joint working to occur (Table 1, p1215). Services rating the helpfulness of each strategy to promote partnership working between intellectual disability and specialist palliative care services. Most services viewed these initiatives in a positive light with no significant difference by type of service. The following strategies to promote partnership working between intellectual disability and specialist palliative care services were rated as very helpful and/or helpful by all the respondents (n=47, 100%).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Fellowship Scheme in Northern Ireland.	had experience of caring for a person with an intellectual disability at the end of life. **Sample size:** Phase 1 included intellectual disability services (n=18), specialist palliative care services (n=28) and nursing homes designated to care for people with intellectual disabilities (n=20). Phase 2: 30 health and social care professionals from these services. **Outcomes measured** Service outcomes. **Follow-up** Not reported.	1. Increased focus on training. 2. Willingness within services to learn from each other. 3. Joint education with both services on palliative and end of life care for people with ID. 4. Recognising when the need arises for expertise from both service. 5. Early identification of need by generalist/primary care services to facilitate timely specialist referral. The following strategies were rated as very helpful and/or helpful by most of the respondents but not all the respondents. 6. More funding (n=40/47, 85%). 7. More detailed referral systems to palliative care services outlining specific needs of person with ID (n=44/47, 93%). 8. Focus on palliative care/intellectual disability in undergraduate training (n=44/47, 93%).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		9. Understanding of ethos, philosophy and professional roles in both services (n=44/47, 93%), 10. Regular multidisciplinary meetings involving professionals across services/sectors to facilitate coordinated care (n=42/47, 89%). 11. Clinical placement exchanges between services (n=37/47, 79%) (Table 2, p1216). Overall, services recognised the value and benefits of joint working and learning in the assessment and care process, such as working with people who had prior knowledge of the person such as professionals or family carers. This facilitated assessing and meeting the holistic end of life care needs of someone with an ID. Learning needs were identified relevant to joint working and learning such as communication and assessment, management, carer support and bereavement care, decision-making, understanding intellectual disability and coping with death and self-care. **Narrative findings** Phase 2 qualitative data from 30 practitioners on how to effectively meeting the palliative and end of life care needs of people with ID.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		A. Challenges and issues in end of life care 1. A marginalised life – services not tailored for people with intellectual disabilities or their needs 'When our clients are well at the best of times they present lots of challenges about access to services and about co-operation and stuff ...' (P2 – intellectual disability service) (p1217). 2. Equity of access to service provision – people with ID had the right to an equitable service at the end of their life, including widening access to hospice care: 'I think ... it is about equity – in that this is a population who is very vulnerable – and it is about ... the valuing of human beings and it's about humanity' (P3 – specialist palliative care service) (p1217). 3. Better coordination and continuity of care – some areas highlighted as more coordinated care, with better communication: '… I wasn't clear of my role and the whole process was disjointed, un-coordinated ... what would be helpful is a lead person to co-ordinate palliative care services and if all the relevant professionals were then invited to a case discussion and there was a clear plan and pathway' (p16 – intellectual disability service) (p1217). 'The thing which made the huge difference was having people who had known her in her other life coming to the hospice	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		and explaining that she liked and needed her dolls ... and once the nurses were able to see that then they were empowered to continue to nurse her' (P1 – specialist palliative care service) (p1217). 4. Importance for the person to die in their familiar place of care: 'That eye contact was there for forty years ... people who had worked with him and that he knew ... yes it was a hospital, but it had been his home all of this life' (P14 – Intellectual disability service) (p1217). **B. Sharing and learning** 1. Learning needs in palliative care services 'understanding learning disability', knowing where and how to access local intellectual disability services and issues around communication and assessment: 'I would identify it as an area we do need, as a team, more education, in assessment, communication, ethical issues' (P22 – specialist palliative care service). 2. Learning needs in intellectual disability services, knowing about pain and symptom management, conditions in end of life care, bereavement care and caring for people with cultural differences. Other learning needs were self-care in coping with death and dealing with professional grief: 'the	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		patients in our care have been here for a considerable length of time ... and staff are nursing them 37½ hours a week for maybe 20 years and you still have that barrier that you're a professional, but staff do get very extremely attached on an emotional and on a personal level' (P6 – intellectual disability service) (p1217). **C. Supporting and empowering between specialist palliative care and intellectual disability services to dispel fear and provide mutual support** 1. Increasing confidence in working with ID: 'think I would be happier now that we have good established links and I think it was the recognition of my own inabilities and the limitations of my practice in relation to this group' (P3 – specialist palliative care service) (p1217). 2. Increasing confidence in working with death and dying. 'I think with the involvement of the palliative care team it certainly gave us the confidence ... to work with this lady, I think there would have been issues had we not had the team' (P6 – intellectual disability service) (p1218). **D. Partnership in practice**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		1. Benefits of partnership – an important outcome was the person being able to die in their place of care, with continuity of care by familiar people: 'They could see in action palliative care at it's best and it had a good outcome for the organisation because the staff worked to their finest level – the patient got to die in their place of care, the family were content' (P3 – specialist palliative care service) (p1218). 2. Enabling partnership – such as knowing how to contact services, 'regional meetings', joint 'study days' and joint working and acknowledging their knowledge deficits 'They recognised that they had limited knowledge and understanding in palliative care, and the same for myself in learning disabilities. We were open with each other and we planned that care together ... it was a two way process. I relied on them and vice versa' (P29 – specialist palliative care service) (p1218). The role of the GP in early identification of need and specialist referral was highlighted: 'I think there needs to be a greater appreciation of patients with learning difficulties in primary care, then they would come to the attention of the palliative care specialists at an earlier stage and probably better care can be delivered' (P17 – specialist palliative care service) (p1218). **E. Challenges and barriers to partnership**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		Such as the ‘medical’ versus ‘social’ model of care, time, lack of access and limited referrals to specialist palliative care services, mistrust between people, at a human level, coming together to collaborate: ‘I think its difficult because we are slightly “siloed” and slightly ostracised from the health service in palliative care services or in learning disability’ (P1 – specialist palliative care service). ‘If personalities were involved ... where maybe learning disability nurses feel that they are losing ownership ... or that they are being told what to do’ (P6 – intellectual disability service) (p1218). In summary, practitioners from specialist palliative care and intellectual disability services reported that equity of access to EOL care for people with ID was limited and ‘marginalised’ and they felt it important for the person with ID to die in their familiar place of care.	

Review question 8 – Findings tables – Health, social care and other practitioners’ views and experiences

1. Bailey M, Doody O, Lyons R (2016) Surveying community-nursing support for persons with an intellectual disability and palliative care needs. British Journal of Learning Disabilities 44: 24–34

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Validity ratings**
Study aim: To describe the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs. **Methodology:** Survey. **Country:** Ireland. **Source of funding:** The Irish Hospice Foundation.	**Participants:** Professionals/practitioners, public health nurses (PHNs), community nurses, practice nurses, hospice at home nurses and palliative care nurses. **Sample characteristics:** Not reported **Sample size:** Total 96 **Outcomes measured:** Service outcomes – provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs.	**Narrative findings** Qualitative data from response to open-ended questions in questionnaire surveys. **Factors that facilitate and/or hinder care giving** Table 4 (p28). **1. Family involvement and support** **Facilitators**: Family cooperation and understanding a. Recognition that the family know the person best. b. The openness of the family to develop a working relationship with healthcare professional. **Barriers:** a. Lack of cooperation from the family member/s b. Uncertainty causing over protective family member/s. **2. Previous experience of intellectual disability** **Facilitators:** a. Past experience and care episodes of working with people with intellectual disability and their family/s, b. Development of understanding and skills (non-verbal, observational). **Barriers:** a. Limited education b. Lack of understanding and lack knowledge of intellectual disability (specific conditions).	**Overall assessment of internal validity:** - **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	Follow-up: Not reported.	**3. Teamwork and collaboration** **Facilitators:** a. Support for team members and colleagues b. Collaboration, coordination and cooperation between all care providers c. Shared responsibility. **Barriers:** a. Absence of critical team members b. Decision-making processes within organisations and family/s. **4. Supportive professional carers in intellectual disability services** **Facilitators:** a. Recognition and acceptance of the need for palliative care support within the intellectual disability service b. Willingness of intellectual disability staff to share their knowledge and skill to support palliative care service. **Barriers:** a. Delay in recognition of transition to end of life b. Delay in referral to palliative services for end of life care. **5. Personal attributes** **Facilitators:** a. Knowledge of services available and access to those services b. Humanistic approach – listening,	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		communicating, advising, kindness, awareness, honesty, caring, understanding, sincerity. **Barriers:** a. Fear due to lack of knowledge, education and experience b. Lack of confidence in communicating with a person with intellectual disability. **6. Knowing the person** **Facilitators:** a. Recognising resources – long-term carers of the patient/client b. Building a relationship and sharing the journey c. Building trust of the client and the family d. Early referral and advance planning. **Barriers:** a. Poor referral information b. Delayed referral and lack of advanced planning c. Interpreting communication differences of people with intellectual disability. **Views** **1. Educational needs** 'Appropriate education is needed that is tailored to the person with intellectual disability and palliative care, but we need to be supported to develop our own approach to the clients and develop our understanding of their condition and	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		fears and of existing intellectual disability services' (p29). 'Workshops are needed to develop an understanding of communication methods and interpreting their needs, sign language is a measure that could facilitate caring for a person with an intellectual disability.' **2. Exposure and experience of caring for a person with an intellectual disability** 'More exposure to clients with intellectual disability would give a greater understanding of needs and their family's needs and help use understanding their disability more' (p29). **3. Communication and collaboration to overcome knowledge deficit** 'If we develop closer working relationships and good communication processes with those specializing in care of patients/clients with an intellectual disability this would help and support us in our role … we need a direct link with the intellectual disability nurses who know the client so well' (p29). 'Working together as a team would strengthen the services that sometimes can be fragmented; more communication between all would lead to greater awareness of what is happening' (p30).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		4. Improved communication, shared documentation As a means of developing interagency communication” ‘It would be helpful if client records were available to be utilised in home communications with the family and patient/client and insure they are always at the centre’ (p30). **5. Access to and availability of resources** Additional resources would enhance support. A total of 5 resource categories were identified: physical aids, services including specialised services, time, advanced care planning and funding. **6. Early referral and advanced care planning** This was reported as essential to provide more time to develop a trusting relationship. ‘It is difficult to get to know a family if you are only introduced at the end stage of life and you have to remember the patient/client is your focus so if it is very late you may be into pain management and have very little time to engage, support and build a relationship with the family’ (p31).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		Relevant quantitative data **Education** Nurses reported that they would like to be provided with professional support in terms of in-service and further education in the areas of intellectual disability and palliative care, with their preferred educational delivery format and mode of educational delivery being in-service education with lectures (74.5%) and workshops (64.9%). In summary, community nurses reported the lack of knowledge, lack of understanding, lack of confidence and communication skills and lack of resources as main barriers which hinder their end of life caregiving to people with ID. Other limiting factors included late referrals and lack of time. The nurses emphasised the benefits of liaison between family and professional and non-professional carers, and collaborative working to promote the development of mutual understanding as to when and how to involve each other in the care process – crucial to ensure optimal palliative/end of life care for people with ID.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		Teamwork, advance planning, knowing the person and best practice would improve the provision of palliative/end of life care for people with intellectual disability.	

2. Cartlidge D, Read S (2010) Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective. International Journal of Palliative Nursing 16: 93–8

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To identify what skills hospice staff felt were needed to enable them to feel confident in providing specialist palliative support for people with learning disabilities. **Methodology:** Focus groups and an open-ended questionnaire. **Country:** UK	**Participants:** Qualified and unqualified members of the hospice at home and inpatient unit. **Sample characteristics:** • Age <40 years, n=7. >41 years, n=19 • Gender f=25 m=11. Ethnicity – Not reported. Religion/belief – Not reported. Disability – Not reported. Long-term health condition – Not reported.	**Narrative findings** **Experience/expertise of/with working with people with learning disabilities and their families** Experience among nursing staff varied. They felt it was important to have access to learning disability nurses to give them confidence and provide professional development. Particularly helpful in teaching them how to manage and understand particular behaviours (they had received no specialist training in identifying and understanding the complexity of these behaviours). **Importance of trust and building relationships**	**Overall assessment of internal validity: -** **Overall assessment of external validity: +**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Source of funding: Not reported.	Sexual orientation – Not reported. Socioeconomic position – Not reported. **Sample size:** Total 17	Staff felt it was very rewarding caring for people with learning disabilities at the end of their lives. They said it was difficult but very important to get to know them and build up trust and confidence. **Communication** Staff found it difficult to discuss patients' health status, treatment compliance issues; their understanding of conditions and gaining valid consent was also hard. Particular challenges included getting to know the patient and adjusting communication to suit their individual needs. Having realised these difficulties, staff developed more effective ways of communicating, namely being patient and repeating things several times in different ways until the patient could absorb and understand the information. **Caring for someone with a learning disability at the end of life compared with caring for the 'general population'** There were a number of similarities, including 'every person is unique'. Family dynamics are often challenging and staff should expect the unexpected. The differences included a lack of social skills among the learning disabled people (although this related to the behaviour of a family member of a dying person rather than a patient).	

3. Cross H, Cameron M, Marsh S et al. (2012) Practical approaches toward improving end-of-life care for people with intellectual disabilities: effectiveness and sustainability. Journal of Palliative Medicine 15 (3) 322–6

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: The project was 'aimed at exploring ways of increasing access to palliative care services by people with ID within one geographical area' by assessing the effectiveness and sustainability of 3 different approaches: (1) training of ID staff on basic end-of-life care (2) training of palliative care staff on how best to meet the needs of people with ID (3) a link-worker scheme where	**Participants:** Professionals/practitioners – project manager, trainers, link workers, delegates of the training programmes, hospice and care home staff and managers as well as the project steering group comprising experts from the fields of ID and palliative care, people with ID and carer representatives. **Sample characteristics:** Age – Not reported. Gender - Not reported. Ethnicity – Not reported. Religion/belief – Not reported.	**Findings** **Narrative findings** The key findings of the evaluation were as follows: • There was virtually unanimous agreement that care home staff benefited from the training and were able to put it to good use. • ID community teams were seen as having benefited from the programme – not least by learning what palliative care is and how it can be accessed. • There was less agreement on whether palliative care professionals had derived lasting benefit. • The training was particularly valued for promoting reflection about complex issues and thinking about difference, as well as for acknowledging fears and constructively working with them. • The link workers scheme was generally disappointing and unsuccessful.	**Overall assessment of internal validity: -** **Overall assessment of external validity: +**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
professionals from both professional areas would have a designated point of contact for support and information. **Methodology** The study collects and presents data from face-to-face and telephone interviews with practitioners/stakeholders and draws on discussions with the project's steering group. Data is also presented from evaluation forms. **Country:** UK. **Source of funding:**	Disability - Not reported. Long-term health condition – Not reported. Sexual orientation – Not reported. Socioeconomic position – Interviewees are practitioners holding professional posts. **Sample size:** Not mentioned. **Intervention:** The project included the following 3 features: 1. Thirty-one 2-day courses for palliative care staff which addressed practice issues in working with people with learning disabilities. 2. Two-day courses for learning disability staff,	• Both palliative care and ID were widely viewed as being rather forbidding and perhaps even frightening areas, each with its own unfamiliar language. Searching questions were raised by interviewees about 'who does what, why?' in relation to the care of people with ID at the end of life. • 'The project was working in very difficult and demanding territory, with a wide range of stakeholders. Critically, the project mostly involved direct health and social care professionals, trainers and voluntary sector organisations, not system managers and not local users and family carers. This might explain some of the problems experienced in partnership working' (p325).	

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Validity ratings**
Voluntary/charity. The King's Fund.	providing information about palliative care. 3. A 'link worker' scheme whereby 10 professionals, coming from both fields of practice, filled a 'contact point' role in workplaces (each community learning disability team and each hospice), providing information and support on issues relating to palliative care for people with learning disabilities. **Duration, frequency, intensity** Training was 2 days long for both staff groups. **Content/session titles**		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	Training for palliative care professionals included the following: 'communicating with people with ID' (this session was co-facilitated by several people with ID) assessment of pain and other symptoms in people with severe communication difficulties capacity and consent; and bereavement' (p324). **Training for learning disability staff included:** 'what end-of-life care is; who provides it; how to		

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	care for a dying person; exploring loss, talking about dying, bereavement, and remembering; and self-care strategies' **Location/place of delivery:** Training for both groups took place in 4 local hospices. **Follow-up** There was no follow-up assessment.		

4. McCarron M, McCallion P, Fahey-McCarthy E et al. (2010) Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia. Journal of Policy and Practice in Intellectual Disabilities 7: 143–52

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To understand carer concerns in supporting persons with intellectual disabilities and advanced dementia. **Methodology:** Qualitative study. Focus groups. **Country:** Republic of Ireland. **Source of funding:** Government. Health Research Board of Ireland. Voluntary/charity: Irish Hospice Foundation.	**Participants:** Professionals/practitioners, Learning disability service providers and staff from 1 specialist palliative care service. **Sample characteristics:** Not reported. **Sample size:** Total 57.	**Narrative findings** **The person at the centre – knowing the person** Knowing the person's likes/dislikes was seen as being central to good dementia care. Respondents felt that LD services have a strong philosophy of person-centred care – maintaining relationships. Keeping links with family/staff was seen as really important throughout the continuum/progress of dementia. So, for people living in learning disability housing, this would often mean that staff working there would not want the person to be moved on to a specialist palliative care setting. If people were transferred, staff from the LD unit would often visit and bring friends/residents from the unit, ensuring the person doesn't die alone, '... the service does ensure somebody regular would be with the resident ... can spend time with the resident if they do pass away that somebody that was familiar to them is there' (p145). **Place of care – home vs. out of home** All agreed that the ideal place of care was people's own home although recognised it's not always possible. Staff in the LD home said they could support people in place up to a certain point and then physical barriers made it difficult, such as needing hoists and help with bathing. Nurses experienced in	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		care for people with LD said that as long as there was adequate support, then it was preferable for people with dementia and LD to die in their own (community) home: ‘it has a huge impact unless you have staff that are actually qualified ... the last few days are very intense and I don’t know whether the community houses would actually be able to physically and emotionally manage ... in years to come if the proper supports were put in place maybe – if they had a team that was mobile that would be the ideal thing ... cause ideally it would be nice for people to die’ at home’ (p145). Everyone agreed about the importance of having a peaceful environment at the time of death. If this couldn’t be provided, then respondents felt this could be a reason to move people out of their usual place of residence although opinion was divided about whether a specialist dementia or palliative care setting was most appropriate. There was also debate as to whether a specialist unit for palliative care would be better than a palliative care section of a community setting. In some sites people were reported to be moving in and out of hospital towards the end of their life and no one thought this was ideal – neither staff nor family. **Quality care and comfort** Respondents described the importance of paying attention to the detail of providing a good death. For example, spending time with the person, playing music instead of having the TV on etc.	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		However it's not clear whether these were responses from people working in SPC or LD services. **Spiritual care** Staff in all sites said that spiritual care was really important, '... they need the time for both medical and spiritual care. You can see it in their eyes. At the very end you can see that fear ... petrified ...' (p146). However, some said they didn't have the skills needed to give spiritual care. **Planning care – involving families** Everyone recognised that families were often the legal decision-makers with regard to the end of life care planning/choices. However they differed in their views about family involvement. Some felt it was important to involve families early on to discuss possibilities around end of life care, especially staff from the SPC service. Others felt they actually knew the individuals better than their own families and that it was therefore difficult to put families in a position of making decisions about end of life care. **Coordination of care**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		Sites were mixed with regard to the extent of planning that takes place. When planning doesn't take place, this results in reactive decision-making and stress. By contrast, 1 site was described as having a dedicated physician and dementia team and families who were active in dementia care and planning. According to 1 participant, the problem with LD services is the use of contract medical staff so they argued that LD nurses should take the lead in future planning in order to ensure continuity of care. **Working with hospitals** Participants were frustrated that when people were transferred to acute hospitals, decisions were being made about their end of life care without discussion with LD staff from their usual place of residence. They felt that acute hospital staff were poorly equipped to make these decisions because they lacked experience and didn't know the individual. **Understanding dementia and palliative care** Across all sites, the views were that staff needed training in dementia. Some from LD services said they had no experience of dementia. The same was true in the SPC unit. They questioned how they were supposed to manage 'wandering' in the context of a hospice and said that perhaps the LD services	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		needed support with palliative care so people could be supported in place at the end of life. Therefore a more collaborative approach would be welcomed, '... I think that is the way to go ... collaboration would be important ... where a service can consult with specialist palliative care services on symptom management in the later stages for example ...' (p147). **Pain assessment and management** LD staff said they had a lack of knowledge around pain and symptom management. They were open to and welcomed of specific training in this area. **Maintaining adequate hydration and nutrition** This is complex in people living with advanced dementia. Participants were frustrated with inadequate end of life planning, shown especially keenly when people are transferred to acute hospitals, e.g. 'they end up with a PEG tube ... a few days before they die ... it's a big problem' (p148). Some recalled that when they've looked after people with PEG feeding it's resulted in a distressing, suboptimal death. Others said PEG feeding wasn't a problem and they hadn't had anyone with a PEG tube so the question of whether 'to feed or not to feed' hadn't been an issue. Others said it was very distressing when families told them not to use a PEG so they were left with no guidelines other	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		than a note in the person's chart saying 'stop all fluids and food'. Participants in SPC emphasised the complexity of this kind of decision-making and felt this wasn't necessarily recognised in LD services. **Resuscitation** Across all sites it was felt that people with LD and dementia should die in their own home/usual place of residence. However staff in group homes didn't feel equipped to deal with the dying experience. So dying in the community is possible as long as it's properly resourced. **Cultural differences** Participants were drawn from 4 different nationalities. Cultural differences were identified across sites. Some commented on difficulties experienced when decisions about a person and their care were not being made in their wider family context. Others stated that they had to learn and adapt to the person's culture and be open to other ways of doing things.	

5. McLaughlin D, Barr O, McIlfatrick S et al. (2014b) Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study. Palliative Medicine 28: 1213–21

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To elicit the views of people with learning disabilities and family carers, concerning palliative and end of life care. **Methodology:** Qualitative study Focus groups, semi-structured interviews. **Country:** UK, Belfast NI. **Source of funding:**	**Participants:** Service users and their families, partners and carers. People with ID and Family carers. **Sample characteristics** Age People with ID: age range 40–59 years. Sex People with ID: females (n=12); males (n=5). Family carers: females (n=4); males (n=1). Ethnicity, religion, disability, long term health condition, sexual orientation,	**Narrative findings** **Combined data (views of people with ID and their family carers)** 'In focus groups, people with ID were shown a drawing of a lady called Susan who had learning disability, sitting with her dog, and were told that this lady, was very ill and was going to die, and were asked what people could do to help her. A number of focused open questions were used around how Susan might be feeling and how she could be best supported and made comfortable' (p532). **A. Information and preparation – roles of professionals** **1. At diagnosis** – people with ID said it's important that professionals explained about the illness, treatment and prognosis in a way that they could understand, using 'signs' or 'hearing aids' if needed. 'She'd want to know what her illness really is … Try to explain it someway to her' (p533). **2. Meeting information needs** – Should people with ID be told that they had not long to live? 'Yes they (professionals) should tell her how long she's going to live …' ; 'I think it's up to a member of the family to tell them … if she can't	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
HSC Research and Development Doctoral Fellowship Scheme in Northern Ireland.	socioeconomic position Not reported. **Sample size:** People with ID (n=17). Family carers (n=5). **Outcomes measured** Service user-related outcomes. Family- or caregiver-related outcomes. Satisfaction with services. Service outcomes. **Follow-up** Not reported.	understand the doctor' (p533). Family carers would find it helpful to receive information rather than this having to be self-sought. 'I went to every course, or information day … but if I wasn't that type of person, I don't feel I would have anybody coming to me' (p533). **3. Being prepared for the death** – people with ID may be concerned about who would take care of practical arrangements around the death: 'She'd be wondering who's her next of kin to arrange her funeral … She might have worries about that' (p533). **4. Family carers angry in not being told that her son was dying, as she could not prepare his siblings** – 'The nurse thought that I knew he was dying, but if I had of knew I wouldn't have left the hospital … Because I could have got my other kids prepared' (p533). **B. Provision of care** **1. Place of care – from people with ID** – 'She might want to stay in her own home' 'In hospital…she'd get better care- nurses and doctors'; 'Maybe in a nursing home where they can be looking after her' (p534). Person should be able to have access to physical, social, emotional and spiritual support from 'social workers', 'the minister', 'a	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		psychiatrist' the 'community nurse' and 'physiotherapist' were highlighted. Other practical help included: 'Bring some help in to do cooking, washing, dishes, cleaning her house'; 'It's a pity a nurse wouldn't come in at night and say a prayer for her' (p534). A hospice, as a preference for place of care, was not identified by people with learning disabilities in this study. Family carers felt that professionals needed more awareness of the right of people with ID to access equitable palliative care: 'A young adult who has a disability … they can't say I am dying … what is going to happen … will it be sore, – they don't have those thought processes, but they are due exactly as much as the adult who does know the journey they are about to take …' (not clear here how old/young the person with ID was) (p534). **2. Supporting family members** – Family members and carers need bereavement support such as 'a counsellor' who understood about people with learning. 'If someone in your family dies…you would be entitled to go for grief counselling…' (p534). **C. Family-centred care** **1. Being with family** – doctors, nurses and other professionals needed to know the importance of having	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		family around familiar to and with the person, at the end of their life. 'Time with her own family' 'Her brother … grandmother … daughters also inside her in own heart.' **2. Professionals to acknowledge and work in partnership with family carers who had prior knowledge of the person** – 'We just read him by facial expression and the expression in his eyes … he would have moaned – that was the only way we could tell that he was in pain' (p534). **3. Having friends and familiarity around** – Important relations such as the 'dog' 'She might just want the ones that she's used with, but she might not want strangers' 'And her dog … company-pet' (p534). **4. Maintaining familiarity** – This was seen as being about the personhood of someone with a learning disability which professionals should be mindful of. It helped family members to cope, adapt and be resilient in a long-term caring role. 'If he's happy with somebody sitting reading him a story or holding his hand I think that they (professionals) need to see that even though it's a child going into adulthood with a very severe physical and learning disability … they have to see them as a whole person and the parents are part of that' (p535).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		In summary, people with learning disabilities wanted to be able to access support and information around the illness, treatment and prognosis.	

6. Morton-Nance S, Schafer T (2012) End of life care for people with a learning disability. Nursing Standard 27: 40–7

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To explore the experiences of district nurses caring for people with a learning disability at the end of their lives. **Methodology:** Qualitative study Interviews with open-ended questions.	**Participants:** Professionals/practitioners healthcare professionals (disability nurses and district nurses). **Sample characteristics:** Not reported. **Sample size:** Total n=6 (3 community learning disability nurses and 3 district nurses).	**Narrative findings** Five major themes emerged from the data analysis. **A. Attitudes affecting quality of care** 1. A lack of basic understanding of each other's roles, where minimal sharing of important information was evident: 'I don't think I've ever rung anyone from learning disability services about a patient with a learning disability ... and the mental ones tend to keep to themselves... and we all stick with that divide … for it is very much a divide, isn't it?' (district nurse 3) (p43). 2. A general protective and paternal attitudes and approach to a person who is dying, a perception that the person with a	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Country: Essex, UK. **Source of funding:** Not reported.	**Outcomes measured** Service outcomes, views and experiences. **Follow-up** Not reported.	learning disability was vulnerable and in need of protection, resulting in a deliberate withholding of important information (with good intention) to prevent causing distress to the dying person: ‘They say that everybody has the right to know their diagnosis, but within learning disability they tend to, well, the carers all know the diagnosis, but the person with a learning disability usually doesn’t … if they don’t know, then it’s not going to hurt them’ (district nurse 3) (p43). 3. ‘... that how can you get that concept of death across or should you … or should you … no actually … that may be cruel’ (learning disability nurse 3) (p43). **B. Good experiences** 1. Sharing positive experiences when palliative care involved person-centeredness, good planning, preparation, outreaching and sharing of information with other healthcare professionals: ‘A good experience is when the family are prepared. The carers were good and accepting of what was happening and the patient seemed to be prepared for it’ (district nurse 2) (p43). 2. Insights on what was meant by a ‘good death’ and the importance of patient choice affecting dignity in death: ‘… giving them choices … empowering them somehow to have	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		the right to say what it is they want to say and contribute to decisions about treatment' (learning disability nurse 1) (p43). 3. Ensuring the dying person was comfortable: 'I think that's one of the most important jobs that I can do as a nurse … is to support people and make them comfortable, at the end stage of their life' (district nurse 2). 4. Taking the initiative in their caring role, by acting proactively rather than reacting to significant events: 'We got him to the GP and told him ... we've done this … this … and this … in clinic and during this assessment it is now very evident that he [person with a learning disability] is losing his skills... it is clear now that he has dementia' (learning disability nurse 1). 5. Building therapeutic relationships with patients is important, and working proactively: 'We try to anticipate and fulfil all their [patients'] needs. Certainly the team I work in would all go the extra mile if we know what the person wants … helping to facilitate the planning for the death as well ... and the funeral ... and the aftercare' (district nurse 1) (p43). **C. Poor experiences**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		1. Reflecting on negative experiences concerning end of life, such inequalities and limited choice in accessing care for people with ID. 2. Insights into experiences of poor, undignified deaths, as being an apathetic attitude toward people with a learning disability: 'When things happen, where there isn't somebody familiar around ... in my experience the person with a learning disability just ends up in hospital ... which then creates all sorts of other problems' (learning disability nurse 3) (p44). 3. No documentation in place of specific choices and decisions: created conflict and affected collaborative working: '… and the paperwork that is available is often not in place because people don't know that it is available, it's very hard… the place of preference for where you [people with a learning disability] want to be if something should happen to you, it's often not completed ...' (learning disability nurse 1). 4. Witnessing ineffective symptom control had a significant effect, physical and mental pain experienced by people with a learning disability often not addressed or controlled satisfactorily: 'You could actually see the torture in her [person with a learning disability] face … she couldn't talk to us though … that was difficult …' (district nurse 2) (p44).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		5. Reactive rather than proactive interactions to significant health events: '… it happened so quickly … and we saw the amount of blood in the loo ... he died about three weeks later ... that was a shock for everyone' (learning disability nurse 3). 6. Behavioural changes in people with a learning disability had not been taken seriously: '… sometimes their [person with a learning disability] behaviours are not behaviours, it's the pain that's making them behave like that because there is something really, really wrong' (learning disability nurse 1) (p44). **D. Communication a major barrier to understanding patients' needs.** 1. Difficulties in communication between healthcare professionals and a failure to share important information appropriately, making it difficult to meet patients' basic needs: 'Communication between the different people and professionals involved … that is generally very fragmented' (learning disability nurse 1) (p44). 2. Patients' inability to communicate their needs exacerbated the problems: '… he [person with a learning disability] ended up being doubly incontinent on the ward, but that was only	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		because he didn't know where the toilet was and he hadn't got the ability to ask to go to the toilet …' (district nurse 1) (p44). 3. Inexperience and lack of understanding, skills and training affected quality of care at the end of life. 4. Breaking bad news and communicating with openness to a person with a learning disability was difficult: 'How do people view death and what is death? And how do you explain that to a person with a learning disability?' (learning disability nurse 1). 'I wouldn't know where to begin. It is very hard to say to somebody you may not survive this... I mean how would you couch it?' (district nurse 1) (p45). **E. Future needs** 1. Participants identified the need to raise awareness and provide training in palliative care at all levels, also training needs surrounding understanding government policy. Care and ongoing support should be extended to carers: 'They [carers] don't get that emotional support to deal with the fact that they are dealing with caring for a person who is dying, somebody that they may have cared for years, and they know that they are going to lose that person' (district nurse 3).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		2.The important need for collaborative working and sharing of expertise across disciplines: '… better joint working practices... actually linking in with the appropriate people and being able to access these services' (learning disability nurse 1) (p45). Overall, community nurses reported the positive experience when palliative care involved person-centeredness, good planning, preparation, outreaching and sharing of information with other healthcare professionals. They found that the main barriers to improving quality of care to end of life care included the difficulty for people with ID in accessing palliative care; poor and undignified deaths because of the apathetic attitude toward people with a learning disability; reactive rather than proactive approach to end of life care; difficulties in communication between healthcare professionals and a failure to share important information, inexperience and lack of understanding, skills and training, making it difficult to meet patients' basic needs. Community nurses identified the need to raise awareness and provide training in palliative care at all levels and emphasized the importance of effective collaborative working and sharing of expertise across disciplines.	

7. Ryan K, McEvoy J, Guerin S et al. (2010) An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. Palliative Medicine 24(6): 556–72

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To describe the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. **Methodology:** Mixed methods. Focus groups and a survey.	**Participants:** Professionals/practitioners. Palliative care staff and learning disability services staff. **Sample characteristics:** Age, gender, ethnicity, religion, disability, health condition – Not reported. Socioeconomic position – Data describing the occupation and workplace of survey respondents reported. **Sample size:**	**Survey results** Total 389 questionnaires were distributed, 261 returned (RR of 67%). **Level of importance placed on the provision of end of- life care by learning disability staff.** On a 100mm Visual Analogue Scale respondents were asked to define how important they felt it was for their organisation to provide good end-of-life care for service users. 'Not at all important' being 0mm and 'very important' being 10mm. They rated its importance extremely highly by giving it a mean score of 95.99 (n=201, sd=8.04). There were no sig differences in opinion between all 4 major staff groups. **Level of staff experience in the care of service users with learning disabilities towards the end of life.** Total 59.3% (n=57) of PC staff had provided care to a person with learning disabilities towards the end of life. In terms of frequency, 63% had not cared for any individual with learning disability in the last year and 19.6% had cared for only one	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Country: Republic of Ireland. **Source of funding:** Government. The work was supported by a Research Fellowship from the Health Research Board, Ireland (Grant number HSR 2005/09).	**For survey** Intellectual disability (ID) staff = 312. Palliative care (PC) staff = 77. **Focus groups** Total 91 participants.	individual. Palliative care staff therefore had a low level of experience in caring for people with learning disabilities. The number of LD staff who had cared for a service user towards the end of life was 67.3% (n=136). So the overall experience of LD staff in providing care was greater than that of PC staff. In terms of frequency, in the last year, 59.5% of LD staff had cared or at least one person with intellectual disability at the end of life. LD staff thought they would have to care for more people at the end of life in future. Of staff who said they had never cared for a person with LD at the end of life, 73.8% stated that they felt that it was likely that they would do so in the future. **Assessment of confidence levels of staff in managing pain, symptom control and communication issues involving people with learning disabilities towards the end of life** Respondents used a 100mm Visual Analogue Scale to rate their confidence levels in a variety of situations, 0mm being 'Not at all confident' and 100mm representing 'very confident'. Palliative care staff were highly confident of their ability to provide palliative care to the general population (mean confidence level, 86.85) BUT only moderately confident of their abilities when caring for people with intellectual	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		disabilities (mean confidence level 63.47 with the difference being significant). **Confidence levels for other areas** Confidence of PC staff in ability to manage pain/symptom control issues for general population 81.86 (n=44, sd=18.24). Confidence of PC staff in ability to manage pain/symptom control issues for people with ID 54.38 (n=45, sd=28.43). Confidence of PC staff in ability to manage communication issues for general population 84.32 (n=53, sd=13.64). Confidence of PC staff in ability to manage communication issues for people with ID 51.40 (n=52, sd=26.75). Confidence levels of learning disability staff: confidence of ID staff in ability to manage issues of pain/symptom control for people with ID but who do not have life-limiting illness 68.92 (n=165, sd=31.88) –Confidence of ID staff in ability to manage issues of pain/symptom control for people with ID with life-limiting illness 60.77 (n=165, sd=35.69). Confidence of ID staff in ability to manage issues of communication control for people with ID but who do not have life-limiting illness 76.47 (n=170, sd=25.96). Confidence of ID staff in ability to manage issues of communication control for people with ID with life-limiting illness 58.72 (n=183, sd=32.63) (Both staff groups equally lack confidence in the areas of pain/symptom control and communication in the end of life care setting.)	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		Focus group findings Supported the survey findings. Palliative care staff were willing to provide care to people with learning disabilities but restricted in doing so due to their lack of knowledge. They said it was ‘different’ and more ‘difficult’ to provide EOLC to people with learning disabilities and they doubted their own ability to meet people’s needs ‘... You do the best you can within the situation, and you hope that it’s appropriate to the situation’ (focus group 1; R3: 783–784) (p570). Similarly although LD staff had a breadth of experience of supporting people with LD their training to date hadn’t prepared them for caring for people with learning disabilities at the end of life. ‘I remember, you know, when I was training it was – I can even see the section in the book – it was like, maybe two pages … Care of the Dying Patient’ … two pages … and ‘Preparing the Body. I’m like, “Oh my God! Is this what I’ve to do?’” But that was it. There was no such thing … I don’t remember the buzz-word of “palliative care” at the time …’ (focus group 11; R1: 336–40) (p570).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		Palliative care staff said they felt dependent on LD staff or carers and would follow their lead in the management of the person's end of life care. All staff recognised problems could be overcome if they worked in partnership but there was no evidence that collaboration happened and instead they persisted with their own in house solutions. Finally, experience seems to have a positive impact on confidence but staffs were providing end of life care for people with learning disabilities so infrequently that they were unable to retain the skills they'd learned or translate them into organisation wide knowledge.	

8. Todd S (2013) 'Being there': the experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 215–30

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To develop an understanding of how staff interpreted and responded to the death of a person with	**Participants:** Professionals/practitioners. Total 22 staff in 5 different providers and who had experienced, in total, 27	**Narrative findings** **A. The sense of 'being there' was important** Staff saw themselves as escorts across the transitions from living to dying, from being alive to being dead and from being physically present to being absent and from being seen to	**Overall assessment of internal validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
intellectual disability and the values that shaped their accounts of these. **Methodology:** Qualitative study. In depth qualitative interviews. **Country:** UK, Wales. **Source of funding:** • Not reported	deaths of people with intellectual disability. The age of the people with ID for whom the 22 staff cared at end of care was not reported. **Sample characteristics:** Not reported. **Sample size:** Total 22 staff who worked with 5 intellectual disability service providers in England and Wales. **Outcomes measured** Service outcomes. **Follow-up** Not reported.	being remembered. '… We stayed at the hospital, with the family. They decided to turn her ventilator off, she wasn't responding. The family asked us to be there. I have to confess that I felt that I didn't want to. But we all said our Goodbyes! It was a very precious moment. Her dad said 'Don't go, I want you here. Emma wants you here.' It was the longest 10 minutes of my life. The monitors went silent and we wept. It was over' (p219). **B. Types of death: deaths which prevented or obstructed staff from 'being there' were seen as failures of their own or other systems of care, or as 'bad deaths'** 1. Expected death of a resident could be sudden come with startling shock and with long-lasting impact. The role of staff as death escorts is to communicate deaths to others, as being a witness to and a messenger of death. Many unexpected deaths came with concerns that death may have been the outcome of negligence or a lack of proper surveillance. Such deaths associated with a sense of blame and responsibility and with insecurity that others might blame staff: '..... I wanted his parents to know that we just didn't give up. It was the middle of the afternoon. We had guidelines on what to do and who to contact. But I had to go to the parents' house to tell them directly. That was hard but I couldn't do it on the telephone … She was pacing and becoming more aggressive.	**Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		'How could you let this happen?' What have you done to my son?' As if it was our fault … It was awful!' 'she came back here on the Monday she was taken into hospital. By Friday she was dead. Between the Monday and the Friday most staff had been to see her in hospital. On the Thursday a relative made accusations … That we kept her outside in the pouring rain?' (p219). 2. When deaths came after a lengthy period of illness, staff stressed the importance of 'being with' the individual through the dying journey. When death came unexpectedly so that the person died alone, staff felt that they had failed to 'be there'. 'He died alone, I was angry. We were all prepared, we'd put up a fight for him to die here at home and he ended up dying alone.' 3. Death seemed to provoke a reflective review of how it might have been prevented: I was with her every step of the way … She knew she was going to die I'm convinced of it … She was told that she had cancer..... The cancer had spread to her bones but she was never told that. I blame myself really. I should have made sure that she was regularly checked … know. I question myself so much.' (p220). 4. 'Being there' in some cases, took its toll on staff. Feeling unsupported in the face of unrelenting conditions of dying	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		forced some staff, and with some guilt, to withdraw from 'being there'. '... We are employed as support workers, so where's the support? … Maybe in a hospital you'd have support round you. Here I felt we were on our own' (p221). **C. Places of death and dying were seen as key factors indicative of both quality of their care and their commitment to individuals, though there could be little or no control over the place of death** For expected death, hospital deaths were seen as being inappropriate , as failed deaths as the person 'failed' to die at home in the company of familiars: 'A hospital death would have been a bad death. She'd lived in a hospital before. So it was right for her to die at home!' '... He hated hospitals. He would've preferred to have come home I'm sure. I wished he had, it just wasn't right. We were willing for him to come home' (p221). 1. Staff perceived that hospital staff 'didn't know anything about intellectual disability or how to communicate with him', or about the value of the person with the intellectual disability, '... I don't blame them they've never had any contact with people with learning disabilities. To begin with they never consulted or involved us in any decisions about his care. But we didn't give up … but in the end I think they had a lot of	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		admiration for us … They'd explain what was happening and how we could help. They learned to rely on us' (p222). 2. Tension over decision as to whether someone could die at home (i.e. residential homes), which depended upon agreement between staff, service managers and relatives. Dying at home was viewed as appropriate and provided the perfect place for accompanied and peaceful dying. Some staff who had experienced caring for a resident who was dying at home, this led to them reviewing the appropriateness of the service as a place for dying: 'His death wasn't easy. He was in a lot of pain. There was a lot of mess. It was a horrendous death. There was a lot of blood…it upset the other tenants' (p223). **D. Awareness of dying** 1. Staff felt that person with intellectual disability may not have an awareness of dying which was seen by staff as involving emotional suffering, and staff prevented this by managing a dying individual's awareness of it. 'Being there' involved masking dying from the person with intellectual disability, for reasons of care and emotional protection: 'We never told Stephen … He's suffered all his life so why make it worse now. I think it was the right thing to do. But it was hard to keep it going for him ….'; 'We kind of said "Don't worry, everything	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		will be ok!" … I don't think she'd have coped. She was someone we loved and cared for. So what was the point in upsetting her?' (p223). **E. Being there after death, staff felt appropriate to be involved, in managing the person's transition from living to being dead and from 'being' to 'being remembered', such as funeral planning** Boundaries between staff and family became problematic: 'Some families are happy for us to take the lead; others want little or no involvement from us. It's a very difficult and complicated thing.' **F. Staff found it insensitive and were critical of management's role in filling too quickly the 'void' (not an emotional or social void but an economic one) left by the person who died** 'An empty bed that needs to be paid for. If there's no-one in it, then it's a void. I guess it means things (getting a new resident in) are speeded up a little, for the money's sake … It's a bit indecent. It would have been nice though if we had had more time to get used to him not being there.' **G. The privileged but unrecognized role of being there**	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		1. Staff felt caring for dying people a privileged status which did have some emotional impact upon staff, but which also demonstrated and revealed their personal values. These were not well recognised within their employing organisations. Staff felt under-supported in their achievement: ‘You’re too involved with people to be distant. I’m human … I felt as if we had no support. How could you not get involved? I’m a human being ...’ (p225). ‘I think that you are expected to draw a line around it. To be professional. To have no emotions or feelings. They are clients not our friends, not our family … but caring isn’t factory work … You’re supposed not to have feelings or maybe you’re just not supposed to show it’ (p225). In summary, staff at residential homes (where people with ID stayed most of the time) gave personal accounts of their experiences of staff in dealing with issues of death and dying. They accepted that death of their clients as an important part of their work and death should not means the end of their relationship and commitment to the deceased individuals. They felt that the residential homes were an appropriate place of death for people with ID under their care. ‘Being there’ through the transition from living to dying and to being remembered was perceived by the staff to be important, a reflection of their personal and human values. ‘Good deaths’ were deaths that allowed staff to express ‘being there’, despite the emotional pain and the impact of death of a	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		resident on the staff, though this concept might create tensions with the dying individual's immediate family. The emotional dimensions of care work for the dying of people with ID was felt by the staff as not often recognised. These were demands that the staff reported they're willing to adopt but ill-prepared and under-supported in their achievements.	

9. Tuffrey-Wijne I, Giatras N, Butler G et al. (2013) Developing guidelines for disclosure or non-disclosure of bad news around life-limiting illness and death to people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 231–42

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
Study aim: To examine stakeholders' preferences and reasons around disclosure and non-disclosure of bad news about life-limiting illness and death to people with intellectual disabilities, and to	**Participants:** Service users and their families, partners and carers. People with intellectual disabilities and family carers.	**Narrative findings** **A. Views on non-disclosure to people with ID who had a life-limiting illness with a short prognosis** 1. People with ID reported a mixed response. 2. Family carers felt strongly that it was better to protect their son or daughter from the truth. 'If [my son] was to ask us what's going to happen to me, I think I'd lie. I'd lie for his own good. But I wouldn't say "you're going to get better", I'd say	**Overall assessment of internal validity: ++** **Overall assessment of external**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
develop guidelines about these issues. **Methodology:** Qualitative study. Focus groups, interviews (telephone, face-to-face, one-to-one, online). **Country:** UK: London and Cornwall, and across England. **Source of funding:**	Professionals/practitioners. Health and intellectual disabilities professionals. **Sample characteristics:** Age People with ID: ranged from 24 to 49 years old. Sex Not reported. Ethnicity Not reported Religion/belief Not reported. Disability Not reported. Long-term health condition People with ID: with life-limiting conditions. Sexual orientation: Not reported.	"we'll see how you are and maybe in a week's time you'll be feeling better". I can't see the point in telling the end situation.' Participant 87 (father of 26-year-old son with mild/moderate ID). 'I think your motherly instinct overtakes you and think, "Why give them more misery?" … overwhelming instinct as a mother has got to be to protect your children' (participant 18, mother of 29-year-old son with severe ID) (p234). 3. Intellectual disabilities professionals were overwhelmingly in favour of disclosing bad news to someone with intellectual disabilities. They felt that the person had a right to know and were not sure whether they even had the right to withhold information about the person's health from the individual concerned. 'I don't feel confident as a manager that I'd have the power not to tell somebody' (participant 14, manager of a respite service for people with ID). 4. Medical healthcare professionals (doctors and nurses working in hospitals, hospices/palliative care services) felt that the person with intellectual disabilities should be told about their own ill health and poor prognosis, but only if full disclosure was right for the particular individual. 'We always tell them in a simple way, simple words that they can understand easily. Because you cannot lie to them. At the end of the day it's them, you know, they are at the centre of their care' (participant 50, nurse, hospital ward manager). 'I think each case must be	**validity:** +

Research aims	**PICO (population, intervention, comparison, outcomes)**	**Findings**	**Validity ratings**
A grant from The BUPA Foundation.	Socioeconomic position: Not reported. **Sample size:** Total n=109 in total (21 people with mild/moderate ID, 28 family carers, 26 specialist intellectual disabilities professionals from health or social care services, 34 general health professionals including nurses, physicians and allied health professionals specialised in cancer or palliative care). **Outcomes measured:** Satisfaction with services,	looked at on an individual basis with the needs of the patient and their level of understanding and comprehension kept central to the decision making process' (participant 74, hospital consultant in palliative medicine) (p235). **B. Reasons for non-disclosure/ disclosure of bad news around life-limiting illness and death to people with intellectual disabilities** 1. Preventing distress: 'There's part of me that thinks that people with learning disabilities have so much to contend with … they have so much suffering, and so one of the good bits about being learning disabled is the ignorance of death. I do think ignorance is bliss if you can get away with it' (participant 19, mother of a 26-year-old daughter with severe/profound ID). 'I got an email to say the staff team had decided not to tell her [that she was terminally ill] and not to discuss it with her because it would upset her' (participant 10, community ID nurse). 2. Too difficult for the bearer of bad news 'We label that as "oh, the person is not ready for it or they couldn't cope" but actually it is us that can't cope with it sometimes' (participant 61, consultant psychiatrist, ID services) (p237).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
	views and preferences **Follow-up:** Not reported.	3. The potential bearer of bad news lacks knowledge or were unable to accept the news Some respondents found it difficult to disclose and talk about bad news because they lacked full information. ‘Somebody became acutely ill and was asking me, “Am I going to die?” And I wasn’t able to answer that question, because I didn’t fully understand the prognosis …’ (participant 16, community ID nurse) (p237). ‘His parents are busy trying to convince themselves he is going to be completely cured. They fell to pieces when told… He must feel so ill, he asked again this week if he is going to die, as he feels as if he is, and mum and dad smiled and replied “it’s just the treatments”! I think he knows!’ (participant 9, community ID nurse) (p237). 4. Unable to understand: ‘He had very complex needs and a very severe learning disability and there was no way that we could have explained it in any way’ (participant 59, manager of residential care home, ID services). ‘He won’t understand what cancer is anyway. I’m not going to say to him, “you’re going to die”’ (participant 90, father of 24 year old son with moderate ID) (p238). 5. Lack of a sense of time which made explanations of future events difficult to put into perspective. ‘To tell someone they are going to die can have no meaning unless it is going to happen today, tomorrow or within the week. Some people with a learning disability live in the moment and cannot think about	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		next week' (participant 10, community ID nurse). 'My son's understanding is very concrete. He takes things literally … So if you told him he was going to die, he would ask: "When? What day? What time?" You can't tell him something is going to happen, and then not tell him when' (participant 83, mother of a 24 year old son with mild/moderate ID and autism) (p237). 6. Conflicting views and disagreement among stakeholder groups about whether the person with intellectual disabilities should be told the truth. Doctors were clear about their duties around disclosure with regards to the Mental Capacity Act. 'The person comes first. The family are not my patient' (participant 61, consultant psychiatrist, ID services) (p238). **C. Reasons for disclosure to people with ID who had a life-limiting illness with a short prognosis** 1. Right to know: 'As long as they've been supported by somebody, then I think that they have the right to know as an adult, because if it was any of us we feel like we would' (participant 66, ID speech and language therapist). 2. Understanding helps people cope: 'It depends on what treatment is offered, because obviously if you don't tell the patient what the diagnosis is, and then you send them for treatment, you are going to have a dilemma … they have to	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		know what's happening and why it's happening' (participant 43, hospital ward nurse) (p238). 3. Involvement and planning: 'Someone might want to have a chance to do something or to say, is there any people you want to speak to you, is there any people you want to go and visit …' (participant 14, manager of a respite service for people with ID) (p238). **D. Could disclosure be harmful?** The truth could be overwhelming: 'A service manager told her that we was "very poorly" … Her response was to shut her door, refuse to get dressed, and she did not leave the house for eight months … I just think she was told too much too soon, and it has blocked our ability to support her, because she now won't let us in' (participant 11, community ID nurse) (p238). 'To people with no concept of time this would be dumping untold anxiety on them' (participant 78, mother of 26 year old son with moderate ID). Too anxious to cope with distressing information: 'I think his anxiety may overwhelm his understanding. Some things are really counterproductive for him to know' (participants 81 and 82, parents of 24-year-old son with severe ID) (pp238–9).	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Validity ratings
		In summary, the reasons for non-disclosure/disclosure of bad news around life-limiting illness and death to people with intellectual disabilities 1. Non-disclosure: 'he'll get upset'; 'I will get upset'; 'He can't understand'; 'He has no concept of time'; 'Others don't want him told'. 2. Disclosure: 'He has a right to know' (rights); 'Understanding will help him cope' (Coping); 'He needs to be able to plan' (involvement). (Figure 1, p234). 3. Potential reasons why disclosure of bad news could be harmful, resulting in confusion and distress: a. Inability to balance the information due to poor concept of time and inability to see the bigger picture b. Inability to understand and retain the information Disclosure of bad news to people with ID with life-limiting condition and poor prognosis would depend on the person's capacity to understand abstract concepts and an assessment of 'What parts of the truth should the person be helped to understand, and when?' This involved the way how information is given, taking into consideration the issues of the person's right to information.	

Review question 8 – critical appraisal tables – the views and experiences of people using services, their families and carers

1. McLaughlin D, Barr O, McIlfatrick S et al. (2014a) Service user perspectives on palliative care education for health and social care professionals supporting people with learning disabilities. BMJ Supportive & Palliative Care 5: 531–7

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To develop a best practice model to guide and promote partnership practice between specialists palliative care and intellectual disability services, by gathering quantitative and qualitative data from practitioners from these services. **Methodology:** Mixed methods. Phase 1 – survey using self-completed questionnaires with 8 quantitative questions and 4 open qualitative questions;	**Is the context clearly described?** Clear. For people with ID: Interviews and focus groups (each lasting 30 mins) took place within the advocacy network offices. The discussion was recorded with participants' permission. Field notes were made. For family carers: given an information pack about the study, signed consent form. Interviews took place in their home, lasted 40–60 mins,	**Does the study's research question match the review question?** Yes. Views of people with learning disabilities, and their family carers concerning palliative care. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was obtained from the Central Office of Research Ethics Committee Northern Ireland and ORECNI (09/NIR/03/38).	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Phase 2 – Phase 2: semi-structured interviews. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. **How well was the data collection carried out?** Appropriately. Using a pictorial approach (illustrations and drawings).	were conducted in a sensitive manner and recorded with their permission. Field notes were made. All were provided with written details on counselling, support services and a named person to contact after the interview if needed (p533). **Was the sampling carried out in an appropriate way?** Appropriate. A purposive sample of adults with learning disabilities recruited via an advocacy network, and family carers recruited from health and social care trusts and hospice care across	Subjects give written consent by signing a consent form. Each focus group took place in a private room within the advocacy network offices. Discussion was recorded with participants' permission. **Were service users involved in the study?** Yes, as participants of the study. **Is there a clear focus on the guideline topic?** Yes. To elicit the views of people with learning disabilities, and their family carers concerning palliative care. **Is the study population the same as at least 1 of the groups covered by the guideline?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Open questions were asked verbally, using straightforward language and also in clear, written format.	Northern Ireland (p532). **Were the methods reliable?** Somewhat reliable **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. Data were transcribed verbatim and content analysed using a recognised framework. Transcripts were also independently analysed by two other members of the team, and agreement on themes reached through	Partly. Age of people with learning disabilities in this study ranged from 19 to 61+ years, some of the qualitative data were from or refers to young people with ID. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Within the advocacy network offices. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	discussion (p533). **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	**guideline?** Partly. Only the views from older people with ID will qualify as the data included all ages from 19 to 60+ years. **Does the study have a UK perspective?** Yes. Belfast, NI.	

Review question 8 – critical appraisal tables – health, social care and other practitioners' views and experiences

1. Bailey M, Doody O, Lyons R (2016) Surveying community-nursing support for persons with an intellectual disability and palliative care needs. British Journal of Learning Disabilities 44: 24–34

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To describe the provision of community nursing support for persons with an intellectual disability and palliative/end-of-life care needs. **Methodology:** Survey. **Objectives of the study clearly stated?** Yes. To describe the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs. **Research design clearly specified and appropriate?** Yes. Survey questionnaires collecting quantitative and	**Basic data adequately described?** No. Demographic data of participants not fully reported. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Partly. Because of incomplete demographic data. **Results internally consistent?** Partly.	**Does the study's research question match the review question?** Partly. This study described the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs, but not clear if the people with ID the participants referred to is old or young (no information on the age range). **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval granted by the University Research Ethics Committee. Consent was implied through return of the completed questionnaire.	**Overall assessment of internal validity: -** **Overall assessment of external validity: +**

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
qualitative data (response from open-ended questions), which would be extracted. **Clear description of context?** Yes. Community health services. **References made to original work if existing tool used?** Unclear. **Reliability and validity of new tool reported?** Yes. Reliability and validity of the instruments by piloting the questionnaire to determine whether questions were	**Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Yes. Quantitative data were analysed using SPSS version 18. Descriptive analysis was conducted to describe frequencies. (Not extracted for this study.) Qualitative data were analysed using thematic analysis framework (taking memos after each interview, reading transcripts and making notes of general themes, repeated reading and generating open coding headings to describe all aspects of the data, reducing	**Were service users involved in the study?** Yes. As participants of the study. **Is there a clear focus on the guideline topic?** Partly. This study described the provision of community nursing support for persons with an intellectual disability and palliative/end of life care needs, but not clear if the people with ID the participants referred to is old or young (no information on the age range). **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Practitioners – public health nurses	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
clear and unambiguous. An expert review panel (statistician, quantitative researcher, 2 palliative care clinical nurse specialists and a senior researcher) verified face validity of the instrument and assured usability. Based on feedback from the review panel, minor revisions were made to the wording of individual questions (p26). **Survey population and sample frame clearly described?** Yes. The sample consisted of a total population of public health nurses (PHNs), community nurses, practice nurses, hospice at home nurses and palliative care	the codes under higher order headings, returning to the data with the higher order codes and collating the organised data for reporting. Reviewed, compared and discussed independently by 2 researchers to reach consensus. **Methods appropriate for the data?** Yes. [Info] response from open-ended questions from questionnaire surveys. **Statistics correctly performed and interpreted?** Partly. Low response rate (32%)	(PHNs), community nurses, practice nurses, hospice at home nurses and palliative care nurses, providing end of life care to people with ID. Community nursing support for persons with an intellectual disability and palliative/end of life care needs, but not clear if the people with ID the participants referred to is old or young (no information on the age range). **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community health staff. **Does the study relate to at least 1 of the activities covered by the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
nurses, currently working in a HSE region in Ireland. Access to all nurses gained through the relevant directors of nursing/public health nursing (p26). **Representativeness of sample is described?** Yes. Total population of PHNs, community nurses, practice nurses, hospice at home nurses and palliative care nurses, currently working in a HSE region in Ireland. **Subject of study represents full spectrum of population of interest?** Yes. Total population of PHNs,	would limit interpretation of findings **Response rate calculation provided?** Yes: 94 of 290 nurses responded (response rate 32%). **Methods for handling missing data described?** No. Not reported. **Difference between non-respondents and respondents described?** No. Not reported.	**guideline?** Yes. RQ8-EOLC. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Limerick, Ireland.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
community nurses, practice nurses, hospice at home nurses and palliative care nurses, currently working in a HSE region in Ireland. **Study large enough to achieve it's objectives, sample size estimates performed?** Partly. Sample size calculation not reported. Low response rate. **All subjects accounted for?** Partly. Low response rate (32%).	**Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Partly. Authors' comments: 'This needs to be considered in light of the fact that only 32% of the population surveyed responded and the probability is that those who did not respond had not experienced the phenomenon under investigation.' **Results can be generalised?**		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
All appropriate outcomes considered? Yes. **Response rate** Total 32% (n=94). **Describes what was measured, how it was measured and the results?** Yes. Relevant quantitative data and all qualitative data from response to open-ended questions from surveys collected and examined. **Measurements valid?** Yes.	No. Poor response rate. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** Unclear. **Conclusions justified?** Partly.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Measurements reliable? Yes. Quantitative data: frequency counts; qualitative data: thematic analysis framework. **Measurements reproducible?** Partly. Qualitative data may not be reproducible.			

2. Cartlidge D, Read S (2010) Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective. International Journal of Palliative Nursing 16: 93–8

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To identify what skills hospice staff felt were needed to enable them to feel confident in providing specialist palliative support for people with learning disabilities. **Methodology:** Focus groups and an open ended questionnaire. **Is a qualitative approach appropriate?** Appropriate. Because the research seeks to understand subjective experiences about the provision of end of life care for people with learning disabilities, which could not have been addressed via a quantitative approach.	**Is the context clearly described?** Unclear. Apart from age and sex, there is little information about the characteristics of participants. Data were only gathered via focus groups (arguably too large to generate in depth, meaningful results) and through questionnaires. It would have been beneficial and provided opportunities for triangulation had observations of practice taken place. Context bias is not discussed. **Was the sampling carried out in an appropriate way?** Not sure. Although it is not clear, it appears that all inpatient unit staff was sent questionnaires, thereby missing out the hospice at home staff. The focus group involved staff from	**Does the study's research question match the review question?** Yes. The study examined hospice staff views about the end of life care they are able to provide to people with learning disabilities and reflected on their need for professional development to improve the quality of this care. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was granted by the hospice's clinical governance committee (a subcommittee of the board of directors).	**Overall assessment of internal validity: -** **Overall assessment of external validity: +**

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Is the study clear in what it seeks to do? Clear. **How defensible/rigorous is the research design/methodology**? Somewhat defensible. The design is appropriate to the research question and a clear and convincing rationale is given for using a qualitative approach. However, there are no clear accounts of the rationale/justification for the sampling, for example why some and not others were involved in the focus group. Methods for data collection and data analysis are clearly described and justified.	both the hospice at home and inpatient unit although we have no idea how they were sampled. **Were the methods reliable?** Somewhat reliable. Methods do investigate what they intended to but data collection would have been improved by adding one-to-one interviews and/or observations of practice. Also, the focus group involved 17 people, which the author admit was too large to handle and prevented participants being able to have their say. **Are the data 'rich'?** Poor. The context of the data is not particularly well described and there does not appear to be any diversity in the findings. Very little detail is provided	**Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the least one of the settings covered by the guideline?** Partly. There is nothing to suggest that the focus is on older people with learning disabilities. However, it is clearly on adults with learning disabilities and given that care being	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
How well was the data collection carried out? Somewhat appropriately The data collection methods are described in limited detail but they are appropriate to address the research question. There is little information about the collection of data within the focus group, apart from that it was audio recorded. Record keeping appears to have been systematic although there is no information about the software used for storage and analysis.	and there is no contrast or comparisons across the 2 sites, e.g. the hospice at home and inpatient unit. **Is the analysis reliable?** Somewhat reliable. The data were collated, transcribed and independently analysed by the 2 researchers who met to discuss themes and sub themes. There is no description of how differences resolved although it assumed they were discussed between the two researchers. Participants did not feedback on the transcripts/data. Discrepant results have not been reported. **Are the findings convincing?** Somewhat convincing The findings are not terribly clearly presented but they seem internally coherent.	provided is at the end of life we might assume that at least some people being referred to by staff will be 'older'. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. The provision of end of life care. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	There are no extracts from the original data – either from the questionnaires or the focus groups. **Are the conclusions adequate?** Somewhat adequate. Although they seem to be derived as much from other referenced material as from the collated data.		

3. Cross H, Cameron M, Marsh S et al. (2012) Practical approaches toward improving end-of-life care for people with intellectual disabilities: effectiveness and sustainability. Journal of Palliative Medicine 15 (3) 322–6

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings.
Study aim: The project was 'aimed at exploring ways of increasing	**Is the context clearly described?**	**Does the study's research question match the review question?** Partly.	**Overall assessment of**

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings.**
access to palliative care services by people with ID within one geographical area' by assessing the effectiveness and sustainability of three different approaches: (1) training of ID staff on basic end of life care (2) training of palliative care staff on how best to meet the needs of people with ID (3) a link worker scheme where professionals from both professional areas would have a designated point of contact for support and information. **Methodology:** Face-to-face and telephone interviews and evaluation forms.	Unclear. There is some discussion about the policy and practice context for the research in terms of general information about the need for end of life provision for people with learning disabilities to be considered. No information is provided about the contexts in which the face-to-face and telephone interviews took place which provides the data, and context bias is not discussed. The range of posts held by the stakeholders interviewed is stated, but no further information is given about them, including the numbers interviewed. A number of quotes are presented, and while some of them are attributed to a particular post, e.g. care home manager, others are simply attributed to 'evaluation form'	The study does deal with end of life care for people with learning disabilities. It does not have a specific focus on providing this service for older people with learning disabilities, although the introduction does acknowledge that there is in England a growing number of people with learning disabilities who are aged over 50, and within this group an increasing number with life-limiting conditions associated with old age. **Has the study dealt appropriately with any ethical concerns?** No. The study does not make any statement about ethical clearance or ethical considerations. It does not seem to provide any information that could identify the participants or the people they work with. **Were service users involved in the study?** No.	**internal validity: −** **Overall assessment of external validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings.**
Is a qualitative approach appropriate? Appropriate. In line with the project's aim of exploring ways of improving end of life care for people with learning disabilities, interviewing practitioners seems an appropriate way of evaluating whether training that aimed to bring this about was effective in doing so. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology**? Somewhat defensible. The study researches a project that attempted to fill a shortfall in services by	or 'evaluation interview'. **Was the sampling carried out in an appropriate way?** Not sure. No description is given of how interviewees were selected for interview. There was an element of self-selection in attending the training which was the subject of the study, in that it was on offer to all 228 residential learning disability homes in the catchment area, but only 46 (20%) attended, although attendance was said to be high. Two of the 4 hospices in the catchment area withdrew from the project. It is to be presumed (although not stated) that interviewees were drawn from those who actually participated in the training, but how many were interviewed and how they were selected is	**Is there a clear focus on the guide-line topic?** Partly. The topic is end of life care and support for people with learning disabilities, many but not all of whom will be in the older age range. **Is the study population the same as at least 1 of the least one of the settings covered by the guideline?** Partly. The study deals with meeting end of life care and support needs of people with disabilities, many of whom will be older. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. The study relates to care and support at the end of life. **Are the views and experiences reported relevant to the guideline?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings.
designing a programme that trailed ways of filling that shortfall, and then investigated what worked and what didn't from the methods they used. As they wanted to find out people's views about what worked, a qualitative approach was an appropriate method, although the study does not provide a theoretical justification for its approach. The study takes place in a single, large geographic area, South West London, and is described as 'drawing on well-established links and networks across South West London, involving four hospices and 228 care homes' (p323). No theoretical justification is given for using this particular area, which sounds like a convenience sample. **How well was the data collection carried out?**	not stated. **Were the methods reliable?** Not sure. It is stated only that data was collected via face-to-face and telephone interviews with staff about the training, and a focus group about the link worker scheme. It is also stated that there were discussions with the steering group during this process. However, the study does not present information about how any of these interviews were conducted, nor about the role of the steering group in the process. **Are the data 'rich'?** Rich. The study does deal with the differing perspectives of palliative care staff and learning disability staff, as well as the viewpoint of	Yes. The views and experiences reported concern the effectiveness of staff training to improve end of life care for people with disabilities, and of a 'key worker' scheme for a practitioner to act as an 'information point' in their workplace about end of life care for people with disabilities. The views and experiences would be relevant generally to end of life care and support for older people with learning disabilities. **Does the study have a UK perspective?** Yes. South West London.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings.**
Not sure/inadequately reported. The project was evaluated using face-to-face and telephone interviews with a variety of stakeholders. No information is provided about the format of these interviews, e.g. how structured they were, whether there was a topic guide, whether there was thematic analysis of the data. The 'link worker' scheme was considered in a focus group that included 'over half' of the 10 practitioners who were recruited to that role, but no information is provided about how the focus group was conducted.	participants from both backgrounds in the link worker scheme. Quotes to illustrate these responses are provided. The study deals openly with successes and failures of the project. **Is the analysis reliable?** Not sure/not reported. No information at all is provided about how data from interviews was analysed. The evaluation of the project which forms the basis for this report is said to have been carried out by 'two independent evaluators' who were 'commissioned in the second year of the project' (p324) but no information is provided about them, including whether or not they have contributed any authorship of the report.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings.
	Are the findings convincing? Convincing. Despite the limitations in terms of information about the methodologies used for interviews and analysis, the findings do present as convincing, in that they are internally coherent, address the issue the project aimed to cover, and are open about the parts of the project that did not work so well. Reporting is clearly written, and includes appropriate illustrative quotes from the data. **Are the conclusions adequate?** Somewhat adequate. The key findings of the project (pasted elsewhere) are clear and coherent, and are clearly linked with the data presented in the study. However, the		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings.
	discussion about the findings then describes two areas of tension which are not strongly linked with the data presented in the study. These tensions are: 1. Specialist vs. generic work, which is said to be a tension affecting both staff groups. The researchers state that this is a tension that needs to be fully acknowledged before changes in practice can take place, but provide no data about how this tension manifests itself. 2. Minority access vs. mainstream services, in that 'within the project there was a view of people with ID as a minority wanting access to services, producing the tension of special support versus being in the mainstream' (p325). There was some reference to this earlier in the report, in that some palliative care providers		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings.
	were unwilling to attend the training because of low numbers of referrals of people with learning disabilities.		

4. **McCarron M, McCallion P, Fahey-McCarthy E et al. (2010) Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia. Journal of Policy and Practice in Intellectual Disabilities 7: 143–52**

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To understand carer concerns in supporting persons with intellectual disabilities and advanced dementia. **Methodology:** Qualitative study. Focus groups. **Is a qualitative approach appropriate?**	**Is the context clearly described?** Unclear. The characteristics of the participants and settings are not clearly defined – we only know how many participants were drawn from the learning disability services and how many from the specialist palliative care service. Data were only gathered via the focus groups with no individual interviews or observations.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was also received from the research ethics committees of all the participating service providers. Written consent was obtained from all of the participants.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Appropriate. The research question seeks to understand subjective experiences so a qualitative approach is appropriate. **Is the study clear in what it seeks to do?** Clear. Although the 'aim' of the study is only 1 sentence long, it is clear in its intention and the need for the study is supported by existing literature. **How defensible/rigorous is the research design/methodology**? Somewhat defensible. The design is appropriate to	There is no discussion of context bias. **Was the sampling carried out in an appropriate way?** Not sure. Although this was a convenience sample, the reason for this is not described and it is difficult to understand whether this is appropriate. **Were the methods reliable?** Somewhat reliable The methods investigate what they claim to but only one means of data collection was used, which means there was no opportunity for triangulation. The study might have benefitted from	**Were service users involved in the study?** No. Neither as co-researchers nor participants. **Is there a clear focus on the guideline topic?** Yes. EOLC for people with LD and dementia. **Is the study population the same as at least 1 of the least one of the settings covered by the guideline?** Partly. It is clear that participants work with people with learning disabilities and advanced dementia but the authors do not specifically state that people are 'older' (although this might be implied). **Does the study relate to at least 1 of the activities covered by the guideline?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
the research question, with a rationale given for using a qualitative approach: 'A descriptive qualitative design particularly suited to understanding the lived experience of the staff participants, the so-called emic (i.e., insider's) view of the participants (Sandelowski 2000), was adopted' (p144). A 'convenience volunteer sample' (p144) was used but there is no explanation or justification for this. **How well was the data collection carried out?** Somewhat appropriately The data collection methods are clearly described and appropriate data seem to have been collected to address the research question - although we are not provided with a topic guide and do not know what questions it included, we	observation work. **Are the data 'rich'?** Mixed. A good diversity of perspective and content has been explored with detail and depth well demonstrated. Responses are compared and contrasted across participants in the different settings. The key weakness is that it is not always clear whether the data relate to a learning disability or specialist palliative care setting or whether end of life care is being discussed or simply care/support for people with a learning disability and dementia. **Is the analysis reliable?** Somewhat reliable. Although not explicitly stated it	Yes. End of life care for people with learning disabilities. **Are the views and experiences reported relevant to the guideline?** Partly. The only reservation being that there is no explicit mention of the staff supporting older people with learning disabilities and dementia (although this may be inferred). **Does the study have a UK perspective?** No. Republic of Ireland.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
are simply told that it 'addressed the broad aims of the study' (p144). Data collection appears to have been systematic but there is no evidence that the 'extensive field notes and reflective journal' were systematic.	does appear that more than one researcher reviewed the transcripts, 'From reading, listening, and reflecting on the first three transcripts, the research team recognized ...' (p144) However there is no description of how differences in interpretation were resolved. Participants did not feedback on the transcripts but we are assured that, 'The collaborative nature of the focus group interviews enabled the researcher and the participants to come to a collective understanding of their experiences ...' (p144) **Are the findings convincing?** Convincing. The findings are clearly presented in themes and sub themes and they appear to be		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	internally coherent. Extracts from the original data are included but the main problem is that it is not always clear whether respondents are speaking from the perspective of having supported people with dementia and a learning disability at the end of life. **Are the conclusions adequate?** Adequate. The findings are certainly relevant to the aims of the study and there are clear links between data, interpretation and conclusions. The study and findings do enhance understanding of the research		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	topic although there are clear limitations in terms of transferability, about which the authors are clear.		

5. McLaughlin D, Barr O, McIlfatrick S et al. (2014b) Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study. Palliative Medicine 28: 1213–21

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To elicit the views of people with learning disabilities and family carers concerning palliative and end of life care. **Methodology:** Qualitative study. Focus groups, semi-structured interviews. **Qualitative component**	**Quant component** Phase 1 – survey using self-completed questionnaires with 8 quantitative questions and 4 open qualitative questions. **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** Partly.	**Does the study's research question match the review question?** Yes. To develop a best practice model to guide and promote partnership practice between specialists palliative care and intellectual disability services by gathering quantitative and qualitative data from practitioners from these services.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Phase 2: semi-structured interviews **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. To explore services' experience and perceptions of partnership practice, relating to providing end of life care for people with intellectual disability. **Is the process for analysing qualitative data relevant to address the research question?** Yes. Qualitative data obtained from open questions in Phase 1 and interviews in Phase 2 were individually transcribed and content analysed using a	A key informant was identified for each of the 66 services (purposive sampling). **Is the sample representative of the population under study?** Yes 'Participants were representative of disciplines across the multi-disciplinary team within hospital, hospice and community settings' (p1216). **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** Yes. Self-completed questionnaires. **Is there an acceptable response rate (60% or above)?** Yes.	**Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval obtained from the University Ethics Committee and Office for Research Ethics Committees in Northern Ireland. Consent forms signed by participants. **Were service users involved in the study?** Yes. Users as participants in the study. **Is there a clear focus on the guideline topic?** Yes. EOLC for people with ID. **Is the study population the same as at least 1 of the groups covered by the guideline?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
recognised framework. Total 22 transcripts were also independently analysed by 2 other members of the team and agreement on themes reached through discussion. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes. Interviews took place in participants' clinical settings, within a private dedicated area, and lasted between 40 and 60 min and audio-recorded with participants' permission. Field notes made. **Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants?**	In all, 47 services of the 66 services approached (71.2%) responded, including intellectual disability services (n=10: 56% response), specialist palliative care services (n=22: 79% response) and nursing homes designated for people with intellectual disability (n=15: 75% response)(p1215). **Mixed methods component** **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Yes. **Is the integration of qualitative and quantitative data (or results) relevant to**	Partly. Services and practitioners working in intellectual disability and palliative care services in primary and secondary care, who had provided end of life care to adults with intellectual disabilities. Not sure the age group of the people with ID (i.e. old or young people). **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community and service settings. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. EOLC for people with ID.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Unclear.	**address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Unclear.	**Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Ulster, NI and Dublin.	

6. Morton-Nance S, Schafer T (2012) End of life care for people with a learning disability. Nursing Standard 27: 40–7

Internal validity – approach and sample	Internal validity –- performance and analysis	External validity	Validity ratings
Study aim: To explore the experiences of district nurses caring for people with a learning	**Is the context clearly described?** Clear.	**Does the study's research question match the review question?** Partly.	**Overall assessment of internal validity:** +

Internal validity – approach and sample	**Internal validity — performance and analysis**	**External validity**	**Validity ratings**
disability at the end of their lives. **Methodology:** Qualitative study interviews with open-ended questions. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. To explore the experiences of learning disability and district nurses caring for people with a learning disability at the end of their lives. **How defensible/rigorous is the research design/methodology?**	Healthcare settings. **Was the sampling carried out in an appropriate way?** Appropriate. Purposive sampling. **Were the methods reliable?** Reliable. **Are the data 'rich'?** Mixed. Small sample, data based on 6 nurse participants. **Is the analysis reliable?** Reliable. Recorded interviews transcribed and transcripts were sent to participants for	This study explored the views and experiences practitioners caring for people with ID, but not clear if the people with ID the participants referred to in this study is old or young (no information on the age range). **Has the study dealt appropriately with any ethical concerns?** Yes. Formal ethical approval obtained; and participants completed a consent form to confirm their voluntary agreement to participate and for their interviews to be recorded. **Were service users involved in the study?**	**Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity — performance and analysis	External validity	Validity ratings
Defensible. Semi-structured qualitative study. **How well was the data collection carried out?** Appropriately. Interviews with open-ended questions.	verification. The data analysed using thematic analysis. **Are the findings convincing?** Somewhat convincing. Based on views of 6 nurses (small sample), but no information was given as to how old these people with ID were to whom the nurses provided EOLC. No demographics of the nurses were presented. **Are the conclusions adequate?** Somewhat adequate. Not clear if the practitioners were referring to old or young people with ID in this study as no information	Yes. As participants of the study. **Is there a clear focus on the guideline topic?** Partly. This study explored the views and experiences practitioners caring for people with ID, but not clear if the people with ID the participants referred to in this study is old or young (no information on the age range). **Is the study population the same as at least 1 of the groups covered by the guideline?**	

Internal validity – approach and sample	Internal validity — performance and analysis	External validity	Validity ratings
	given on the age range of the people with ID.	Partly. This study explored the views and experiences practitioners caring for people with ID, but not clear if the people with ID the participants referred to in this study is old or young (no information on the age range). **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Healthcare settings. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. EOLC for people with ID.	

Internal validity – approach and sample	Internal validity — performance and analysis	External validity	Validity ratings
		Are the views and experiences reported relevant to the guideline? Yes. **Does the study have a UK perspective?** Yes. Essex, UK.	

7. Ryan K, McEvoy J, Guerin S et al. (2010) An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. Palliative Medicine 24(6): 556–72

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To describe the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. **Methodology:** Mixed methods. Focus groups and a survey.	**Quant comp description** **Survey** **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** Unclear.	**Does the study's research question match the review question?** Yes. The views of staff about their confidence in providing end of life care to people with learning disabilities.	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
Qualitative comp 1: Focus groups. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** • Partly. The sampling is purposive, which is appropriate to the research question and lends itself to the collection of relevant and rich data. However it is unclear how many people were invited to participate and declined and their reasons for doing so. **Is the process for analysing qualitative data relevant to address the research question?** Yes.	The source of the sample is relevant to the population under study but there is no formal sampling frame – the approach is described as convenience sampling with managers distributing the questionnaire so it is entirely possible they performed a gate keeping role. **Is the sample representative of the population under study?** Partly. The authors state that the sample is drawn from learning disability and palliative care organisations which are representative of the spectrum of services provided in Ireland, although there are no data to support	**Has the study dealt appropriately with any ethical concerns?** Partly. The authors state that 'local research ethics approval' was obtained but no further details are given about the nature of the authority or board. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. EOLC for people with learning disabilities **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The EOLC for people with learning disabilities but not mention that this is specifically older people.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
The method of data collection is clear as is the form of the data (recorded and transcribed). The qualitative data analysis (framework analysis as developed by the National Centre for Social Research) addresses the question and appears to be systematic. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Partly. The sample – for both the survey and focus group participants – was drawn from the population of 1 Health Service Executive	this claim. They also provide a breakdown of the occupations and workplaces of the survey respondents and although we have no way of telling whether they are a representative sample, there is a there seems to be a large cross section of nursing, social care and education staff. **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** Partly. The authors do not provide the survey questionnaire for reference but they do explain that a panel of experts (n=7) assessed content validity and pilot tested the	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Learning disability and palliative care services. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. End of life care. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. They are relevant to people with learning disabilities but not specifically older people with learning disabilities. **Does the study have a UK perspective?** No. Republic of Ireland.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
area in Ireland. The area is served by 3 learning disability and 1 specialist palliative care organisation. According to the authors, the organisations are representative of the spectrum of services provided in Ireland. The authors describe the administration of the organisations and the range of people supported but no comparative data are provided which illustrate the extent of similarities with other health service executive areas or organisations in Ireland. We therefore do not have a clear view about the extent to which context might affect	instrument to ensure usability. There are no details about any changes made to the questionnaire after piloting. **Is there an acceptable response rate (60% or above)?** Yes. Of the 389 questionnaires which were distributed, 261 were returned (67%). **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Partly.		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
the data. **Is appropriate consideration given to how findings relate to researchers' influence; for example, through their interactions with participants?** No. The authors do not critically explain how findings relate to their perspective, role and interactions with participants. Any influence on focus group findings could have been mitigated by having more than one researcher interpreting data, identifying themes and discussing disagreements but there is no sign that this was incorporated in the methodology.	The rationale for integrating qualitative and quantitative methods is not described by the authors but the data produced do complement each other well with the focus group findings adding detail/explanations to some of the survey findings. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Unclear. Although the 2 sets of data complement each other there is no evidence that they were formally brought together at any point in the		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	analysis. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** No. There is no consideration of the limitations of the mixed methods approach – just about the limitations of the component parts (e.g. convenience sampling for the survey).		

8. Todd S. (2013) 'Being there': the experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 215–30

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To develop an understanding of how staff interpreted and responded to the death of a person with intellectual disability and the values that shaped their accounts of these. **Methodology:** Qualitative study. In-depth qualitative interviews. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. To explore staff perspectives on the deaths of a client with	**Is the context clearly described?** Clear. Residential care. **Was the sampling carried out in an appropriate way?** Appropriate. Opportunistic sampling: the staff who took part in the research was identified by service managers as potential participants. **Were the methods reliable?** Somewhat reliable. There was a considerable degree of external control in the selection of participants. **Are the data 'rich'?** Rich.	**Does the study's research question match the review question?** Partly. This study described the experiences of staff in dealing with matters of dying and death in services for people with ID. However, not clear if the people with ID the participants referred to in this study is old or young. **Has the study dealt appropriately with any ethical concerns?** Partly. Ethical approval or consent not reported. All named contacts agreed to participate, and 'assurances were given about their anonymity and the confidentiality of their views' (p216).	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
intellectual disability and the challenges such deaths posed for them. **How defensible/rigorous is the research design/methodology?** Defensible. **How well was the data collection carried out?** Appropriately. Individual semi-structured interviews.	**Is the analysis reliable?** Reliable. A qualitative thematic analysis of interview data, which were extracted, coded, collated and categorised into different themes. **Are the findings convincing?** Somewhat convincing [Info] Not clear if the practitioners were referring to old or young people with ID in this study as no information given on the age range of the people with ID **Are the conclusions adequate?** Somewhat adequate. Not clear if the practitioners were referring to old or	**Were service users involved in the study?** Yes. As participants of the study. **Is there a clear focus on the guideline topic?** Partly. This study described the experiences of staff in dealing with matters of dying and death in services for people with ID. However, not clear if the people with ID the participants referred to in this study is old or young. **Is the study population the same as at least 1 of the groups covered by the guideline?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
	young people with ID in this study as no information given on the age range of the people with ID.	Partly. Not clear if the people with ID the participants referred to in this study is old or young. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Residential service setting. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
		Yes. Wales, UK.	

9. **Tuffrey-Wijne I, Giatras N, Butler G et al. (2013) Developing guidelines for disclosure or non-disclosure of bad news around life-limiting illness and death to people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26: 231–42**

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Study aim: To examine stakeholders' preferences and reasons around disclosure and non-disclosure of bad news about life-limiting illness and death to people with intellectual disabilities, and to develop guidelines about these issues. **Methodology:** Qualitative study. Focus groups, interviews (telephone, face-to-face, one-	**Is the context clearly described?** Clear. **Was the sampling carried out in an appropriate way?** Appropriate. 'Participants were selected to represent a wide a range of views and experiences from as many relevant stakeholder groups as possible. They included stakeholder groups identified	**Does the study's research question match the review question?** Yes. To assess preferences and reasons around disclosure and non-disclosure of bad news of life limiting illness and death to people with intellectual disabilities. **Has the study dealt appropriately with any ethical concerns?**	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
to-one, online). **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. **How well was the data collection carried out?** Appropriately: 10 focus group meetings, 3 online focus groups, semi-	in the literature' (p232). 'Participants volunteered to take part following a call through internet forums and email groups, and through members of the Research Advisory Board contacting their own networks' (p232). **Were the methods reliable?** Reliable. **Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. Data tape-recorded and transcribed verbatim; field notes written immediately	Yes. Ethical approval obtained from the national NHS Research Ethics Committee. All participants given the contact details of the principal researcher, her qualifications, experiences and training. Staff members present to give support (such as having a break if needed) when people with ID interviewed. Team debriefing sessions. Ethical aspects also scrutinised and supported by a research advisory board. **Were service users involved in the study?** Yes. As participants. Some notes were sent to the interviewees	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
structured interviews (face-to-face or by telephone for family carers and health professionals). 1. Focus groups with people with ID met 4 times, facilitated by the principal researcher and 2 co-researchers who had intellectual disabilities themselves with a fourth researcher taking notes, using a wide range of data collection methods, including storytelling, role play and, at the last session, nominal group technique to rank a range of statements that had emerged during the earlier group sessions. 2. All other face-to-face focus groups met once, facilitated by the principal researcher, supported by other members of the research team. 3.	after telephone interview. Data were triangulated between different stakeholder groups and with the literature. All data were analysed using content analysis (grounded theory). Interview schedules adapted to reflect emerging themes. Initial findings were discussed among researchers and presented to the research advisory board for feedback. Qualitative data management and analysis supported by NVivo software. **Are the findings convincing?**	for verification, correction and additional comments. **Is there a clear focus on the guideline topic?** Yes. Issues relating to EOLC for people with ID. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Practitioners and carers. Not clear if the people with ID referred to by the practitioners were old or young (source of qualitative data from quotation notes suggested people with ID referred to in this study	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Validity ratings
Online focus groups lasted between 3 and 5 weeks, with the facilitator posing 1 main question/week and participants' emailed responses sent to the whole group, so that participants could respond to each other's contributions.	Convincing. **Are the conclusions adequate?** Adequate.	ranged from 24 to 49 years). **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. EOLC for people with ID. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Validity ratings**
		London and Cornwall, also across England.	

Review question 9. Care and support in health settings

a) What are the views and experiences of older people with learning disabilities and their carers about care and support in health settings?

b) What are the views and experiences of health, social care and other practitioners about the care and support of older people with learning disabilities in health settings?

Review question 9 – findings tables – the views and experiences answering Qa and Qb

1.

1. Lalor A, Redmond R (2009) Breast screening for post-menopausal women. Learning Disability Practice 12: 28–33

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'The aim of this study was to identify practices in relation to breast surveillance for post-menopausal women with learning disabilities, and to identify challenges that affect their attendance at mammography screening services. The practices related to clinical breast examinations were also explored' (pp29–30). **Methodology:** Survey. **Country:** Republic of Ireland.	**Participants:** Service users and their families, partners and carers. Information was gathered by proxy from primary care staff. **Sample size:** Total 90 individuals were interviewed. **Outcomes measured:** Satisfaction with services. The study describes how many women received breast screening notifications, how many attended appointments and the reasons why some did not complete the screening procedure.	The study found that 2/3 of the 90 participants had successfully completed a mammography. This figure is lower than the national average; 14 of the same had not received an invitation to a mammography, because they were not included on the database. Of those who attended, more than 3/4 completed the mammography. Those that completed are all classed as having a 'mild' disability. Those with a 'moderate' disability attended the appointment and two thirds completed the procedure. This with greater levels of disability had more issues with attendance and competition. Most of those who did not finish their mammography, did not because of 'a lack of cooperation' (p31). Other reasons were: 'fear of the equipment, agitation, discomfort, dislike of physical touch, challenging behaviour, distress and a fear of the staff' (p31). Communication difficulties were also a reason for non-completion. All those who did not complete the procedure had some level of communication difficulties. A quarter of the participants received clinical breast examinations. And of those who did not have a mammography, a	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Source of funding: Not reported.	**Follow-up:** No follow-up. **Costs?** No.	quarter had clinical examinations. Less than a fifth of participants had both types of test and of those who did not attend mammography appointments, only a few were offered clinical examinations. Some relatives declined the mammography on behalf of their relatives, and others refused further attempt to complete the procedure if it had been unsuccessful once.	

2. **Truesdale-Kennedy M, Taggart L, McIlfatrick S (2011) Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. Journal of Advanced Nursing 67: 1294–304**

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The aim of the study was to describe understanding of breast cancer and experiences of breast mammography among women with an intellectual	**Participants:** Service users and their families, partners and carers. **Sample size:** Total 19.	**Women's understanding about breast cancer** Knowledge – The women had heard of cancer and the most common types but they were unable to describe what it is. They did agree that breast cancer is a 'lump' in the breast. Signs and symptoms – There was limited knowledge about signs and symptoms, with only a small number able to name 'lump', 'spots' or a 'red area'. Risk and protective factors – The women cited lifestyle factors as the main	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
disability. **Methodology:** Qualitative study. Focus groups. **Country:** UK. Northern Ireland. **Source of funding:** Voluntary/charity. Breast Cancer Campaign, London.		causes of cancer (drinking, smoking, diet, lack of exercise). Much probing was needed for the women to cite the same factors as being protective (e.g. an improvement in lifestyle). Sources of awareness – Most women had heard about breast cancer either though TV programmes or receiving invitations for breast mammography. They were only able to name 2 organisations that give support and info about breast cancer (Cancer Research and Marie Curie). It was generally said that 'the level of knowledge about breast awareness, breast cancer and prevention among the women was mainly limited'. A small number of women knew about cancer through having a family member with the disease. Only a few had ever attended a health promotion or education class where they'd been shown how to examine their breasts. **Women's experiences of breast mammography** Lack of understanding – A lack of understanding about the breast screening process was linked with stress and anxiety. Less stress and anxiety were experienced when the women had the whole process of the examination explained to them before hand by a family carer or nursing staff. 'If they explained it more to you for women with	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		learning difficulties it wouldn't be so bad ...' (p1298). Fear, pain and discomfort – Fear was attributed to the unfamiliar surroundings, especially the mammography equipment. 'Oh if you see the machine its very big oooh! It's a big brut of a thing oh my God' (FG4) (p1299). Most of the women who'd experienced a mammography described it as painful, uncomfortable or sore. Positive experience – Despite fears beforehand and pain/discomfort during the mammogram, afterwards the women said it wasn't as bad as they thought it'd be. 'I didn't mind at all. The quicker you got it done the better and that was it. The sore goes away again' (FG3) (p1299). Support from nurses and carers – Some of the women reported how friendly and chirpy the staff were at the breast screening unit. This helped alleviate fear. It was clear that the process was easier if a carer, staff member or someone the woman knew was present during screening. **Perceived barriers to attendance** In fact the 2 main barriers were probably 1 fear and 2 embarrassment– and having to remove their clothing	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		(although some were fine with this and thought it perfectly natural). **Perceived solutions to barriers** Although breast mammography clearly had the potential to cause distress, overall the women recognised the importance of screening. The women thought the key solutions to encourage others to access breast screening were informational and emotional support. Example responses about information: 'A wee story or pages to give … people like us would give people that weren't able or worried or scared to go' (FG2) (1299) and about support 'Talk to them, try to explain to the ones who can understand that it's for their own health reasons and it's not as scary or if some of their carers or whoever explained what it was going to be' (FG3) (p1299). The women also suggested 'user friendly', accessible (big writing, easy to understand) leaflets be made available to explain breast awareness and cancer prevention. Author's observation: 'Adequate information and support and reassurance from others including breast screening staff were seen to reduce the adverse effects of breast mammography.'	

3. Webber R, Bowers B, Bigby C (2010) Hospital experiences of older people with intellectual disability: responses of group home staff and family members. Journal of Intellectual and Developmental Disability 35: 155–64

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'This paper uses a subset of data from a larger, longitudinal study that was designed to explore the pathways into residential aged care (nursing homes) for people ageing with an intellectual disability who are living in group homes. This paper focuses on perspectives of group home staff and family members concerning hospital experiences of group home	**Participants:** Service users and their families, partners and carers – family members. Professionals/practitioners – group home supervisors. **Sample size:** Interviews with 55 people: 17 family members, 16 house supervisors, 11 accommodation programme managers, 11 staff. These people were clustered around 17 residents with intellectual difficulties.	General views findings, thematically grouped into themes relating to the experience of hospitalisation. Twelve of the 17 residents at the centre of the study went into hospital once or more during the 2.5 period of the study. And all but one had been hospitalised in the last 5-year period prior to the study. Carers' perceptions of hospital experiences. Staff attitudes: carers said that they felt that staff were 'generally uncomfortable with or indifferent to the needs of people with ID' (p157) 'they don't wash them. They don't even brush their hair or clean their teeth. They don't put their glasses on them and they, it's just like it's too hard, go away' (aged care staff) (p157). Carers felt that staff did not acknowledge the needs of older people with learning difficulties and were not sensitive to the needs. In some cases it was felt that additional treatment was not necessary based on the person's disability: 'We had a guy here who recently broke	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
residents, including the strategies they used to support residents while in hospital' (p156). **Methodology:** Qualitative study. Qualitative interviews. **Country:** Australia. **Source of funding:** Government. Australian Research Council.	**Outcomes measured:** Service user-related outcomes – The study explores perceptions of hospitalisations for older people with learning difficulties. **Follow-up:** Participants were interviewed 2–4 times over a 2.5-year period. **Costs?** No.	his foot … I was told he was deemed unsuitable for rehabilitation and I mean I cringed … that was so far below anything that was a reasonable expectation' (disability staff) (p157). Knowledge about learning difficulties. There was a perceived issue with hospital staff having inadequate experience or training in learning difficulties. 'I don't think they have an understanding of anything in the disability field, I don't think they're trained or given any information …' (disability staff) (p157). Some of the older people needed help with self-care, carers commented that the hospital staff were not responsive to these needs. Family and professional carers had concerns about eating and toileting. There were comments that food was left uneaten and this went unchallenged by staff. 'When we visited him in hospital on his table was a bottle, a sandwich, unopened because he probably couldn't do it with the one hand' (family) (p158). Another concern was those who were continent but were not taken to the toilet, instead being given incontinence	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		pads, or people were not taken to the toilet promptly following an accident: '… and they hadn't even changed him, he'd had an accident and even when he came back from hospital, his pyjamas were all dirty' (family) (p158). Interviewees also criticised hospital staffs lack of sensitivity to people with learning difficulties need for predictable routine and also regular pain management. Both of which could lead to disruptive behaviour. Hospital Staff Communication. A key concern among carers was a lack of, or inappropriate communication from hospital staff. Either talking to patients about ideas that they could not understand, or failing to describe treatment or diagnosis to them when they did have capacity to understand. 'She was really upset when I went in this particular afternoon; I said ''What's the matter Betty?'' And she said, ''The doctor he talks over of the top of me and I don't understand and he wouldn't answer my questions,'' so they'd had obviously a conversation about her ovarian cancer and modalities of treatment over the top of her. (Aged care staff)' (p.158) Another communication issue was that staff did not take	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		the time to interact with patients. This led to misunderstanding, challenging behaviour and patients not getting the opportunity to ask for what they needed. 'Many residents with ID were unable to tell hospital staff when they needed something, whether it was for relief from pain, a trip to the toilet, or simply to unwrap a sandwich' (p158). Carers said that staff misinterpreted the needs of older people who could not speak. And did not listen to the advice of the carers who knew them well. As such, hospital staff were not aware of treatment preferences and fears and phobias, this led to difficulties with treatment and challenging behaviour from the patient. Challenging behaviour was felt to be the result of patients not understanding what was happening and having to undergo unfamiliar procedures. '… she doesn't like being there, because people hurt her there and she doesn't understand why they're doing it, and you can't explain it to her, she doesn't have any concept of it. She's only about two or three, intellectually' (family) (p159). Challenging behaviour was thought to have knock-on effects such as early discharge, because it was felt group home environments were better to care for these patients	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		with learning difficulties, even if staff did not have medical knowledge or the capacity to implement discharge plans. 'There were several reports of group home staff being pressured to take the resident home despite their inability to provide appropriate and 24-hour care. Refusal to accept a patient who needed ongoing care sometimes resulted in a referral to aged care. Group home staff often viewed this as a threat' (p159). Positive experiences – There were times when experiences were positive. Staff allowed extra time to accommodate the needs of older people with learning difficulties. Staff adapted to the non-verbal need of patients. Clear discharge policies allowed for additional support in the group home. 'She [dental specialist] said if it is uncomfortable and it hurts put your hand up … she was so patient' (family). (p159). 'We were well catered for [eye specialist] all the way through, everybody was very, very helpful from the anaesthetist right through so we got on very well' (family) (p160). Positive experience all occurred in hospitals that had clear policy and guidance around caring for this group. Carer strategies – The interviews with carers revealed that they had developed strategies to minimise the stress of	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		hospitalisation. These strategies were: Being present – Spending time on the ward was felt to minimise stress, provide support and ensure appropriate treatment. 'Well my husband and I watched her for the week, and there was somebody with her all the time … to get it done properly without any complications and things and it did work' (family) (p160). Some carers struggle to be present as much as they were like, but it was thought by some that they could assist in making medical procedures go more smoothly. 'The nurse came and she tried to take blood from him and because he wriggled his hand, she said come here quick and help me. So I went around to help … and I held him so she could do it' (family) (p160). Carers were able to keep older people engaged while in hospital, explain procedures and work with staff to make the hospital less frightening. They could also help contain challenging behaviour. Information packages. Carers developed written materials about the individual to help hospital staff understand communication, preferences and medications. 'We tell them how the person communicates, we tell them any ongoing health needs, we tell them you know their likes or dislikes. How they like to	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		be toileted, how they eat, if they eat, we've had a man with a peg feed go into hospital and the nurse tried to stuff a banana down his throat' (disability staff) (p160). Carers did say that they did not think that hospital staff read the information, and so they adopted measures like sticking key information to the wall and hanging up booklets to try and get information read. 'We actually even did up a book that we hung on her bed which said, "This is what I like to do, this is what I like, if this happens, this is what you can do to help me out"' (disability staff) (p160). Carers commented that a lack of willingness among hospital staff to read the information contributed to distress of residents and misunderstandings. Partnering with hospital staff – Some carers worked to develop partnering relationships with hospital staff in order to communicate likes and dislikes and potential issues when carrying out medical procedures and helping to complete tasks. 'The [eye doctor] was relying on me to get him to put his head up here, get him to do this, get him to do that, and like she had to put drops in his eyes first … She is saying, "Well you open his eyes and I will put the drops in."' He is going "No, no, no I want …" He calls me Chook. "Chook puts the drops in," he says. I said, "Okay	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		Chook will put the drops in" (disability staff)' (p161). Both group home staff and family carers were called upon by hospital staff to help with the patient and this could be a mutually beneficial relationship: 'The intention and ability of staff involved in the care of the residents to share information and to cooperate with and respect each other's skills and knowledge was seen as essential for the reduction in stress of a resident during a hospital stay. Partnering required both giving and receiving information' (p161). Carers commented that being involved in decision-making was particularly important. Carers stressed that if they were made aware of issues and procedures in advance they could help. Carers described negative experience where decisions were made without their input. In these instances, they could feel 'railroaded' by hospital staff (p161). Advocacy – Advocating was felt to be a tactic to avoid problems like premature discharge. Carer described heated exchanges and sometimes, a failure to achieve the desired result. In general the problems experiences by older people with Learning difficulties took their toll on family carers and care staff. Staff had to stay for extended	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		periods in the hospital, and sometimes cover had to be arranged in the group home. Family carers struggle to provide the support they felt was needed due to work commitments etc.	

4. Whitehead LC, Trip HT, Hale LA et al. (2016) Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers. Journal of intellectual disability 60: 389-397

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: 'This paper explores how people with intellectual disabilities (ID) and their support workers experience and practice autonomy in relation to the	**Participants:** Service users and their families, partners and carers: 14 service users were interviewed. Professionals/practitioners: 17 practitioners were interviewed. **Sample size:** Total 31 interviewees: 14	**Narrative findings – qualitative and views and experiences data** The data from the interview transcriptions generated 3 main themes, all relating to the way that the people with learning disabilities negotiated autonomy in their diabetes management with their support workers. The themes were 'negotiated autonomy day to day, the renegotiation of autonomy during times of transition and negotiating increased autonomy' (p392). In terms of day to day autonomy, participants with ID were almost all responsible for initiating their own blood glucose	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
management of diabetes' (p389). **Methodology** Qualitative study. Semi-structured interviews. **Country** Not UK. Study conducted in New Zealand. Researchers are from academic bodies in New Zealand and Australia. **Source of funding** Not reported.	who have learning disabilities (described as intellectual disabilities or ID in this study) and 17 who are support workers. **Outcomes measured** Not applicable. **Follow-up** Not applicable. **Costs** No cost information provided.	monitoring and testing themselves independently, with half of the participants with ID completing own blood glucose monitoring 3–4 times a day, showing that they knew how to carry out the tests, and were aware what readings would be low or high. Most participants taking medication in the form of tablets managed this themselves, getting support from time to time. All but one taking insulin administered this themselves, with support worker or community nurse oversight. 'The process of medication administration, including insulin and additional medication based on blood glucose readings was described by all as a negotiated process, with participants working together to follow the prescribed regime as safely as possible without undermining the participant' (p392). Day to day, managing diets was seen as the most challenging area, with participants open that they found it difficult to avoid sweet and fatty foods. Support workers discussed strategies on dietary choices with people with learning disabilities, reminded, encouraged and supported them to make healthy eating choices when they were out shopping, describing the process as an ongoing one of negotiation and support rather than being a contest: 'I think it's still an on-going process, like we still find pamphlets and things and I think Dora is still learning about the right things' (support worker, p392). 'All participants described the support worker role as one of facilitating choices and enabling access to healthy food' (p392). It was seen as	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		important for a trusting relationship to be built between the person with the learning disability and their main support worker, so there could be open and honest communication by support workers about blood glucose levels and by people with learning disabilities about symptoms they were experiencing. Relationships that did not work well are described as being 'underpinned by a didactic approach to diabetes management' (p393), e.g. 1 participant stated they were avoiding diabetes clinic because they felt pressured about putting on weight. Where it was working well 'Recognising the person with ID's right to make their own decisions and live their own lives was described as underpinning relationships' (p393). This has involved discussion with the person with ID about the risks and benefits of the choices they make. In terms of renegotiating autonomy at times of transition, the transitions referred to were exemplified as ill health, or changes to treatment programme or home circumstances. The participants with ID were still expected to manage their diabetes as independently as possible, e.g. if they required a higher level of blood glucose testing for a period they would still be responsible for tests, although they might be provided with more oversight – e.g. when 1 participant with ID wanted to improve her health through diet and exercise her support worker stated 'It used to be 'oh well, we just make sure she's	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		safe', whereas now there's a lot more sort of being able to support Joyce to get so healthy and thin, she's so much more proactive about it herself…' (p394). In terms of renegotiating autonomy in relation to goals, this was stated to refer to goals around increasing independence for daily living. Examples are provided of discussions with the participants with ID about goals they wanted to achieve, and through the discussions steps being identified to help them get there, e.g. people with ID who wanted to live independently were assisted with taking steps that would make this possible, such as being more confident about administering insulin independently, or changing work environment away from a fast food outlet, so there would be less temptation to follow an unhealthy diet. The researchers found that 'management of diabetes was characterised by the negotiation of autonomy between the participant with ID and their support worker' (p394). There was a range of support to assist them with being as independent as possible in managing their condition. 'The process of negotiation was fluid, responding to situational events such as changes in health or medication regime, and during these times, autonomy was renegotiated' (p394).	

Review question 9 – Findings tables – the views and experiences answering Qa only

1. Fender A, Marsden L, Starr JM (2007) What do older adults with Down's syndrome want from their doctor? A preliminary report. British Journal of Learning Disabilities 35: 19–22

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: To find out what OPLD want from their doctor, including what it is OK for the doctor to do and to ask. Also to involve OPLD in the research process. **Methodology:** Qualitative study. **Country:** UK. Scotland. **Source of funding:** Voluntary/Charity - The Health Foundation.	**Participants:** Service users and their families, partners and carers. **Sample size:** Total 5. **Costs?** No.	The group talked about 'how do we know when a person is not feeling well if they can't/won't tell you?' They made 4 suggestions. 1. Ask other people (ask whether something has happened to the person, e.g. whether they're staying at home more, not wanting to go out or whether they're not doing things they normally do or whether they're crying a lot and blaming themselves). 2. Look at the person (check whether they seem happy or are moving around as usual). 3. Listen to the person (to see if they're in pain or are angry). 4. Weigh the person. The following lists show what the groups thought about. Questions the doctor might ask Good things to ask: How old are you? What kind of house do you live in? Who helps you? Have you got any hobbies or interests? How is your breathing, tummy etc.? OK things to ask: Have you got any illnesses? Do you	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		take any tablets? Can ask people but with care: Do you smoke? How are you sleeping? How many meals do you eat each day? Can you get on and off a bus? How big is your bedroom? Have you got another outdoor coat at home? Things the doctor should not ask people: How many pairs of shoes have you got? Can you cut your own toenails? The group discussed thing doctors might do to them and agreed some things were good and some were OK: Very good things to do: Check blood pressure; Check peak flow (how fast you can breathe out); Check skin elasticity and condition; Check if right or left handed, footed, eyed etc. Good things to do: Weigh; Measure height, demi-span (length from middle of chest to fingers); Measure chest, waist and hips; Check if can balance on one leg; Check how many times can stand up and sit down again in 20 secs; Check strength of grip. OK things to do: Wear a white coat.	

Review question 9 – findings tables – the views and experiences answering Qb only

1. Northway R, Holland-Hart D, Jenkins R (2016) Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff. Health and social care in the community 25: 923–931

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
Study aim: The introduction to the study states that 'while residential care staff play an important role in meeting the health needs of those they support, this is not always formally recognised as part of their role' (Crimes 2014). 'Little is known about how such staff respond to age-related health changes among those they support (Webber et al. 2010a) and this	**Participants:** Professionals/practitioners. House managers of supported living services for people with intellectual disabilities. **Sample size:** Total 14. **Outcomes measured:** Not applicable. **Follow-up:** Not applicable. **Costs:** The issue of costs is not dealt with.	**Narrative findings – qualitative and views and experiences data:** After thematic analysis, 5 major themes emerged from the interview data, 3 of which are reported in this study – the others are reported separately. There are several sub themes within each major theme. The first major theme was 'meeting health needs'. The health conditions most commonly reported were 'epilepsy, diabetes, infections, dementia and other mental health issues. Other age-related health problems reported included cardiac problems, sensory loss and reduced mobility (in some instances requiring the use of a wheelchair)' (p4). Residential staff's roles involved recognising, monitoring and meeting health needs, including the promotion of healthy lifestyles. Most interviewees (10/14) stated that their tenants were supported to have annual health checks, although this was resisted by some GPs, particularly where the GP had to visit to carry out the check, or in hospitals if staff are not trained to work with people with learning disabilities. Problems arose when hospital staff expected that residential staff would stay with a tenant who had been admitted, although this was not seen by the managers as being part of their role once the	**Overall assessment of internal validity:** + **Overall assessment of external validity:** ++

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
study seeks to begin to address this gap in knowledge' (p2). **Methodology:** Qualitative study. Semi-structured individual interviews. **Country:** UK. Wales. **Source of funding** Not reported.		person had been settled, due to difficulties with insurance cover and funding not covering 24-hour individual support. Problems with hospitals also arose when there was not enough planning around patients being discharged. Record-keeping was seen as playing an important role in ensuring that health-related information was passed on between staff. A health passport or 'traffic light' system to highlight which information should go with a tenant being admitted to hospital had been introduced, but was reported as not always working effectively as information was not always passed on as required. Some interviewees mentioned the part played by medication in their role of monitoring and maintaining the health of the tenants. There were concerns about side effects of medication, interaction between medications, and the possibility that the use of medications could mask other conditions, e.g. dementia. The second major theme was 'the consequences of ageing'. It was noted that tenants could need more support due to changes associated with ageing, e.g. becoming more frail, weak, forgetful and generally slower. There was a general willingness to support ageing in place, keeping tenants in their homes. In part this was due to the difficulties of finding suitable alternative places for older people with learning disabilities. However, because of the additional support and finance needed to keep a tenant in place, as well as the	

Research aims	PICO (population, intervention, comparison, outcomes)	Findings	Overall validity rating
		unsuitability of the physical environment, sometimes it would be necessary for them to move. Adaptations could sometimes be made to the physical environment however. They could end up by providing end of life care to the tenants. An instance was given where a tenant dying from cancer was refused a place in a hospice because of his intellectual disability. The third major theme was 'relationships'. It was seen as important for staff and health professionals working with the person with an intellectual disability to know the person, so as to recognise changes in health status, and in order to be able to work with them effectively. However, within this it was important to respect organisational policies relating to the boundaries of these relationships, which were seen as protecting staff and tenants. Positive, sustained relationships were seen as having positive effects, although staff turnover could make this difficult. One interviewee described difficulties with interprofessional relationships with healthcare staff: 'I actually think … because we have not got the labels on us of nurses or health professionals that (they think) we don't really know what we are talking about …They will take no notice of us until we get a health professional in to help us' (p6).	

Review question 9 – critical appraisal tables – the views and experiences answering Qa and Qb

1. Lalor A, Redmond R (2009) Breast screening for post-menopausal women. Learning Disability Practice 12: 28–33

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'The aim of this study was to identify practices in relation to breast surveillance for post-menopausal women with learning disabilities, and to identify challenges that affect their attendance at mammography screening services. The practices related to clinical breast examinations were also explored' (p.29–30). **Methodology:** Survey. **Research design clearly specified and appropriate?** Partly. The questionnaire does not seem to elicit a great deal of rich data. **Objectives of the study clearly stated?** Yes.	**Clear description of context?** Yes. **Survey population and sample frame clearly described?** Yes. **Describes what was measured, how it was measured and the results?** Partly. We are told broadly the methods and the types of information sought by the questionnaire but not much about the analysis of results. **Measurements valid?** Unclear. **Measurements reliable?** Unclear. **Basic data adequately described?** Yes. The data is presented in a table and also in narrative. **Results presented clearly, objectively and in enough detail for readers to make**	**Does the study's research question match the review question?** Partly. The views focus is somewhat missing from this paper, the aim is more to gain general sense of the reasons for non-compliance than any rich data. **Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** Yes. Surveys	**Overall assessment of internal validity:** + **Overall assessment of external validity:** +

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	personal judgements? Partly. The findings are compared to the findings of other literature in the discussion, but it is unclear how systematically this literature has been sought, and it's sometimes confusing as to which findings are from this study. **Results internally consistent?** Yes. **Clear description of data collection methods and analysis?** Partly. SPSS was used for analysis and content analysis was conducted. No open questions were asked but more information could be recorded. **Methods appropriate for the data?** Partly. **Results can be generalised?** No. The sample is small, authors acknowledge this as a limitation. Findings are not representative. **Conclusions justified?** Partly.	were completed by proxy. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Residential care. **Are the views and experiences reported relevant to the guideline?** Partly. Survey findings are not presented in	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
		great detail. **Does the study have a UK perspective?** No. Republic of Ireland.	

2. **Truesdale-Kennedy M, Taggart L, McIlfatrick S (2011) Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. Journal of Advanced Nursing 67: 1294–304**

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: The aim of the study was to describe understanding of breast cancer and experiences of breast mammography among women with an intellectual disability. **Methodology:** Qualitative study. Focus groups. **Is a qualitative approach appropriate?** Appropriate. Because the research question seeks to illuminate subjective experiences/meanings.	**How well was the data collection carried out?** Appropriately. Data collection methods are clearly described and the appropriate data appear to have been collected to address the research question. Data collection and record keeping appear to have been systematic. **Is the context clearly described?** Unclear. Data were gathered via only one method – focus groups. No interviews or observations. The characteristics of the	**Does the study's research question match the review question?** Partly. Because although the focus is on health experiences, it is not specifically examined from an older people's perspective. **Has the study dealt**	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
Is the study clear in what it seeks to do? Clear. The background, aims and design of the study are all clearly described. **How defensible/rigorous is the research design/methodology?** Defensible. The design is certainly appropriate to the research question and the rationale for using a qualitative approach is provided, 'Given the exploratory nature of this sensitive topic and the dearth of information from the service user's perspective, a qualitative approach using focus groups was chosen.' (p1295). There are also clear accounts of the rationale/justification for the sampling (purposeful), data collection (focus groups, data recorded) and data analysis (thematic content analysis of transcribed findings).	participants are not clearly defined – we only the age of the women and the fact that they have attended for breast screening in the previous 12 months. **Was the sampling carried out in an appropriate way?** Appropriate. The rationale for purposeful sampling was clear. It is unlikely that recruitment affected what the respondents said in the focus groups. However, it is not entirely clear whether residential facility managers contacted all women who had experience of mammograms or whether they specifically targeted certain women who may have been expected to provide particular views. **Were the methods reliable?** Somewhat reliable. The data was only collected via 1 method (focus groups) but the authors do discuss their findings alongside other studies. **Are the data 'rich'?** Mixed. The data is not poor – supporting quotes are provided. However, there is not a huge amount of	**appropriately with any ethical concerns?** Yes. The Office for Research Ethics Committee in Northern Ireland (ORECNI) granted Research Ethics Committee approval for the study and permission was obtained from the 3 Health and Social Care Trusts in Northern Ireland. The women's capacity to consent was assessed jointly by the research team and the residential manager, who knew the women well on the initial meeting: it was deemed by both parties that each woman had the full	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	detail or description of people's experiences. **Is the analysis reliable?** Reliable. The research team referred back to original transcripts in order to ensure that the context of each woman's contribution was maintained. Peer debriefing enhanced that credibility of the data by allowing the second author to check the themes for accuracy; agreement was sought on any disparities before finalising the labels of the themes and sub themes. **Are the findings convincing?** Convincing. The findings are clearly presented under 4 main themes and seem to be internally coherent. Extracts from the original data are included and referenced. **Are the conclusions adequate?** Adequate. The findings are certainly relevant to the aims of the study There are clear links between data, interpretation and conclusions and the conclusions are plausible and coherent. Alternative	capacity to give consent. Informed consent was reassessed throughout the focus group. **Were service users involved in the study?** Yes. But not extensively. Some of the women checked the focus group transcriptions for verification. **Is there a clear focus on the guideline topic?** Yes. Although there is not a clear focus on older people's issues. **Is the study population the same as at least 1 of the**	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	explanations have been explored e.g. that in fact the knowledge and understanding of breast cancer among women with learning disabilities may not be inferior to the understanding among the general population. Authors discuss the study limitations – namely the small sample size, which affects the transferability of findings.	**groups covered by the guideline?** Partly. Most of the participants were aged 50–69 and 3 were 31–50 years. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Health care experiences (breast screening). **Are the views and experiences reported relevant to the guideline?** Partly. They are views and	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
		experiences of women with LD and although the majority are aged 50–69 years, there's no specific reference to or description of them being 'older' or 'old'. **Does the study have a UK perspective?** Yes. Northern Ireland.	

3. Webber R, Bowers B, Bigby C (2010) Hospital experiences of older people with intellectual disability: responses of group home staff and family members. Journal of Intellectual and Developmental Disability 35: 155–64

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'This paper uses a subset of data from a larger, longitudinal study that was designed to explore the pathways into residential aged care (nursing homes) for people ageing with an intellectual disability who are living in	**How well was the data collection carried out?** Appropriately. Interviews were carefully designed and adapted to suit follow up interviews. Modes of analysis and coding are described and appropriate.	**Does the study's research question match the review question?** Yes. Related clearly to the views and experiences	**Overall assessment of internal validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
group homes. This paper focuses on perspectives of group home staff and family members concerning hospital experiences of group home residents, including the strategies they used to support residents while in hospital' (p156). **Methodology:** Qualitative study. Qualitative interviews. **Is a qualitative approach appropriate?** Appropriate. Appropriate for gathering views and experiences. The study used open questioning and a non-directive style. Initial interviews were carried out in person, follow-ups over the phone. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. Methods and modes of analysis are clearly described. Sampling is justified and attrition rate is given.	**Is the context clearly described?** Not sure. We do not get that much detail about the older people whom the interviewees are clustered around. We do not know about the severity of their conditions, their exact ages or genders. We also do not know how representative this group our in the context of the area. **Was the sampling carried out in an appropriate way?** Appropriate. The sample was found in 13 group homes in Victoria. Sampling was purposive, which is appropriate for this study. **Were the methods reliable?** Reliable. **Are the data 'rich'?** Rich. A good deal of quotations are provided, we gain testimony from family carers and staff carers and the themes are explored in detail. **Is the analysis reliable?** Reliable. The process of transcription, coding and analysis are well described. It is not clear how many researchers coded each	of older people with learning difficulties in a health setting. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** No, staff and family members who worked with 17 individuals were interviewed. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes.	**Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	interview script but analysis was collaborative. There is also description of how interviews were developed based on the first round. **Are the findings convincing?** Convincing. Themes are coherent and responsive to the research question. Lots of original data is used to support conclusions. **Are the conclusions adequate?** Somewhat adequate. The study links itself to broader literature and acknowledges its limitations as small study. But limitations are not addressed. The study does provide a valuable insight into the health setting experiences of older people with learning difficulties.	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No. Australian perspective.	

4.Whitehead LC, Trip HT, Hale LA et al. (2016) Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers. Journal of intellectual disability research. 60: 389–397

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: 'This paper explores how people with intellectual disabilities (ID) and their support workers experience and practice autonomy in relation to the management of diabetes' (p389). **Methodology:** Qualitative study. Semi-structured interviews. **Is a qualitative approach appropriate?** Appropriate. The question deals with the experiences of	**How well was the data collection carried out?** Appropriately. The study notes that 'semi-structured interviews were conducted by one member of the research team (HT), a nurse with over 20 years of clinical experience in the field of ID. The interview covered knowledge about diabetes, the type of support provided in terms of routines, exercise, meals and responsiveness to changes in blood sugar levels. [...] The participant with ID's support worker was present as requested; however, the interviews were run separately with each participant rather than jointly' (p391).	**Does the study's research question match the review question?** Yes. The study is closely aligned with the review question, as it does present the experiences of people with learning disabilities and their support workers in the way they manage health, albeit it only deals with 1 particular health issue, which is diabetes. **Has the study dealt appropriately with any ethical concerns?** Yes. 'Ethical approval was obtained through the Health and Disability Ethics Committee, Ministry of Health, New Zealand (number URA/09/04/029). To facilitate the process of informed consent, a face to face meeting was held between the researcher and the person with ID and their support worker to discuss the study. If all were willing to proceed, a date was made for the respective interviews, and consent was confirmed prior to commencing the interview' (p391). Researchers state that they obtained participants' consent before accessing their files and medical information. **Were service users involved in the study?** No. Only as participants being interviewed, not involved in design, carrying out interviews or analysis.	**Overall assessment of internal validity:** ++ **Overall assessment of external validity:** + A concern about giving this study a higher rating for external validity is that it does not pay enough attention to the issue of the age of the population of people with learning disabilities in the study. Although the mean age of participants is 50.9, the age range is 23–69, meaning that some of the

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
people with learning disabilities and support workers of managing negotiated autonomy in health care. Researchers report that a 'constructivist lens informed both data collection and analysis as the experience and process of autonomy were explored through the research encounter' (p390). **Is the study clear in what it seeks to do?** Clear. The study provides a clear description of the	**Is the context clearly described?** Unclear. The study states that interviews took place in residential and independent living settings, but without reporting where they took place within these settings, and how much privacy they had. It does report that participants with ID could have their support worker present if they wished - it does not state how often this happened. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. The sample was identified by approaching primary health organisations and disability services. The researcher acknowledges that this was a convenience sample, and	**Is there a clear focus on the guideline topic?** Yes. The guideline topic is the care and support for older people with learning disabilities, and this study deals with care and support for diabetic people with learning disabilities, most of whom (in the study) would be considered as being within the older age range. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. The study deals with the management of diabetes by people with learning disabilities. Although it is not specifically a study of older people, the average age of the participants with learning disabilities is 50.9. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. The participants with learning disabilities were living independently at home, in supported independence, or in residential care. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. The study relates to one of the points in key area 5 of section 1.3 of the guideline scope: Support to prevent and manage chronic health conditions and to adopt and maintain healthy lifestyle choices.	participants could not be considered 'older'. There is no data about any variation according to age.

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
general context around people with ID who have diabetes in which it is taking place, providing literature references to support the need for the study to take place, as well as for some of the observations in the discussion in the findings. Although it does not have a specific section describing the study's aims, we would judge that there are statements within the study that do make its aims clear. There is a brief discussion about autonomy	cannot be taken as being representative. However, given the amount of work that would have been needed to work out what a representative sample would look like and then find them, I think it understandable that they did not attempt to do this, and the sample they found still provides insightful data. **Were the methods reliable?** Somewhat reliable. Using 1 interviewer who had relevant knowledge and experience could have ensured consistency in carrying out these semi-structured interviews, and ensured that follow-up questions were based on a sound knowledge of the field of study. However, the use of	**(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. The views and experiences in the study relate to people with learning disabilities being supported to manage a serious health condition as independently as possible, through negotiations about their autonomy. However, the study includes participants with a wide range of ages, and there is no analysis specifically of the experiences of OPLD, although with a mean age of 50.9 and a range of 23–69 the majority of participants are likely to be at an age when the ageing process is having an impact on them. **Does the study have a UK perspective?** No. Study was conducted in New Zealand.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
and best practice approaches to service delivery. **How defensible/rigorous is the research design/ methodology?** Defensible. The researchers state that they used a qualitative approach because they wanted to explore views and experiences. Such an approach seems appropriate for the sort of data that was wanted, i.e. an understanding of how negotiated autonomy was working for management of	only 1 interviewer and only 1 method of data collection means that the methods used can only be considered somewhat reliable. **Are the data 'rich'?** Rich. The study provides information about the context of people with ID having a higher incidence of diabetes than the general population, and this being likely to increase. Although it is a study which includes only a small sample and has quite a narrow remit, it does seem that there has been a thorough exploration of the issues within that remit, e.g. the way autonomy is negotiated differently in different circumstances. The study also presents the wider context of the findings		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
diabetes. The researchers describe how they recruited participants, through primary health organisations and disability services, and the criteria for inclusion. Interviews were carried out by 1 member of the review team, who was a nurse with 20 years of clinical experience in this field. Although the sample was small, this does not invalidate the findings, but it does (as the report acknowledges) mean that further	within existing knowledge, e.g. that there is not generally a good awareness of opportunities for facilitating supported decision-making for people with ID. **Is the analysis reliable?** Somewhat reliable. Although there was a research team of 4, the wording of the study does not make it clear that more than 1 of the team was involved in generating the themes from the interview transcripts. However, it does describe a very thorough process of reading and reviewing the transcripts in order to identify themes. The study also states that there was a process of group analysis and discussion involving all 4 of the study's authors. There is no		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
research could be required.	discussion about whether any differences of opinion arose and hence of how any such differences might have been resolved. The study does make clear where their findings may not apply to all participants by stating where findings applied to 'most' or 'half' of them. Information is given about some exceptions, e.g. where a relationship was not working well to support a participant with ID's diabetes. **Are the findings convincing?** Convincing. The findings are clearly presented, and the presentation of the themes generated by the data is clear and coherent, with quotes from the interviews presented illustratively.		

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
	Are the conclusions adequate? Adequate. The conclusions reached are in accord with the data generated by the interviews, and the findings are plausible and coherent across the three themes. The researchers are aware of the study's limitations. However, the study does provide a useful examination of an approach which it shows can work well to managing diabetes for people with ID, but is not well enough known or used.		

Review question 9 – critical appraisal tables – the views and experiences answering Qa only

1. Fender A, Marsden L, Starr JM (2007) What do older adults with Down's syndrome want from their doctor? A preliminary report. British Journal of Learning Disabilities 35: 19–22

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim: To find out what OPLD want from their doctor, including what it is OK for the doctor to do and to ask. Also to involve OPLD in the research process. **Methodology:** Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Mixed. The aims/objectives etc. are not formally set out within the body of the article so this could have been much clearer. **How defensible/rigorous is**	**How well was the data collection carried out?** Somewhat appropriately. Data collection methods are clearly described and it appears that the appropriate data were collected to address the research question although from the account, it appears that people's views could have been explored in more detail. The method of data collection was not clearly described so we do not know whether this has been done systematically and there are no details at all about the record keeping except to say that OPLD were involved. **Is the context clearly described?** Unclear. The	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Partly. The study seems to have dealt with consent and involvement but there is no mention of an application for ethical approval. **Were service users involved in the study?** Yes. Although they weren't involved in the design of the study from the beginning, OPLD did become involved, recording the outcomes of meetings, directing the agendas for meetings 2–5 and then	**Overall assessment of internal validity:** + Although on the weaker side of 'moderate'. There are some serious limitations that the Guideline Committee should consider. **Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
the research design/methodology? Somewhat defensible. A qualitative design is defensible since the study aimed to explore people's subjective views and experiences. The focus groups, directed by participants, were an appropriate of gathering the data. Note that it is unclear whether all members of Down's Syndrome Scotland received letters of invitation of whether staff targeted specific people.	characteristics of the participants are not at all defined. The only thing we know about them is that they are 'older people' with a learning disability and since they were recruited via Down's Syndrome Scotland we assume the have Down's syndrome. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. It is appropriate to provide potential participants with information leaflets and for them to be self-selecting. However the paper does not tell us whether all members of DS Scotland were invited to participate or just a select number. This introduces the risk of selection bias. **Were the methods reliable?** Somewhat reliable. Data were only collected via 1 method,	afterwards those who wished to continue to be involved in dissemination and applications for the next stage of research. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	focus groups. Therefore no opportunity for triangulation. **Are the data 'rich'?** Mixed. The contexts of the data are not at all well described. It is not clear how well diversity of perspective and content have been explored, the description of the focus groups is more about what happened and what participants engaged in rather than the data collected. When the findings are presented in 3 boxes, very little detail and depth are presented. **Is the analysis reliable?** Not sure/not reported. There isn't really any information to help us understand whether analysis was reliable. For example, we do not know whether transcripts or notes were themed and coded let alone whether this was done	**Does the study have a UK perspective?** Yes. Scotland.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	by more than 1 researcher. The only thing we do know is that participants 'looked at the results of the research' but we do not know whether they could comment or input into the interpretation and write up. Discrepant results were not reported. **Are the findings convincing?** Somewhat convincing. The findings are clearly presented but very few, if any (it's difficult to decipher) extracts from the original data are included and this certainly introduces a risk of bias in the findings. **Are the conclusions adequate?** Somewhat adequate. Links between findings and conclusions are fairly clear and conclusions are plausible albeit very thin. The findings relate to other		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	research in the area and given that the views of OPLD themselves are presented this does enhance understanding of the topic. There is no discussion of study limitations.		

Review question 9 – critical appraisal tables – the views and experiences answering Qb only

1. Northway R, Holland-Hart D, Jenkins R (2016) Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
Study aim The introduction to the study states that 'while	**How well was the data collection carried out?** Not sure/inadequately reported. Very little detail is	**Does the study's research question match the review question?** Yes. The subject of the study is the delivery of healthcare by	**Overall assessment of internal validity:** +

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
residential care staff play an important role in meeting the health needs of those they support, this is not always formally recognised as part of their role (Crimes 2014). Little is known about how such staff respond to age-related health changes among those they support (Webber et al. 2010a) and this study seeks to begin to address this gap in knowledge' (p2). **Methodology** Qualitative study. Semi-structured	provided about data collection, other than that it was done through semi-structured interviews. Details about the topic guides used for these interviews are not provided. More details are provided about the analysis, which was carried out using NVivo software. The 5 major themes that emerged from the data are listed, although the study only presents the sub-themes for the 3 major themes covered in this study, with the other 2 major themes being written about elsewhere. **Is the context clearly described?** Unclear. Participants are described as '14 house managers [...] from five-third-sector organisations providing supported living	non-specialist staff in supported living arrangements to OPLD. **Has the study dealt appropriately with any ethical concerns?** Yes. 'Ethics approval for this study was granted by the Faculty of Life Sciences and Education at the University of South Wales Ethics Committee. All potential participants were provided with an information sheet outlining the study and the voluntary nature of participation, and given the opportunity to seek clarification regarding any issue. Those agreeing to take part were asked to sign a consent form before interviews commenced' (p3). All quotes are anonymised. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. The study specifically concerns care and support of older people with learning disabilities. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Through interviews with managers who manage a service provided to them, the study deals with care and support needs of older people with learning disabilities.	**Overall assessment of external validity:** ++

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
individual interviews. **Is a qualitative approach appropriate?** Appropriate. The study is seeking the sort of data which can only be provided by people expressing their views in an interview, so a qualitative approach is appropriate. **Is the study clear in what it seeks to do?** Clear. Although the study does not state a research question, its introduction provides a clear	services to people with intellectual disabilities in Wales' (p3). Although the study does, for context, describe the typical role of a house manager, details of the specific duties of these house managers is not given. No details are provided about the context where the interviews took place, although there is some information about the Welsh context for OPLD who are in supported living arrangements. **Was the sampling carried out in an appropriate way?** Somewhat appropriate. The sample is described as a 'purposive sample' (p3), meaning the researchers used their judgement in selecting participants for the study. However, no	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. The study describes the accommodation covered in the study as 'supported living settings' (p2), but the staff who provide the support are 'residential care workers' (p4). It is clear that some of the tenants/residents do require 24-hour support, but it is not clear whether the places would be categorised as care homes or supported living. However, they clearly do fall within the scope of the settings described in section 1.2 of the guideline scope. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. The study deals with the provision of support to prevent and manage chronic health conditions and to adopt and maintain healthy lifestyle choices. It also touches on end of life care. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. The views sought all concern the provision of care and support for the health needs of older people with learning disabilities, although they are the views of people managing the residential places where they live rather than OPLD themselves.	

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
outline, with literature references, of the issues it is aiming to address. **How defensible/rigorous is the research design/ methodology?** Somewhat defensible. Although the study does not specify a research question, the abstract does state 'Older people with intellectual disabilities often experience high levels of health needs and multiple morbidities but they may be supported by residential care	justification is given for selecting these particular house managers, and the extent to which they are a convenience sample is not clear. Also, given the stated purpose of the study, no justification is given for only interviewing house managers, when other practitioners and staff, as well as OPLD, could have provided useful insights into the topic. While it is understandable that what is described as an 'exploratory study' (p7) would be small scale, this must still be seen as a limitation when considering the conclusions of the study. **Were the methods reliable?** Somewhat reliable. Only one method of data collection	**Does the study have a UK perspective?** Yes. Wales.	

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
staff with little or no previous experience of identifying and meeting health needs. Little is known regarding how they undertake this health-related role and this exploratory study seeks to address this gap' (p1). However the study tries to collect data about how residential care staff undertake this role only by interviewing people who manage the service they provide, and no interviews were conducted with staff providing the	has been used, which is semi-structured interviews, ranging in length from 30 to 82 minutes, mean time 53 minutes. Details about the topics these interviews aimed to cover is not provided, although the 5 major themes that emerged from analysis of the interviews is stated, with the sub-themes for the 3 themes that are the basis for this study also given. **Are the data 'rich'?** Mixed. Although the participants in the study are all managers of supported living for OPLD, there is no description of the types of supported living which they manage, which means that the study does not provide information about the living contexts for OPLD that they		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
service or with OPLD who are using the service. It could be said that managers have an interest in giving an impression of running a good service, and so details about problems with the day-to-day running of the service, and possibly organisational problems, may not emerge from these interviews.	are describing. It is also hard to know how diverse the perspectives are that are being presented by these managers, and the study does not describe how views might vary between different types of supported living. The data presented does cover a broad range of information and topics through the thematic analysis. **Is the analysis reliable?** Reliable. Transcribed interviews were analysed by different members of the review team, who then met to identify emerging themes and agree a coding framework, which was then entered into NVivo software and coded thematically. A member of the research team reviewed a selection of		

Internal validity – approach and sample	Internal validity – performance and analysis	External validity	Overall validity rating
	the coded transcripts before final coding was agreed. **Are the findings convincing?** Convincing. The findings are clearly and coherently presented, following the themes and sub themes that the researchers identified, and are supported throughout by quotes from the interviews. **Are the conclusions adequate?** Somewhat adequate. The findings are very relevant to the aims of the study. The researchers do recognise some of the limitations of the study: 'this is a relatively small scale exploratory study involving participants from only one area of the United Kingdom and hence it is not possible to generalise from		

Internal validity – approach and sample	**Internal validity – performance and analysis**	**External validity**	**Overall validity rating**
	the findings' (pp7–8). There is no acknowledgement of another limitation, which is that it only presents the views of house managers, who may not wish to be too critical of the service they are responsible for providing. It lacks the perspective of practitioners and staff, OPLD and their carers and families, and of specialist independent advice and advocacy organisations, all of which may have a useful, different perspective.		