NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Care and support of people growing older with learning disabilities

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 11 December 2018

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for care and support of people growing older with learning disabilities. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96.

NICE also produced an EasyRead version and video to explain this guideline.

2 Overview

2.1 Focus of quality standard

This quality standard will cover identifying, assessing and regularly reviewing care and support needs of people growing older with learning disabilities. It will cover all settings where care and support is provided.

2.2 Health and social issues of older people with learning disabilities

People with learning disabilities are now living significantly longer. The population of older people with learning disabilities will increase 4 times faster than the overall adult learning disability population. Many people with learning disabilities, especially those with milder disability, are not known to health or social services whereas others may find it difficult to express their needs and be heard. Management of their needs will therefore be more complex than for other populations.

People with learning disabilities have a poorer health profile than the general population. Practitioners may have difficulty distinguishing the symptoms of a condition such as dementia from those associated with learning disabilities, or with other mental health difficulties. People with learning disabilities may also have poorer health resulting from lifestyle issues such as diet and exercise.

People with learning disabilities also face barriers to accessing healthcare, including health and dental checks. The Michael report on Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities[1] and the subsequent confidential inquiry into premature deaths of people with learning disabilities[2] identified a failure of services to take account of the needs of people with learning disabilities and make reasonable adjustments. This led to misdiagnosis and, in some instances, premature death.

Adults with learning disabilities are far more likely to have sensory impairment compared with the general population, but are less likely to access sight or hearing checks, particularly if they are living independently or with family. Sensory impairment is also a barrier to accessing services. People growing older with learning disabilities also have particular housing and social support needs. Two-thirds of adults with learning disabilities live with their families, usually their parents. In some instances, they may be caring for an older frail parent while they too are getting older.

People growing older with learning disabilities are likely to be placed in older people's residential services at a much younger age than the general population, even though this may not meet their preferences or needs, especially in relation to communication, support and activities.

3 Summary of suggestions

3.1 Responses

In total 24 registered stakeholders, 1 individual and 9 specialist committee members responded to the 4-week engagement exercise 26/07/2018 – 23/08/2018.

Stakeholders were asked to suggest up to 5 areas for quality improvement. The responses have been merged and summarised in table 1 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 2 for information.

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[1] Sir Jonathan Michael (2008) Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities

[2] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities

Table 1 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Identifying and assessing care and support needs • Assessing people's needs for care and support • Communication • Assessing the needs of family members and carers • Social inclusion	ADASS, BDA, BGS, CBF, DSA, FPLD, Mencap, NCD, OLM, PF, RCGP, RCSLT, SCMs, SfC, St Anne's, TT
Planning and reviewing care and support • Planning for the future • Planning - key components • Coordinated care	ADASS, BASW, CBF, CRE, DSA, FPLD, FGDP, LGA, Mencap, NCD, NHFT, NDTI, OLM, PF, RCGP, SCMs, SfC, St Anne's, TT
Identifying and managing health needs • Health checks • Hospital care	ADASS, AHL, BDA, DSA, FGDP, FPLD, LGA, NCD, NDTI, OLM, RCGP, RCPsych, RCSLT, SCMs, St Anne's, TT
End of life care • Planning end of life	ADASS, BDA, Mencap, SCMs,
Additional areas • Statutory responsibilities • Staff skills and expertise	AHL, BASW, BGS, CBF, FPLD, Mencap, PF, RCGP, RCPsych, SCMs, SfC, TT
ADASS, Association of Directors of Adult Social Services AHL, Action on Hearing Loss BASW, British Association of Social Workers BDA, British Dietetic Association BGS, British Geriatrics Society CBF, The Challenging Behaviour Foundation CRE, Care & Repair England DSA, The Down's Syndrome Association FGDP, The Faculty of General Dental Practice FPLD, Foundation for People with Learning Disabilities LGA, Local Government Association Mencap NCD, National Clinical Director (NHS England) NDTI, National Development Team for Inclusion NHFT, Nottinghamshire Healthcare NHS Foundation Trust OLM, OLM Group PF, People First RCGP, Royal College of General Practitioners RCN, Royal College of Nursing (no comments) RCPsych, The Royal College of Psychiatrists RCSLT, Royal College of Speech and Language Therapists SCM, Specialist committee member SfC, Skills for Care St Anne's, St Anne's Community Service TT, Thera Trust	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 275 papers were identified for care and support of people growing older with learning disabilities. In addition, 33 papers were suggested by stakeholders at topic engagement and 90 papers internally at project scoping.

Of these papers, 16 papers have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 Identifying and assessing care and support needs

4.1.1 Summary of suggestions

Assessing people's needs for care and support

Stakeholders highlighted identifying and assessing people's needs for care and support as an area for quality improvement.

They suggested that all assessments of care and support needs for people growing with learning disabilities should be strengths based, person centred and conducted as early as possible.

Communication

Stakeholders suggested effective communication as an area for quality improvement.

Stakeholders suggested that people with learning disabilities may have difficulties communicating their needs. They also suggested that because of poor communication they may not access services or understand the support available to them. Stakeholders highlighted that information needs to be tailored and accessible for people with learning disabilities so that they are able to make informed decisions.

Assessing the needs of family members and carers

Stakeholders highlighted assessing the needs of family members and carers and recognising existing caring relationships as an area for quality improvement.

Stakeholders suggested that carers should be included in care planning for the person with learning disability but they should also receive a carer's assessment and appropriate support. They also highlighted that many families had mutually caring relationships where people growing older with learning disabilities start taking on caring responsibilities for their ageing parents who have always supported them. Stakeholders suggested that these relationships are often not known to services and make people vulnerable if suitable support is not put into place. They also suggested that services are put in place without recognising or taking into account existing caring arrangements.

Social inclusion

Stakeholders highlighted supporting people with learning difficulties to develop their interests and relationships as an area for quality improvement.

Stakeholders suggested that some people with learning disabilities may be isolated and need support to maintain and develop their interests and social networks. They highlighted that some may not have any networks other than their family and carers. Stakeholders also suggested that for some people with a learning disability, getting older can also be a time of increased independence, a time to develop relationships and to become more active – particularly for those that may have been living with parents their entire life.

4.1.2 Selected recommendations from development source

Table 2 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee's discussion.

Table 2 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Assessing people's need for care and support	**Assessing people's need for care and support** NICE NG96 Recommendations 1.3.1, 1.3.2
Communication	**Communicating and making information accessible** NICE NG96 Recommendations 1.1.5, 1.1.6 and 1.1.7 **Assessing people's need for care and support** NICE NG96 Recommendation 1.3.4
Assessing the needs of family members and carers	**Access to services and person-centred care** NICE NG96 Recommendation 1.1.4 **Involving people, family members, carers and advocates** NICE NG96 Recommendation 1.1.9 **Assessing the needs of family members and carers** NICE NG96 Recommendation 1.3.6
Social inclusion	**Planning and commissioning local services** NICE NG96 Recommendations 1.2.11 1.2.12, 1.2.13, 1.2.14 **Assessing people's need for care and support** NICE NG96 Recommendation 1.3.5

Assessing people's need for care and support

NICE NG96 Recommendation 1.3.1

Ensure that all assessments of care and support needs are strengths based, person centred and conducted as early as possible. Follow the recommendations on care and support needs assessment in NICE's guideline on people's experience in adult social care services.

NICE NG96 Recommendation 1.3.2

Practitioners carrying out assessments of care and support needs should have:

- access to the person's full history (medical, social, psychological and the nature of their learning disability) and
- an understanding of their usual behaviour.

Communicating and making information accessible

NICE NG96 Recommendation 1.1.5

Support people's communication and information needs in line with NHS England's Accessible Information Standard. This could also include:

- Seeking advice from, or referring people to, a speech and language therapist whenever needed.
- Providing an independent interpreter (that is, someone who does not have a relationship with the person) so that people can communicate in their first language.
- Finding out before an appointment how the person prefers to communicate and receive information.
- Extending appointment times to give more time for discussion.
- Giving people written information (such as appointment letters and reminders) in different languages or in an accessible format of their choice, for example Easy Read, audio books, films or by using online resources such as specialist learning disability websites.
- Providing information on advocacy services and, if the person needs it and consents to it, providing an independent advocate who will attend appointments.
- Using visual aids and short, clear sentences during consultations and conversations.

- Talking to the person's family members and carers if appropriate, and with the person's consent.

NICE NG96 Recommendation 1.1.6

Provide people with learning disabilities and their family members, carers and advocates with accessible, tailored information about:

- the range and role of different health services (such as health checks and screening)
- how to access health, social care and support services
- the community and specialist services that are available, and their purpose
- housing options that they could think about for the future
- planning for end of life care
- financial issues, including wills, trusts and benefits
- how to raise a safeguarding concern if they have one.

NICE NG96 Recommendation 1.1.7

Social care and primary care practitioners should regularly review the communication needs of people with learning disabilities as they grow older to find out if they have changed. This should usually be when:

- other needs are being assessed, for example, during general health and dental checks
- there is reason to believe their communication needs may have changed.

Assessing people's need for care and support

NICE NG96 Recommendations 1.3.4

Be aware that people growing older with learning disabilities might have difficulty communicating their health needs. When their needs change, think about whether these changes could be age-related and do not assume they are due to the person's learning disability or pre-existing condition (diagnostic overshadowing).

Access to services and person-centred care

NICE NG96 Recommendation 1.1.4

Recognise that people with learning disabilities may be carers, but may not see themselves as such. Ask the person if they have caring responsibilities and, if so, offer them a carer's assessment to meet their needs. [This recommendation is adapted from the NICE guideline on older people with social care needs and multiple long-term conditions.]

Involving people, family members, carers and advocates

NICE NG96 Recommendation 1.1.9

Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this. Regularly check people's willingness and ability to be involved in this way.

Planning and commissioning local services

NICE NG96 Recommendations 1.2.11

Commissioners and service providers should provide opportunities for people with learning disabilities to meet up and socialise, for instance through social clubs and support groups.

NICE NG96 Recommendations 1.2.12

Commissioners and service providers should ensure there is a wide range of community-based physical activity programmes available and encourage people to take part to promote their health and wellbeing. Examples include dancing, swimming, bowls, using the gym, organised walks and chair-based exercise classes.

NICE NG96 Recommendations 1.2.13

Commissioners and service providers should arrange accessible opportunities for people with learning disabilities to engage in education, employment and volunteering.

NICE NG96 Recommendations 1.2.14

Local authorities should consider introducing schemes to make transport easier for older people with learning disabilities. For example:

- providing free travel such as London's 'Freedom pass'
- using minibuses as community transport
- starting 'buddy' schemes to enable independent travel

- developing transport especially for people living in rural locations
- schemes such as 'JAM' cards (Just A Minute) – which can be used to alert transport staff that people have a learning disability
- schemes to help people with a personal budget to travel to activities and self-advocacy groups.

Assessing people's need for care and support

NICE NG96 Recommendation 1.3.5

Practitioners carrying out assessments of care and support needs should help people to think about what they want from life as they age. This should include:

- asking people how they would like to spend their time and with whom, and enabling them to explore personal and sexual relationships
- encouraging them to develop support networks and to build and maintain links with friends and family and with community groups – these might include social, cultural and faith-based groups.

NICE NG96 Recommendation 1.3.6

Practitioners carrying out assessments of care and support needs should take into account the needs, capabilities and wishes of families and carers. Also take into account that there may be mutual caring between people with learning disabilities, and their family members and carers, who are likely to be older themselves and have their own support needs.

4.1.3 Current UK practice

Assessing the needs for care and support

CQC inspections of 145 learning disability services found that 76% of those carried out needs assessments. However, 38% of the providers failed to involve people with learning disabilities and their families in identifying their needs and planning/designing their care[3].

The Confidential Inquiry which looked into premature deaths of 247 people with learning disabilities (CIPOLD) found that 50% of the adults with learning disabilities had had their support needs reviewed within the past 6 months, however 27% of

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[3] CQC (2017) Review of learning disability services

those in residential care settings had not had their support reviewed for over a year, if at all[4].

Communication

The Accessible Information Standard: Post-Implementation Review which included organisations that provide and/or commission NHS care and/or publicly-funded adult social care, voluntary and community sector organisations, professional representative bodies, patient groups, and patients, service users, carers and parents with information and / or communication needs relating to a disability, impairment or sensory loss was carried out in 2017. During the review period:

- 231 surveys for health and social care professionals and organisations were completed
- 1,312 surveys for patients, service users, carers and parents were completed, including 133 in an easy read format
- 66 surveys for support, supplier and representative organisations were completed.

Additional feedback was also received at meetings and events, and via email and letter.

79% of the respondents (patients, service users, carers and parents) stated that they found it difficult or they needed support to see, to hear, to speak, to read or to understand what is being said (respondents who said: ‘always’, ‘most of the time’ or ‘sometimes). Many patients, service users, carers and parents had not received accessible information and / or communication support from NHS and / or adult social care providers[5].

The 2015 Learning Disability Census which provides a snapshot of 3000 inpatients with learning disabilities, autistic spectrum disorder and/or behaviour that challenges, and the services they receive, for patients who were inpatients in NHS and independent services at midnight on 30 September 2015. The census found that 72% were supported by an independent advocate to make sure their views were heard and also to help them make choices about the care they received.[6]

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that even though over a third of people were reported as having difficulty in communicating their pain, pain assessment tools such as the Disability Distress Assessment Tool had been used with fewer than 5% of them. The Disability

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[4] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities

[5] NHS England (2017) Accessible Information Standard: Post-Implementation Review

[6] Health and social care information centre (2016) Learning disabilities Census Report – further analysis

Distress Assessment Tool would provide information about how the person indicated whether they were in pain or not[7].

Assessing the needs of family members and carers

A survey carried out by an organisation Bringing Us together used a questionnaire to ask parent carers about the impact their role had on their health. 1,087 questionnaires were sent back. The main findings from parent carers were:

- 88% experienced ill health related to being a parent carer in the last five years
- 57% told a practitioner about their ill health
- 65% had not been offered carers assessment; common responses:
    - What is a Carers Assessment?
    - Asked for one but still waiting
    - Asked for one but told we don't meet the criteria
    - Offered one but still waiting for it to be completed
- Of those that had the assessment, 61% said that nothing changed as a result of it[8].

A report published by PHE on people with learning disabilities found that in 2013/14, 38,755 assessments/reviews were offered to family carers of adults with learning disabilities aged 18 to 64 years, of which 93% were taken up. This represents 74% of households where an adult with learning disabilities aged 18 to 64 years was reported to be in settled accommodation with family or friends[9].

A report produced by Mencap in 2013 looked at support provided to people who care for family members with severe or profound learning disabilities. A total of 264 family carers responded to a survey on short breaks provision and experiences of caring. The research showed that 8 out of 10 family carers reached, or were close to reaching, breaking point due to a lack of short breaks. Breaking point in this research was a term used to explain the moment of crisis for a carer, often emotional, psychological and physical, where they feel they can't go on. This is frequently caused by the lack of short breaks services, the constant supervision and daily worries finally becoming too much. The research found that 6 out of 10 carers have never had a carer's assessment to identify their needs and 2 out of 10 people had been refused an assessment. What is more, half of the families have not had their

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[7] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities
[8] Bringing Us Together (2018) Parent Carer Health, The impact of the caring role
[9] PHE (2016) People with Learning Disabilities in England 2015

support package reviewed in the last year. Of these families, a third has never had their package reviewed. The report concluded that there had been no improvement in the wellbeing of family carers, a decade after the issue was first highlighted by Mencap[10].

Social inclusion

A report by charity Sense looking at loneliness among people with disabilities highlighted that up to 50% of people with a learning disability experience chronic loneliness. The same report included following results:

- Over 30% of people with learning disabilities spend less than one hour outside their homes on a typical Saturday
- 49% said they would like to spend more time outside their home
- 45% do not think they spend enough time with friends
- 18% feel alone and cut off from other people[11].

4.1.4 Resource impact

None of the recommendations were identified as having resource impact.

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[10] Mencap (2013) Short breaks support is failing family carers

[11] Sense (2017) Someone cares if I'm not there: addressing loneliness in disabled people

4.2 Planning and reviewing care and support

4.2.1 Summary of suggestions

Planning for the future

Stakeholders highlighted person-centred plans as an area for quality improvement.

Stakeholders suggested that health and social care practitioners should work with the person and those most involved in their support to agree a plan for the future. They suggested that people growing older with learning disabilities should be supported to make decisions before their needs, capacity or circumstances change and before they reach a crisis point. Stakeholders also suggested that the plans should be reviewed regularly (at least annually) and involve a lead practitioner.

Key components of the plan

Stakeholders highlighted specific elements which should be included in the care plan as areas for quality improvement.

Stakeholders suggested that planning for the future should include discussing with people with learning disabilities, and their families and carers:

- housing circumstances - how these may change and what the person's preferences would be
- financial and legal arrangements in case of parental death
- advance care directives
- support with bereavement.

Coordinated care

Stakeholders suggested provision of coordinated care as an area for quality improvement.

Stakeholders suggested that people growing older with learning disabilities should work with health and care service providers to ensure the support they receive from all involved meets their needs. There was a suggestion that the plan should identify a pathway which illustrates the changes people are likely to experience as they grow older which should be developed and coordinated between primary care, secondary care and palliative care.

Stakeholders suggested that the coordination of services and outcomes for the person could be improved if people with learning disabilities were supported by a specific person who was responsible for it. They suggested that a case coordinator or lead practitioner who knows the person can ensure cohesive and joined up care planning as well as prevent diagnostic overshadowing as the person grows older.

Stakeholders also highlighted the importance of information sharing between health and other care providers as well as the need for specialist learning disability services to work more closely with older people’s services.

4.2.2 Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

Table 3 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Planning for the future	**Planning for the future** NICE NG96 Recommendation 1.4.5
Key components of the plan	**Person-centred planning and review** NICE NG96 Recommendations 1.4.1, 1.4.4, **Planning for the future** NICE NG96 Recommendations 1.4.6, 1.4.7, 1.4.8, 1.4.10
Coordinated care	**Planning and commissioning local services** NICE NG96 Recommendation 1.2.10 **Coordinating care and sharing information** NICE NG96 Recommendations 1.5.7, 1.5.8, 1.5.10

Planning for the future

<u>NICE NG96 Recommendation 1.4.5</u>

Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the future. Help them to make decisions before a crisis point or life-changing event is reached (for example, the death of a parent or a move to new housing).

Person-centred planning and review

<u>NICE NG96 Recommendations 1.4.1</u>

Practitioners should carry out regular person-centred planning with people growing older with learning disabilities to address their changing needs, wishes and capabilities and promote their independence. This should include planning for the future (see recommendations 1.4.5 to 1.4.13). Involve their family members, carers and advocates as appropriate.

NICE NG96 Recommendations 1.4.4

Give help and information to families and carers, including siblings, as part of planning and providing support for people growing older with learning disabilities. For example, tell them about sources of support for people after a family bereavement.

Planning for the future

NICE NG96 Recommendations 1.4.6

Planning for the future should:

- be proactive
- be led by the person themselves with input from family members, carers or advocates as appropriate (regardless of whether they provide care and support themselves)
- involve a practitioner who has a good relationship with the person and communicates well with them
- involve practitioners who have good knowledge of local resources
- take into account the whole of the person's life, including their hopes and dreams as well as the things they do not want to happen
- include considering the needs of family members and carers
- seek to maintain the person's current support and housing arrangements, if this is their preference
- be reviewed every year and whenever the person's needs or circumstances change.

NICE NG96 Recommendations 1.4.7

Include as key components of a future plan:

- Housing needs and potential solutions.
- Any home adaptations or technology that may address people's changing needs as they grow older.
- Members of the person's support network (both paid and unpaid).

- Any help the person gives to family members, whether this will continue as they age, and the impact this may have on their health and wellbeing.
- Planning for what will happen if someone who the person relies on dies, or is no longer able to provide care and support.
- Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person.
- The provision of information on wills, trusts and benefits.
- Planning for unexpected changes or emergencies.
- Planning for a time when the person may lack capacity to make decisions themselves, in line with the Mental Capacity Act 2005.
- Consideration of deprivation of liberty safeguards, for instance if planned changes to care or the care environment are likely to increase restrictions on the person.
- End of life care decisions – including where the person wants to be when they die. These decisions should be reviewed at least once a year.

NICE NG96 Recommendations 1.4.8

When helping the person plan where they will live in the future and who they will live with, take into account whether other family members rely on them for support.

NICE NG96 Recommendations 1.4.10

Make reasonable adjustments to people's homes as they grow older to make it possible for them to stay in their current home if they want to. For example, consider a support phone line, daily living equipment, telehealth monitoring and home adaptations, such as shower room conversion, wider doorways or a lift between floors.

Planning and commissioning local services

NICE NG96 Recommendation 1.2.10

Commissioners and service providers should establish links between specialist learning disability services and mainstream older people's services. This could be done by bringing them together to help identify gaps and inform service development, sharing information and learning, and linking into voluntary sector umbrella groups.

Coordinating care and sharing information

NICE NG96 Recommendations 1.5.7

Managers in healthcare settings should identify a single lead practitioner to be the point of contact for people with learning disabilities and their family members, carers and advocates. This practitioner could be a member of the community learning disability team or a nurse with experience in learning disabilities.

NICE NG96 Recommendations 1.5.8

Ensure that everyone involved in the person's care and support shares information and communicates regularly about the person's health and any treatment they are having, for example by holding regular multidisciplinary meetings. Involve the person in all discussions.

NICE NG96 Recommendations 1.5.10

Record a person's learning disability and any reasonable adjustments in their health records and share this information when making referrals. With the person's consent, make sure all relevant practitioners in community and acute settings can access this. Also record any specific needs or wishes, for example to do with the person's communication or mobility.

4.2.3 Current UK practice

Planning for the future

A review carried out by CQC looking at how well people are involved in their own care found that people with learning disabilities are not sufficiently involved in making care and treatment plans, or in the choices about the way their care is provided to meet their needs – particularly as they move between health and care services. CQC inspected 145 learning disability services and found that lack of involvement of people and their families in the design of their care and as a result, lack of control over their needs was significant. The review also found that services lacked information about people's preferences, including likes and dislikes about how care was delivered. Often people were not actively involved in the care planning process and care plans were not in appropriate or accessible formats[12].

Research exploring how people with intellectual disabilities make everyday decisions and how care professionals support them when they do interviewed 46 participants across England and Wales. The results found examples of good practice across all levels of care and support services. Support around decision making for day-to-day activities, such as food and clothing, and life choices such as education were generally good. However, there were much lower levels of support around making

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[12] CQC (2016) Better care in my hands: A review of how people are involved in their care

difficult decisions, especially those related to legal issues such as wills, advance decisions and power of attorney[13].

Key components of the plan

A report produced by Mencap on housing for people with a learning disability claimed that even though 174 local authorities in England and Wales said they were fulfilling their statutory obligation to have a local housing strategy which includes dealing with future needs of adults with a learning disability, there was a lack of knowledge about how many people with a learning disability lived in each local authority area. Only 41% local authorities had a local register for adults with a learning disability. Survey carried out by Mencap found that:

- 73% of parents had not planned for the time when they were no longer able to care for their son or daughter to support their future housing needs
- 83% of parents whose son or daughter with a learning disability lived with them had not planned for the time when they were no longer able to care for them
- 56% of parents aged 70 and over whose son or daughter lived with them had not planned for the time when they were no longer able to care for them.[14]

A report published by the Equality and Human Rights Commission found that even if good local authority policies exist, and accessible homes have been built, it remains difficult for disabled people to access information about them. 83% of councils did not have a register of accessible housing in 2014[15].

Coordinated care

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that 19% of people had a “hospital passport” type document but there was no evidence to suggest that this supported medical staff in coordinating the needs of a person with multiple co-morbidities [16]

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) also found that 34% of people with learning disabilities who were on GP registers (92% of the 247 people) had a health action plan. However, there was little evidence that health action plans were used as a mechanism to link people with the

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[13] Birmingham Law School (2017) Everyday Decisions Project Report
[14] Mencap (2012) Housing for people with a learning disability
[15] Equality and Human Rights Commission (2018) The housing experiences of disabled people in Britain
[16] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities

range of services and support that they received, or to share information about them effectively[17].

4.2.4 Resource impact

Making reasonable adjustments to people's homes as they grow older to make it possible for them to stay in their current home if they want to was identified as an area that would have a resource impact. There was no national data existing for the costs of reasonable adjustments to peoples' homes.

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[17] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities

4.3 Identifying and managing health needs

4.3.1 Summary of suggestions

Health Checks

Stakeholders highlighted health surveillance and testing for age related conditions as an area for quality improvement.

Stakeholders suggested that regular health checks allow for earlier diagnosis and more effective treatment but the uptake is variable and specific age-related conditions tend to be missed in people with learning disabilities. They also suggested people with learning difficulties should have health checks at least annually with increasing frequency as they get older.

Stakeholders raised concerns about diagnostic overshadowing which is more likely to happen if the practitioners don’t know the person.

Stakeholders also highlighted specific issues that the quality standard should look at such as dementia, menopause, sensory loss, nutrition, swallowing difficulties, dental health, epilepsy, constipation and medicines optimisation.

Hospital care

Stakeholders suggested support for people with learning disabilities during hospital care as an area for quality improvement.

Stakeholders highlighted the importance of understanding the complex needs of people during and after their hospital stay. They suggested that people with learning disabilities should be able to choose a person who could stay with them if they are admitted to hospital. Stakeholders also suggested that follow up should be carried out at home and if possible by a professional who understands the person with learning disabilities.

4.3.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Health checks and screening	**Health checks and screening** NICE NG96 Recommendation 1.5.12, 1.5.13, 1.5.14, 1.5.17

	Dental care NICE NG96 Recommendation 1.5.24 **Dementia** NICE NG96 Recommendations 1.5.36
Hospital care	**Before and during a hospital stay** NICE NG96 Recommendation 1.5.26 **Transfer of care from hospital** NICE NG96 Recommendations 1.5.28, 1.5.34

Health checks and screening

NICE NG96 Recommendation 1.5.12

Offer annual health checks to older people with learning disabilities as long as these are followed by prompt referral to specialist services wherever needed. Explain what annual health checks involve and how to arrange them. Record any actions identified by the annual health check in the person's health action plan.

NICE NG96 Recommendation 1.5.13

Offer older people with learning disabilities the same routine screening and health checks as other older people.

NICE NG96 Recommendation 1.5.14

Discuss with people the changes that may occur with age. Ask them about and monitor them for symptoms of common age-related conditions or changes in any existing conditions, including:

- blood pressure and cholesterol
- cancer
- dementia (also see recommendations 1.5.36 and 1.5.37).
- diabetes
- dysphagia (difficulty swallowing)
- epilepsy
- hearing loss and sight problems
- incontinence
- osteoporosis

- malnutrition
- menopausal symptoms
- mental health, including depression
- thyroid problems.

NICE NG96 Recommendation 1.5.17

Give people clear, accessible and practical information and advice about keeping well as they grow older. Tell them about, and help them access, services such as breast screening, smear tests, testicular and prostate checks, dental checks, hearing and sight tests, and podiatry.

Dental care

NICE NG96 Recommendation 1.5.24

Dental practices should ensure their services are accessible to people with learning disabilities, for example by:

- reminding people about their appointments by phone
- sending letters in an accessible format, for example Easy Read
- suggesting that the person brings a carer or supporter with them
- ensuring staff have the skills to communicate with people with learning disabilities and put them at ease.

For further guidance on managing oral health, see the NICE guidelines on:

- oral health promotion: general dental practice
- oral health for adults in care homes.

Dementia

NICE NG96 Recommendations 1.5.36

Explain at an early stage to people with learning disabilities (particularly people with Down's syndrome) and their family members, carers and advocates about the link between learning disabilities and dementia. Explain the signs of dementia, how it usually progresses and what support is available. Give people:

- printed information on dementia

- opportunities for one-to-one discussion with a professional
- advice on communication strategies for people with dementia.

Before and during a hospital stay

NICE NG96 Recommendations 1.5.26

When planning a hospital admission, arrange a pre-admission planning meeting, including the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members, carers or advocate. At this meeting:

- complete the pre-admission documentation, which should include information from the person's hospital passport
- discuss any reasonable adjustments needed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact.

Transfer of care from hospital

NICE NG96 Recommendations 1.5.28

Hospitals should develop policies and guidance to enable someone chosen by the person to stay with them throughout their inpatient stay, including overnight.

NICE NG96 Recommendations 1.5.34

After the person is discharged, the hospital learning disability liaison nurse, community learning disability team and primary care practitioners should work together to provide ongoing support to help the person manage their health condition.

4.3.3 Current UK practice

Health checks

2016/17 PHE learning disability profiles indicate that only 49% of eligible adults with learning disabilities had a GP health check[18].

The Confidential Inquiry which looked into premature deaths of 247 people with learning disabilities (CIPOLD) found that whilst 71% of the people who had died had received an annual health check in the previous year, 12% never had a health check. The enquiry also found that there was no relationship between health check

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[18] Public Health Profiles (2018) 2016/17 Learning Disability Profiles

being carried out and a person having a health action plan. A health action plan was found for 34% of people with learning disabilities[19].

Hospital care

A national survey of healthcare commissioners undertaken as part of an annual learning disabilities services audit found that 63 out of the 152 of local areas (41%) were unable to supply information about numbers of people with intellectual disabilities among those admitted to hospital, 47 and 48%, respectively, could not supply this information about out-patient and accident and emergency department attenders. Figures supplied by those able to provide data varied substantially and overall were so low as to suggest considerable numbers had been missed[20].

The Confidential Inquiry which looked into premature deaths of 247 people with learning disabilities (CIPOLD) found that 19% had a hospital 'passport'-type document but there was no evidence to suggest that this supported medical staff in coordinating the needs of people with multiple co-morbidities[21].

4.3.4 Resource impact

This was identified as having a potential resource impact, due to more annual health checks being carried out. The costs of providing annual health checks was established under the national incentive scheme of the Directed Enhanced Services (DESs). GPs can currently claim £140 for providing annual health checks. The overall impact in England was not known.

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[19] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities
[20] Gyles Glover, Sebastian Fox, Chris Hatton, (2016) General hospital care for people with intellectual disabilities
[21] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities

4.4 End of life care

4.4.1 Summary of suggestions

Planning for end of life

Stakeholders suggested making plans for end of life with people with learning disabilities as an area for quality improvement.

It was suggested that planning for end of life can help people with learning disabilities, their families and carers to think about the future, consider their preferences and make appropriate arrangements. It was also suggested that the end of life care plan should include mental capacity considerations.

Stakeholders highlighted particular concern around access to palliative care, hospice care and suitable pain relief for people with learning disabilities who are at the end of life.

4.4.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
End of life care	**Making sure end of life care is person centred** NICE NG96 Recommendations 1.6.3, 1.6.4, 1.6.5 **Involving families and support networks** NICE NG96 Recommendation 1.6.7

Making sure end of life care is person centred

NICE NG96 Recommendation 1.6.3

Identify who the person would like to involve in creating their end of life plan. Include the person themselves and everyone who supports them in discussions and planning.

NICE NG96 Recommendation 1.6.4

Ask the person regularly who they would like to involve in discussions about their end of life plan, in case they change their mind. Do this every 6 months, or more often if the person is close to the end of life.

NICE NG96 Recommendation 1.6.5

Make it possible for the person to die where they wish. This might include adapting their home, working with other practitioners and advocates, and talking to other residents or family members about changes that could be made (for example, moving the person to a room on the ground floor).

Involving families and support networks

NICE NG96 Recommendation 1.6.7

When providing end of life care, learn from family members, carers or advocates about the person's needs and wishes, including those associated with faith and culture, nutrition, hydration and pain management. This is particularly important if the person has difficulty communicating.

4.4.3 Current UK practice

Planning for end of life

The CQC review of end of life care identified inequalities experienced by people with learning disabilities. The review found that people’s needs are not always considered by services and that end of life care is not well coordinated around the person[22].

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found some evidence of end-of-life care planning in 43% of people with learning disabilities. 20% of people received support from a specialist palliative care team, 1 in 10 (10%) had received support from a hospice[23].

4.4.4 Resource impact

None of the recommendations were identified as having resource impact.

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[22] Care Quality Commission (2016) A different ending: End of life care review

[23] CIPOLD Team (2013) Confidential Inquiry into premature deaths of people with learning disabilities

4.5 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 11 December 2018.

Statutory responsibilities

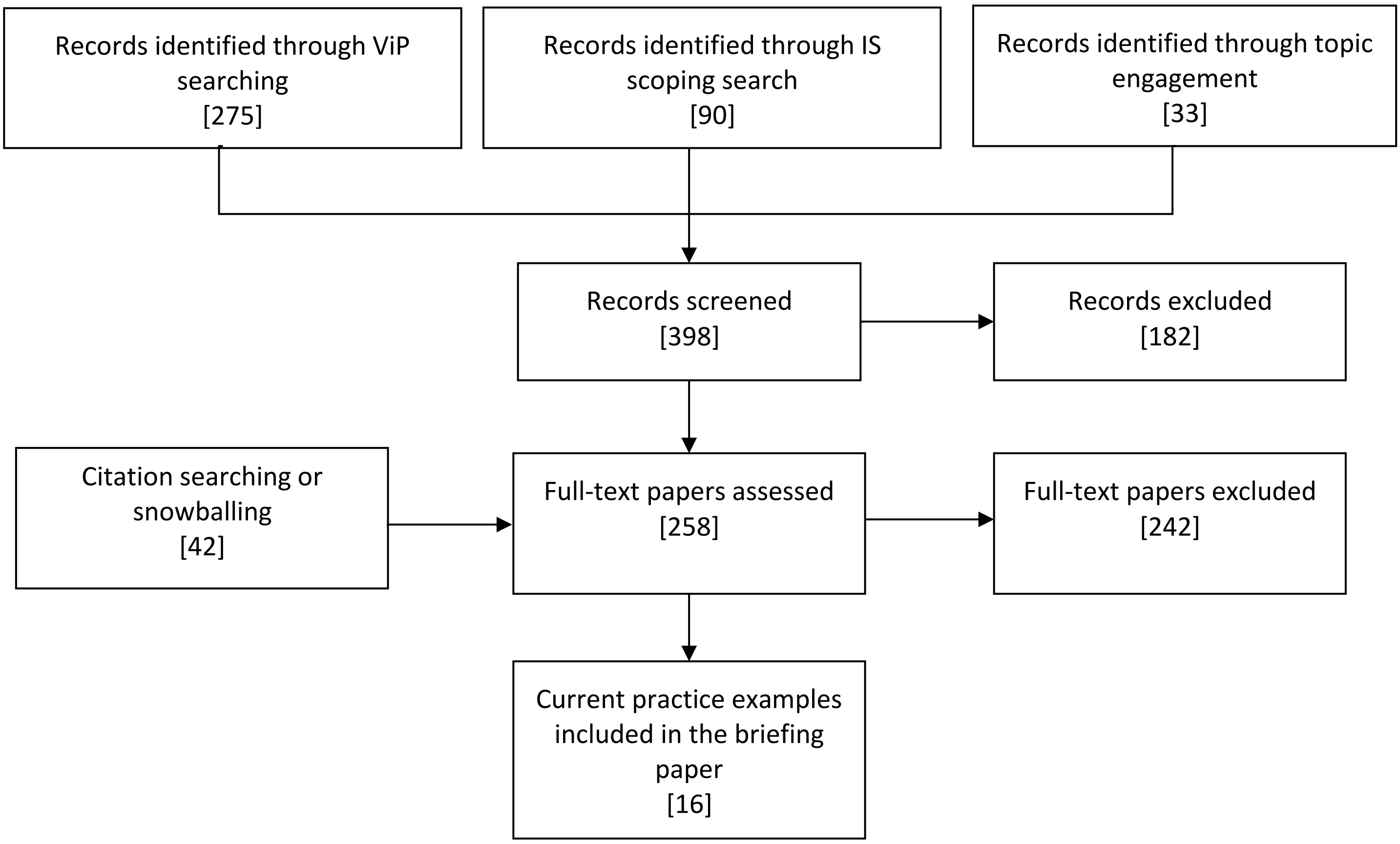
Stakeholders suggested improvements in areas such as equal access to services, having safeguarding processes in place, making reasonable adjustments to services and understanding of the Mental Capacity Act 2005 as areas for quality improvement. These are statutory requirements and as such are not seen as suitable for developing a quality standard. However, specific equality considerations will be added to audience descriptors or highlighted within the equality and diversity considerations where appropriate.

Skills & experience

The skills and experience of staff working with people with learning disabilities was suggested as an area for quality improvement.

This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the skills or experience that enables the actions to take place. The committee is therefore asked to consider which components of care and support would be improved by increased skills. However, skills and experience may be referred to in the audience descriptors.

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?
Identifying and assessing care and support needs				
1	British Geriatrics Society	1.3.1 Ensure that all assessments of care and support needs are strengths based, person centred and conducted as early as possible.	This includes health needs and thus health needs to be viewed from the perspective of the older adult with LD. This may differ from that of health professionals [see Fender A, Marsden L, Starr JM. What do older adults with Down's syndrome want from their doctor? A preliminary report. British Journal of Learning Disabilities 2007;35:19-22; Starr JM, Marsden L. Characterisation of User-defined Health Status in Older Adults with Intellectual Disabilities. Journal of Intellectual Disability Research 2008;52:483-489.], but older adults with LD are able to take the lead in deciding on appropriate assessments [Fender A, Marsden L, Starr JM. Assessing the health of older adults with intellectual disabilities: a user-led approach. Journal of Intellectual Disabilities 2007;11:223-239.]	

2	Foundation for People with Learning Disabilities	Ensure that all assessments of care and support needs are strengths based, person centred and conducted as early as possible.	Early intervention needs to be at the point of referral. Early recognition of changes in need are not supported in a holistic way by the best practitioners and using all information that the elder has prepared by established in their living will.	Follow the recommendations on care and support needs assessment in NICE's guideline on people's experience in adult social care services.
3	Skills for Care	People with mild LD who have not been eligible for much care / issues around them aging and no-one responding to changed needs and / or issues of consent and self-neglect.		
4	British Dietetic Association	We recommend a quality standard on communication. That which enables and gives voice to the individual and tools to those working within this area (including i.e Talking Mats on Eating and Drinking choice, needs and consent for interventions)		
5	OLM Group	Information about the person should be provided in a way that they understand and their family/carers also understand.	Improving the understanding for the person and their carers (including care homes) improves the outcomes for the person. Informed decisions about the future for the persons developing needs can be made. Family carers and care providers will be able to respond quickly to the planned outcomes and make reasonable adjustments to support the persons changing needs. This will prevent breakdowns in placements. The person can be supported to make their own feelings and wishes known.	Public Health England found that 43.3% of family carers were usually consulted, 18.4% had no consultation at all.

6	People First	How staff and services find out what kinds of help and support people need	Older people with learning difficulties may not know what services do and so information would need to be given in an easy read format but I also think that the question should be asked what would older people with learning difficulties once in a service In the same way that there is a minimum level of staffing for an NHS hospital ward I would suggest that every local authority should have a bare minimum level of social care support and this should be monitored. For example there are 30,000 older disabled people in a local authority: In an ideal world a local authority should be able to report how many people they would need in their social care setup to meet the support needs of their old disabled people growing population to meet support need this would be different in every local authority and it should be UK wide we have an NHS plan we should have a social care plan At the moment there are not enough disabled and older disabled people in local community engagement groups like local HealthWatch groups for example. Moving forward there must be a recognition by staff and services to recognise that older and disabled people will not know what they are entitled to and run the risk on a daily basis of being	

			in a crisis because someone forgot to tell them about a service or staff team that could of helped them not get into the crisis in the first place. I am getting at communication sending the mail to an older person with a learning difficulty is not communication, face-to-face communication is communication Two different degrees older people with learning difficulties will need support to make health appointments at the moment if a person misses a health appointment they are fined this must stop this also applies to dental appointments so support to get to a health appointment must become the norm.	
7	Royal College of Speech and Language Therapists	All individuals who require assistive technology to aid or augment communication have access to specialist AAC services and equipment.	NHS England has stipulated that 10% of AAC assessment and equipment provision should be carried out by specialist AAC centres. Local services are responsible for the ongoing support for this 10% of the AAC-using population, as well as for the assessment, provision of equipment and ongoing support of the remaining 90% (Gascoigne, 2012).	The UN Convention on the Rights of persons with disabilities states in Article 9, 2(g) : “Parties shall also take appropriate measures to promote access for persons with disabilities to new information and communications technologies and systems, including the Internet.”

8	Royal College of Speech and Language Therapists	Ongoing and flexible communication support for people with learning disabilities.	There is good evidence that communication intervention for individuals with severe intellectual and development disabilities leads to positive changes (Snell et al., 2010). Communication support is often necessary for adults with learning disabilities and impacts on a wide range of activities of daily living, in turn effecting quality of life. Individuals will have varying and changing needs for communication support throughout stages of life therefore regular assessment and intervention is important.	The UN Convention on the Rights of persons with disabilities states in article 21 that: “Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice...” (b) “...Including by accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions.”
9	SCM1	Care and support planning: Accessible Information	By providing individuals and their families with information in a way they understand and spending time going through this with them at the earliest possible point, they are able to begin planning for the future before a time where emergency interventions may need to be put in place. Staff should be provided with training on alternative communication methods. Additional should be factored in to commissioned cared services for time to support individuals with decision making and planning.	See findings of the NHS Accessible Information Standard

10	SCM2	Providing accessible, tailored information (1.1.6)	Many people with a learning disability and their carers are not aware of what health and support services are available to them e.g. an Annual Health Check, LD Community Teams, etc.	
11	St Anne’s Community Services	Communication and adaptation of screening tools for pain	Due to communication barriers it can be difficult for a person with learning disabilities to express pain – non verbal communication may be missed meaning the client group are at greater risk of being in pain. Communication and adaption of screening tools for pain – re conditions of aging e.g. arthritis. Development of cancers often get diagnosed late as symptoms have not been identified – which often could’ve had better prognosis for treatment if diagnosed earlier.	
12	The Challenging Behaviour Foundation	Understanding and use of effective communication	To ensure the involvement of people with severe learning disabilities and behaviour that challenge staff need to use appropriate and effective communication skills to be able to meet individual’s specific communication needs.	People who have a severe learning disability often do not communicate verbally, but may use other methods of communication, such as signing or using picture systems. Communication methods need to be unique and specific to each individual. This should include consideration to a person’s behaviour. Challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a person’s needs or wishes are understood.

13	ADASS	Additional support for carers of older people with LD	As people with LD live longer their carers, often parents or siblings, may themselves have health issues due to ageing and require additional support	There is some good information to show that caring has an impact on carer health. Mencap have done some work in this as part of their breaking point campaign in the past, more recently the "bringing us together" report has some stark messages.
14	Foundation for People with Learning Disabilities	Practitioners carrying out assessments of care and support needs should take into account the needs, capabilities and wishes of families and carers. Also take into account that there may be mutual caring between people with learning disabilities, and their family members and carers, who are likely to be older themselves and have their own support needs.	Mutual caring is crucial if we are to ensure families can stay together and grow old together if this is what they wish to do. Early intervention crucial in planning both parents and son/daughters needs and planning for all. for example moving to a ground floor house with support in place for both. This will in turn save money as the practice and support will be in place with the least disruption to the person with a learning disability.	https://www.mentalhealth.org.uk/learning-disabilities/our-work/family-friends-community/mutual-caring the examples in this report are still relevant and valid. The use of the Car Act and assessments need to be in place
15	SCM3	Support for older people with learning disabilities and family carers living in the family home	Two-thirds of adults with learning disabilities live in the family home, usually with an ageing parent. Many of these are unknown to social care services until a crisis arises. Support which is provided is often inflexible and does not respect the existing caring relationship.	Family carers play a crucial role in enabling people with learning disabilities to remain in the family home. They are central in person-centred assessment and support planning for personal budgets. Most do not receive a Carer's Assessment and many experience poorer health, financial insecurity and social isolation.

16	SCM3	Working with older people with learning disabilities acting as carers. ‘mutual care’.	More people older people with learning disabilities are assuming caring responsibilities for the person (the parent) who has always been their primary carer.	The person with learning disability does not recognise their role as carer and this is not known or flagged up to services. Without proper support the caring relationship is vulnerable and both parties put at risk.
17	Skills for Care	Issues of mutual care where a family have cared for someone and parents (or siblings) are growing older and they might be managing the household but the leanring disabiled person might be doing physical tasks / care for them		

18	The Challenging Behaviour Foundation	Supporting, engaging and working with families	Supporting, working and engaging with families and carers is an important consideration in ensuring effective care of people. This is especially important in the care of someone with severe learning disabilities and behaviours that challenge.	Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. The National Service Model recognises the importance of involving family carers and other people who know the individual well in their care. Research has shown directly helping families of children and adults with learning disabilities is crucial to ensure the provision of capable and supportive environments for individuals whose behaviours challenge and to ensure a good quality of life for all. Families are diverse – their individual circumstances vary, so understanding each family context is essential to offering appropriate support. However, the involvement of families is not always taking place. Findings from the NHSE Building The Right Support evaluation showed that it can be a struggle to involve families.

19	The Down's Syndrome Association	To understand the complexity of family-carer relationships and appreciate that for this generation of older people with a learning disability especially, many may not be known to services	Many older people with a learning disability may undertake caring responsibilities for their elderly parents and recognition and support for this crucial "mutuality" of caring should be provided	
20	Mencap	Support and opportunities for older people with a learning disability must be person centred, allowing for both growth and transformation in addition to maintaining existing interests and social networks.	The aspiration for people getting older is often on maintaining friendships and relationships and keeping active, which is of course, very important. However, for some people with a learning disability, getting older can also be a time of increased independence, a time to develop relationships and to become more active – particularly for those that may have been living with parents their entire life. It is important people are supported and equipped to cope with change, access new opportunities and make new relationships, as well as maintain old ones. It is also often difficult for people with a learning disability to access bereavement support and much of this role may fall to supporters.	
21	NHS England (NCD)	Is there something we can include about loneliness?		
22	People First	How staff and services support people to make their own decisions and to speak up.	Local authorities that have closed down user led disabled peoples organisations need to reopen them as a start. Services that support people to speak up and make their own decisions and stay independent need to be staffed and	

			funded well. Disabled people need to be supported well to stay out of crisis. Society needs educating so that they know that supporting disabled people can be challenging and hard but it can also be rewarding in so many different ways Moving forward the system needs to adopt a social model of disability approach not a medical model of disability. Disabled peoples wishes to speak up stay independent have good choices to choose from is very important services need to be developed in our way to meet our aspirations and our hopes. Services need to recognise that we are people first we just happen to have a disability Since 2010 to present today because of cuts to services this has made isolation for disabled people a horrible reality that needs to be broken by developing a Society at a local level that has a moral compass to do the right thing. At a national level a lively debate needs to be started to help decision makers that hold the purse strings realise that disabled people want to play their active part in society whatever their age and disabled people are not just interested in disability issues they are interested in what is happening in the world around them.	

23	People First	How staff and services support people to continue doing things they enjoy doing	Support to access and use new technology. There is a big difference between care and support people are now in a position where they need support to access things they use to enjoy and restart the things that they used to like doing. They also need support to find out about things they could do with support that would be new and enjoyable to them. I was at a conference once a speaker was talking about her disabled son who went rock climbing in a wheelchair that came about because it was something that the young man wanted to do all he needed was people that support him to do it in the 21st-century disabled people need to have the support packages to meet their aspirations and to actually have the support to make those aspirations a reality by them happening. Staff that run services at local level need to be ready for that kind of aspiration and ambition whether disable people are old or young. My question is, if you put your mind to it anything is possible if you’ve got the courage to do it.	

24	Royal College of General Practitioners	Person centred care with a focus on community inclusion with developing and maintain social networks	The year 2001 marked the launch of ‘Valuing People’ (Department of Health 2001). This major policy document was based on four principles: civil rights, independence, choice and inclusion, and aimed at improving support to people with learning disabilities. In 2006, the government promised more personalised services in which service users had a stronger voice in what services they used and more influence over service improvement. As a result, in 2007 Putting People First (Department of Health 2007) was published and it emphasised self-directed support – defined by Gardner (2011) as having services available to meet people's needs rather than people having to fit in with the things on offer – as a key development area for Adult Social Care. People with learning disabilities spend a substantial amount of their lives in institutional care . It is vital that their care is individualised to their needs and wishes and they have activities that involve physical activity and stimulation	https://doi.org/10.1111/hsc.12048 The RCGP person centred care and toolkit http://www.rcgp.org.uk/clinical-and-research/our-programmes/person-centred-care.aspx https://www.mentalhealth.org.uk/sites/default/files/older_people_ld.pdf

25	SCM4	Support staff and services	People with learning disabilities should have a good life and should not be isolated. We might need support to make friends and be active. They wouldn't know what opportunities were out there and where to go to get help. Information is really important so you know what's out there. You should get support from all services like mainstream services so you can mix with other people. They should know about learning disabilities though. People with learning disabilities need support to access mainstream services but people who deliver them need support for working with people with learning disabilities. You need help and support in your local area so you don't have to go miles away out of the area because if you are out of the area, you aren't close to home. Staff need training so they know how to communicate with you and meet your needs.	
26	SCM5	Each older person with learning disabilities should have an independent mentor approved and appointed to oversee health and social integration	Many older people with learning disabilities are isolated, both in the community and institutions	Personal experience
27	Skills for Care	Isolation – magnified for people with an intellectual disability and older people and again if the person has autism		

28	Thera Trust	Improved opportunity and access to community provision	• Mapping and promoting access to community activities for older people • Provision of different types of support to enable families to continue to care for older relatives with a learning disability, such as respite provision	
Planning and reviewing care and support				
29	ADASS	Providing the right support at home for as long as possible.(Use of IPC/PHBs is helpful)	This is important as preserving relationships and known environments can be helpful, particularly where dementia is an issue.	Can we measure how personalised budgets are being used to support this?
30	British Association of Social Workers (BASW)	Adults growing older with learning disabilities need to receive support which is person centred and strengths based.	People growing older with learning disabilities need to have the access to appropriate care and support. At times, individuals receive care dependent on their age or specific disability and as such is essential that all care and support is centred upon an individuals own unique situation.	BASW and Shaping Our Lives have developed a joint charter for disabled adults which states • We will start with the disabled person's own views of their situation, priorities, aspirations and preferences • We will be honest about what is possible and what is not • We will have conversations rather than being bound by forms and procedures • The conversations will be meaningful and will be about what disabled adults want.
31	British Association of Social Workers (BASW)	Relationship based social work promotes good outcomes through supporting individuals to live	The named social worker pilot demonstrates the impact of good social work practice upon individuals.	Evaluation of the Named Social Worker Pilot can be found at https://www.scie.org.uk/social-work/named-social-

		independently reducing crisis situations arising.		worker/summary-evaluation-findings
32	Local Government Association (LGA)	Person-centred planning needs to include planning for the future, and support to families/carers of older people with a learning disability.	Early planning/discussions with people will help ensure that the arrangements are in place for the future, and that these have been developed in partnership with the person and family/carers. This is also about ensuring support to families, including emotional support where carers are no longer able to provide the care that they did or additional/different support to carers who are continuing in their caring role but with someone who may need additional support or have different needs as they get older. This is also about recognising the health and wellbeing needs of carers who themselves may have age-related health and support needs.	There is lots of evidence relating to the pressures on unpaid carers and the impact this can have on health.

33	Mencap	Supported decision making, adherence to the MCA and involvement of family and supporters in decision making.	It is important that staff have a good understanding of both the Mental Capacity Act and the support people may require to make decisions. It is particularly important for older people with a learning disability who may be making key decisions about changes to care, medical treatments, palliative care and end of life decisions. For some older people, who may find themselves living away from family for the first time, this may be a new experience. Where someone is not able to make a decision for themselves, it is important that family and others who know them well are involved. The role of individual family members may change as a person gets older and these family members may need to support themselves to understand how they can play a role in best interest decisions about their loved one's care.	Both CIPOLD and subsequently, LeDeR, have recommended better training and compliance with the mental capacity act for health and social care staff. The Getting Things Changed Project from Bristol University has made recommendations on supported decision making based on recent research – with a key focus on the quality of the relationship with supporters.
34	National Development Team for Inclusion	Planning for support needs and transitions in life as people with a learning disability age	Many people with a learning disability are living with parents or family members. As they all age, and people may be bereaved, there is a need for new support or a move into supported living to take plac. This can be hugely distressing for the person unless planned in advance.	

35	National Development Team for Inclusion	Life transitions and inclusion e.g. retirement from work or change from type of service provision.	People without a learning disability assume they will go through a transition to later life with a change in what they do in the day- e.g. retirement, or not looking after grown up children. Older people with a learning disability may have worked, or may have had day support, which they wish to change in line with their age and interests, and changes in health or energy levels. We need to consider how services enable this transition for people so their social and community lives move on appropriately as they age.	I come across people who have been at the same day centre or doing the same thing, from when they are 20 until they die. When people don’t have a natural change such as retirement from work we might forget that they deserve some change to move through later life phases as other people do. I don’t believe much has been done to think about how we enable people to plan and set aspirations for their later lives. Especially if they have not been supported to have aspirations such as work and contributions to society earlier in their lives.

36	Nottinghamshire Healthcare NHS Foundation Trust	If we were talking about people with LD growing up, we would be looking at the procedures in place to help deal with the transition from children's services to adult services... which is a massive area where LD people fail to negotiate that transition. Similarly we need to look at the transition older LD people go through from adult social care to pension eligibility. Are their benefits affected or any contractual agreements affected in their care package? Also now that we are looking into why LD people die earlier than the general population, we will be looking to improve on that, that will lead to even more LD people hitting the pension transition threshold in the near future.		

37	OLM Group	Reviews of person centered plans with the pathways to support the person as they age must take place annually and more as needed. The person MUST be involved in these and supported by a lead practitioner.	Reviews of plans ensure that they are proactive and the person is kept at the center of their support. Reviewing the plans regularly including a review of the housing needs will enable proactive steps to be taken to make reasonable adjustments to the persons current housing which will promote the opportunity for the person to remain in their own home for as long as possible. Collaborative working promotes the persons individuality and therefore challenges any assumptions that may have been made about the person that could adversely affect the support they actually require.	Hidden in plain sight highlighted that it is evidence that people aging with learning disabilities are not supported to live independently to old age. NICE guidelines highlight that there should be adjustments made as the person gets older so they can stay in their current housing.
38	People First	How to make services work better for people with learning disabilities as they grow older	Services need to be more person centred people should not be in the position where when local authority pay for support in a different county support needs to be in the town in which person grew up in and the environment they now. A persons support package should be aiming at keeping the person as independent as possible for as long as possible. Services change their names people move jobs because of this older people with learning difficulties don't know what they are in titled to Who to go to so that needs to be a structure in place where they can get information to people speak to older people with learning difficulties about what support they are	

			entitled to. Older person with a learning difficulty accessing one service that needs to be flagging system on other agencies so that they are notified at some point older person with a learning difficulty may need to access their services The referable system that is currently in place needs to be made much easier so that the person who has a learning difficulty and who is all there is told in a way that meets their access needs. At the moment society may think that older people are into tiddlywinks tea and coffee morning and bowling but for people with learning difficulties who are older that is not the kind of thing that they are into. Weekends away Day trips managing home finances Will always take three times longer than it would if the older person didn't have a learning difficulty this needs to be recognised and support plans for older people with learning difficulty.	
39	SCM1	Planning and commissioning of services	Services should have mechanisms in place to plan for changes to health needs and changes in capacity, with regular opportunities for review, to ensure that any changes are planned as far in advance as possible before emergency interventions are put in place.	

40	SCM1	Person centred planning and future planning	Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the future. Help them to make decisions before a crisis point or life-changing event is reached	
41	SCM2	Planning for the Future (1.4.6)	There is good evidence that planning for a person's older age needs is better than reacting to changes as they arise	More people with a Learning Disability are moved in older age or die in hospital than the general population because appropriate planning has not been carried out
42	SCM5	Social care planning to be put in place	Many have their future unresolved	Personal experience
43	SCM6	Ensuring all assessment and support plans are person centred	Historically services are designed based on what professionals think are needed for people rather than services being based on need and the aspirations of people. We end up fitting people into existing services rather than building support around the person	Person centred plan and good outcomes. Valuing people. There is a wealth of evidence and research which set out what good person centred planning looks like and how it can be achieved.
44	SCM6	Ensuring people are included in any decisions which affect their life.	It is important that people are seen as people first rather than any decision being overshadowed with their learning disability	There is a lack of understanding about the mental capacity act amongst practitioners and other people make decisions about the person life without including them or considering the legislation under the mental capacity act
45	SCM7	Having choice and control	I think informed choices and control come out in everything	
46	SCM7	Planning your care as you get older	Because I think this gets missed out	

47	SCM7	Checking you have the right care and support as you get older	You might not be 'compos mentis' at some point, so you need to check you have the right support as you go. You need to do it before.	
48	Skills for Care	Unsuitable care; their long terms care arrangements are probably not well enough funded to provide the care they need as they age – but they are then moved into older people's services which don't have the time or skills to meet their LD needs		
49	St Anne's Community Services	Encouraging and promoting wellbeing throughout all stages of life.	Forward planning is essential – there is a need and a building evidence base for ensuring people with learning disabilities, their families and professionals who support them need to refocus on health care instead of primary focus being on social care when planning care and support. The idea of a transition phase from adult to older age could be positive as at the moment the main focus seems to be a transition from child to adult but there should be equal focus on transition to older adult as the change can be just as significant	Please see PCPLD Network The Ambitions for Palliative and End of Life Care https://www.england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability/ Also Talking about Dying Research

50	The Down's Syndrome Association	To support individuals with a learning disability to recognise the patterns of life and understand that aging is a part of this	For those individuals who work, retirement will be a natural development and community-based services should be responsive to the changing needs of an older population of people with a learning disability and provide meaningful services to ensure older people with a learning disability live fulfilled lives. It is likely that support needs will increase with age and person-centred planning approaches should reflect this and provide flexibility and additional funding to meet these changing needs.	Evidence from families suggested that this rarely happens and the current provision of adult social care lacks forward planning. This has a detrimental effect on the mental health of some adults with a learning disability we support.
51	Care & Repair England	Consideration of a person’s housing circumstances and wishes as an integral part of their care and support need as they grow older	Having a good, decent, warm, accessible home is important in supporting the delivery of good care and support services people with learning disabilities people living in the community. This might include people living in their own homes, in the home of their parents/ carers, in supported and specialist housing or in residential care where they might wish to live more independently. Housing interventions such as repairs and adaptations to the home or a move to more supported or specialist housing if appropriate are an important ingredient in delivering good care and support services to people in mainstream or specialist homes. Reference to the role of housing in the quality standard would encourage a	Evidence that areas requires improvement include: - Information and advice –Information on the options available and related advice are key to ensuring a positive experience of the provision of care and support services. We consider this should include housing options and solutions more clearly in considerations of a person’s social care and support needs. This has not always been the case. A short study undertaken by older people in the NW of England, for example, identified shortcomings in the information and advice available on housing options locally. We know that this is also the case in other

			greater focus on the delivery of holistic services for people growing older with learning disabilities	parts of the country. Offering bespoke advice and information at the right time and in the right format is crucial to enable people to take more control. http://ageactionalliance.org/search-engine-failure-housing-and-care-advice-in-the-north-west/ Evidence that areas requires improvement include: - Information and advice –Information on the options available and related advice are key to ensuring a positive experience of the provision of care and support services. We consider this should include housing options and solutions more clearly in considerations of a person’s social care and support needs. This has not always been the case. A short study undertaken by older people in the NW of England, for example, identified shortcomings in the information and advice available on housing options locally. We know that this is also the case in other parts of the country. Offering bespoke advice and information at the right time and in the right format is crucial to enable people to take more control. http://ageactionalliance.org/search-engine-failure-housing-and-care-

				advice-in-the-north-west/ Assessment – ensuring housing factors are properly considered will mean that people with learning disabilities live in the right (warm, safe, secure) environment to provide the foundation for their care and support, and their health and wellbeing as they age. The Care Act 2014 expects that housing factors are part of an integrated assessment. It also calls for housing options to be considered in the provision of information and advice highlighted above. This recognises that a consideration of people’s housing needs and circumstances is essential to good social care and support. We would like to suggest that practice in this area could be improved by adding a consideration of where and how people live – their housing -to this quality standard. Care planning and provision We would like to see more focus on ensuring that the care plan and thus the provision on offer includes the person’s housing circumstances and needs. This means identifying and planning actions that will improve their circumstances as people with learning disabilities age - for example

				home adaptations, home repairs or moving options. It also means ensuring that the support needed to undertake these agreed housing changes can be identified, put in place and monitored over time.
52	Foundation for People with Learning Disabilities	Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this. Regularly check people's willingness and ability to be involved in this way.	Ensuring that individuals are able to think about growing older early in order to ensure that their wishes, in case of diminished capacity, to be at the forefront of planning. Evidence suggests that this is not happening.	https://www.equalityhumanrights.com/sites/default/files/research-report-114-housing-and-disabled-people-experiences-in-britain.pdf

53	Local Government Association (LGA)	Decisions about where people live should made with the person and not be based on an ‘automatic’ assumption that a particular setting is the default ‘best’ option for people. This needs to include more options for support in the person’s home.	As noted in the guidance, some age-related conditions can become present in people with a learning disability at a younger age. However, the services that are developed to support people with these conditions are often developed with much older people in mind. This can lead to people with a learning disability using or even living in services that are inappropriate for them in many ways. People who live in a supported living environment can find themselves moved to an ‘older persons service’ when their needs change. The development of appropriate support and adaptations to current living environments should be explored with the person/their family. This can help the person in remaining in an environment that is familiar to them and can support people to maintain relationships.	

54	Mencap	Forward planning, anticipation of changing needs and ability to adapt existing support.	People with a learning disability are more likely to already receive social care support or to live in a residential care setting than the general population. Support services and care plans must be designed and commissioned in a way where early indications of changing needs are taken into account and support provision can be adapted to allow people to continue to live in their current home or receive support from their current provider, where this is what the person wants.	Lack of forward planning can result in crises, which can have a significant impact on the individual, for example, a health crisis (CIPOLD 2013) sudden changes in support, or the need to move. Changing needs can also lead to moves to older people's services – who are often not experienced or skilled in working with people with learning disabilities or indeed that particular person. People with a learning disability may access older people's services e.g. dementia services, at a younger age, which may not be appropriate for their interests or social needs.
55	National Development Team for Inclusion	Supporting people with a learning disability well with bereavement and loss	Growing older naturally increase the likelihood of losing close family and friends. Supporting people well through this transition when they have a learning disability is essential and needs to be done in a way which works for the individual	
56	NHS England (NCD)	Use of digital innovations to help keep people safe in their own homes/communities e.g. early warning/alerts		

57	Royal College of General Practitioners	Help for bereavement and grief in older people with learning disabilities	Bereavement, loss and grief in people with learning disabilities often manifests itself in the person having behavioural problems	https://www.researchgate.net/profile/Sheila_Hollins/publication/13896979_Bereavement_in_grief_in_adults_with_learning_disabilities/links/0fcfd50e45c750aa0c000000/Bereavement-in-grief-in-adults-with-learning-disabilities.pdf
58	Royal College of General Practitioners	Annual health action planning including advanced care planning for all adults aged 40 years and over. This should involve making a will and being involved in a treatment escalation plan so they can stay in their home or residential home until death without the need to transfer to end of life care to hospital or nursing home unless absolutely necessary. All deaths of people with a learning disability should be reported to LeDeR	CIPOLD 2013 reviewed the deaths of 247 people with learning disabilities over the 2-year period in 2010–2012. The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died. http://www.bristol.ac.uk/cipold/	The Learning Disabilities Mortality Review (LeDeR) is the first national programme of its kind aimed at making improvements to the lives of people with learning disabilities. Reviews are being carried out with a view to improve the standard and quality of care for people with learning disabilities. People with learning disabilities, their families and carers have been central to developing and delivering the programme. http://www.bristol.ac.uk/sps/leder/

59	SCM8	Enabling older people with learning disabilities to stay in their own home, inc. Supported Living	There can be a tendency for commissioners to look to Elder residential care when people's needs change due to aging, in particular when they are currently living in a Supported Living environment. However the current generation of older people supported at home (supported living), in the main, have come from long- stay institutions and therefore have relatively recently gained the same social status as other UK citizens. They should now be enabled to "age in place" - increased well-being in old age and continued social inclusion.	People living at home through a supported living arrangement should be highlighted in the quality standards to ensure that they are not disadvantaged because they are already in the care system. As a result of their social history, they are unlikely to have the same personal histories and backgrounds as their non- disabled peers, therefore isolating them in elder care services. The British Institute of Learning Disability have picked this matter up as part of their Aging Well campaign siting the 2008 Sixsmith and Sixsmith report on Aging in Place.
60	The Challenging Behaviour Foundation	Planning Suitable Housing	Majority of people with learning disabilities live with their families. Many people live with elderly parents until their parents die / are too frail to care for them and then they have to make a traumatic move when they are also coping with bereavement.	It has been known for many years that there is a large number of people with learning disabilities living with elderly carers
61	The Down's Syndrome Association	Support should be provided to families to help them plan for the future	This should include i) financial planning for parents to make provision in their wills for adult offspring with a learning disability ii) support to family-carers to make appropriate power of attorney arrangements and iii) sensitive support to individuals with a learning disability to	

			make appropriate advance care directives for their own care, as they age.	
62	Thera Trust	Choice to continue to live in own home including Supported Living environment	• Clear route for re-assessment of both care and housing needs • Promotion of individual choice and opportunity to remain in own home (whether family home or supported living) – “age-in-place” • Adaptations to existing home and introduction of assistive technology • Collaborative working between health and social care professionals alongside the person’s circle of support • Promotion of consistency and continuity of care and support	
63	British Association of Social Workers (BASW)	Adults growing older with learning disabilities receive support in partnership with health and social care professionals.	Professionals working together to provide a network of support based upon working in partnership with the individual involved. Seeking to overcome challenges and barriers to multi disciplinary working.	Evidence states that people with learning disabilities have poorer health – as such the collaborative working between health and social care is essential to promote the wellbeing of individual.
64	Local Government Association (LGA)	There should be an established understanding of the person, their behaviour and health through the use of good practice approaches and tools such as person centred plans, communication passports and behaviour support plans. This will help ensure that any changes to people’s behaviour is recognised, thereby	Professionals may have difficulty distinguishing the symptoms of a condition such as dementia from those associated with learning disabilities. If practitioners know the person well, have a clear understanding of people and their communication methods, they will be more likely to be able to diagnose conditions, including dementia.	Some overlaps here with the NICE guidance on challenging behaviour and learning disability in relation to good practice around supporting behaviours that may challenge services, (i.e. where people with dementia may develop behaviour that challenges).

		reducing the risk of diagnostic overshadowing.		
65	Mencap	Consistent and co-ordinated support for older people with a learning disability.	Consistent, co-ordinated support, with a good understanding of the person and their needs, accompanied by good information sharing is vital. High quality support, with staff who have knowledge and experience of your needs is important at any time for many people with a learning disability, and particularly for older people whose needs are likely to change. Good knowledge of an individual, accompanied by good communication and co-ordination means that supporters, services and commissioners can recognise and respond to changing needs in good time. High quality annual health checks – including baselines and comprehensive health action plans, and additional information on SCRs, can also help to ensure the right information is available at the right time.	CIPOLD highlighted a number of cases where care and support was neither co-ordinated, nor consistent. Examples included frequent changes to provider, moves and poor information sharing, leading to knowledge gaps, difficulties with accessing care and distress for the individual. Vital information was not always kept or shared within or between services, which led to a loss of information about health and support needs – previous diagnoses or signs of deterioration can be missed. In addition, baselines are not always taken or available. Several of the key recommendations from the LeDeR annual report (2018) also relate to a need for improved information sharing and co-ordination of care.
66	NHS England (NCD)	Case coordinator to facilitate pathways/care assuming many will be living with two or more long term (physical or mental health) conditions		

67	OLM Group	Person centered plans need to include a pathway which identifies changes the person may experience as they grow older, These must be developed with a multiagency and provide a pathway between primary care, secondary care and palliative care.	Excellent care is linked directly to the provision of reasonable adjustments being made. Person centered plans are vital to ensure that these adjustments are identified and followed through. The benefits of having a clear pathway for the persons changing needs include the ability to plan for changing needs, wishes and capabilities as the person grows older which supports NICE guidance. Decisions can also be made before crisis or any life changing events.	Hidden in plain sight found that, inequalities experienced by people with learning disabilities are many and the response from those who are there to support them, from policy to practice, is wanting.

68	OLM Group	All people with learning disabilities should have a lead practitioner to coordinate their care. Information needs to be shared between primary health and the service providers	There is evidence to suggest that having a lead practitioner who is familiar with the person leads to a more cohesive and joined up plan of care for the person. Lead practitioners with a good knowledge of the actual person can support avoidance of diagnostic overshadowing when planning for care as the person grows older. Evidence suggests that decisions can be made effectively, about the persons future. This can be done before crisis or life changing events occur. They will ensure that these decisions are proactive, led by the person, and cover the needs and wishes of the person. Following the NICE guidelines the lead practitioner would be able to ensure that for the assessments a full history is available and they have the understanding of the persons usual behaviour. The assessment is then strength based and developed on a deep understanding of the person, this will make it easier to identify changes which need to be addressed.	Evidence suggests that diagnostic overshadowing takes place which leads to the person actual needs being missed and treatment delayed. The learning disability mortality review 2017 found that better communication and coordination of care was required and that records needed to be improved to support this. Evidence provided by Public Health England highlights that there has been a decline in professional support since 2008/2009. 13% of family carers reported that they had not received any support from social services at all.

69	OLM Group	Promoting learning disability champions in care providers and primary care provisions.	Having a champion to explain, accompany, remind the person about appointments, etc improves the outcomes of any medical appointments. Effective and proactive planning can take place with the person having as much input as possible.	Evidence suggests that there is a gap in the experiences of people supported with positive medical appointments. People who do not have information explained, time taken to make adjustments and support to attend and understand information do not receive the same quality of care.
70	The Down's Syndrome Association	To increase the level of cooperation and sharing of expertise between generic aging services	Especially palliative care and end of life support services) and learning disability services to ensure that individuals with a learning disability receive the support that is most suited to their needs.	

71	The Faculty of General Dental Practice	Care Integration	People with intellectual disabilities (ID) have poorer health than the general population, particularly in relation to some specific aspects of their health.	Healthcare professionals providing care for a particularly visible and obvious condition or disability should ensure that other areas of potential morbidity are also assessed and appropriately treated.
Identifying and managing health needs				

72	Action on Hearing Loss	Ensuring deafness and hearing loss are included local health needs assessments.	Evidence suggests that up to 40% of people with learning disabilities have hearing loss. The prevalence of hearing loss is higher in people with learning disabilities compared to the general population and people with learning disabilities are more likely to develop hearing loss and its associated health problems earlier. Older people are the largest and fastest growing group in the learning disability population. By 2030, an estimated 5,000 people with learning disabilities aged 80 and over will use social care services – an increase of 164%.4 Many older people with learning disabilities will also require support for their hearing loss. Hearing loss is a serious health condition that can have an adverse impact on a person's health and quality of life. Hearing loss has been associated with an increased burden of disease amongst adults and an increased risk of mortality. Unaddressed hearing loss can lead to social isolation, emotional distress and withdrawal from social situations. For example, one study found that hearing loss is associated with feelings of loneliness – but only for people who don't wear hearing aids. Evidence suggests that poor communication or lack of awareness of Deaf culture in care homes can lead people who are Deaf	The Department of Health and NHS England's Action Plan on Hearing Loss states that hearing loss is a "major public health issue" that should be considered in the context of strategies and plans aiming to reduce the impact of long-term conditions, such as learning disabilities. The Action Plan states that hearing loss should be "included as part of the process to develop local health needs assessments, Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs)." NHS England has produced guidance to help local authorities and NHS commissioners assess the needs of people who are deaf or have hearing loss living in their local area. This guidance was produced in partnership with the Local Government Association (LGA) and the Association of Directors of Public Health (ADPH) and will be published later this year. Our previous research demonstrated the need for more guidance for local authorities in this area. Our 2012 Life Support report showed that only around one-third (35%) of local authorities in England include

			becoming isolated. Hearing loss has been associated with depression, anxiety and other mental health problems. Evidence suggests that hearing loss doubles the risk of depression. There is also growing evidence of an association between hearing loss, cognitive decline and dementia. A recent study identified hearing loss as the largest modifiable risk factor for dementia. If removed, the study states that 9% of dementia cases could be prevented. Ensuring deafness and hearing loss are properly included local health needs assessments and learning disability strategies is crucial for ensuring commissioning decisions are co-ordinated and reflect local needs. As highlighted in NHS England's Commissioning Framework for Adult Hearing Loss Services, given the growing prevalence and impact of deafness and hearing loss, relying on past activity alone to plan future services will result in avoidable budget pressures and increase the already high level of unmet need.	hearing loss as a specific issue in their JSNAs.
73	Action on Hearing Loss	Improving the diagnosis and management of hearing loss in people with learning disabilities.	There's gold-standard evidence that hearing aids are a cost effective form of treatment that improve quality of life and the listening ability of people with hearing loss. Hearing aids have been	Despite gold-standard evidence that hearing aids improve quality of life and reduce health risks, research shows that only two-fifths of people who need hearing aids have them.14

			shown to have a positive impact on overall health. Research shows that hearing aids reduce the risk of loneliness and depression and early evidence suggests that they may even reduce the risk of dementia. NICE's Hearing Loss in Adults Guideline1 recommends that GPs should consider referring people with a diagnosed learning disability for a hearing assessment every two years, because hearing loss is a comorbid condition. The NICE Care and Support of People Growing Older with Learning Disabilities Guideline also states that GPs and other health and social care professionals should be alert to the sensory needs of older people with learning disabilities. The guideline states that health professionals carrying out health checks for people with learning disabilities should closely monitor symptoms for hearing loss or changes in a person's hearing. It also highlights the importance of providing hearing loss information in accessible formats such as Easy Read. The NICE Hearing Loss in Adults Guideline1 notes that some people with learning disabilities may not be aware of their hearing loss or face difficulties seeking help due to communication	Negative stereotypes about hearing loss and hearing aids as well as fear of stigma itself can be a significant barrier stopping people from seeking help. Older people may view hearing loss as an inevitable part of the ageing process and may find it difficult to access support for their hearing loss due to communication or memory problems caused by dementia or other long-term conditions. Older people with learning disabilities may find it especially difficult to seek help for their hearing loss due to communication difficulties or the lack of accessible information, which can lead to misdiagnosis or ineffective treatment.3 Research shows that people wait ten years on average before seeking help for their hearing loss and when they do, GPs fail to refer up to 45% of those reporting hearing loss to hearing services.18 There is also considerable variation across England in terms of how many people are referred to audiology. The NHS England Atlas of Variation shows an 11 fold variation in the rate of audiology assessments in different areas across the UK, suggesting that GPs vary greatly in terms of how

			problems. The longer people wait before seeking help for their hearing loss, the less likely they are to benefit from hearing aids. The Guideline states that unaddressed hearing loss in people with learning disabilities will “significantly affect understanding and social interactions and will exacerbate underlying cognitive difficulties.”	many people with hearing loss they refer. The NICE development committee for the Hearing Loss in Adults Guideline1 noted that they were not aware of any evidence that hearing is routinely assessed during health checks for adults with learning disabilities. Evidence suggests that the attitudes and awareness of GPs and other health and social care professionals may be an additional barrier preventing people with learning disabilities from seeking help for their hearing loss. For example, one study found the format of GP hearing checks were often inappropriate for people with learning disabilities. Some GPs who were interview as part of the study were reluctant to refer people with learning disabilities for a hearing assessment due to misconceptions that diagnosis and treatment would be ineffective due to communication and/or behavioural difficulties. This finding is supported by another study, which found that carers of people with learning disabilities were often unaware of the early signs of hearing loss or misinterpreted hearing loss as behavioural difficulties.

74	Action on Hearing Loss	Improving access to hearing aid support	After being fitted with hearing aids, people with hearing loss will need further support to get the most out of them. Hearing aid batteries typically last no more than a week and hearing aids will require regular cleaning and maintenance. Without ongoing support, people with hearing loss may find it difficult to adjust to hearing aids and may even stop using them altogether32 – putting them at risk of loneliness and poor care. Older people and people with learning disabilities may require support with hearing aid cleaning and maintenance in their own home or in care homes, especially if they find it difficult to use their hearing aids or to visit their audiologist due to frailty, mobility or communication problems. The NICE Hearing Loss in Adults Guideline1 highlights the importance of ongoing hearing aid aftercare and the need for a flexible approach in the delivery of services to ensure some populations, such as people with learning disabilities, are not disadvantaged. The Guideline states that failing to provide hearing aid aftercare “can result in people giving up using their hearing aids and may consequently have a negative impact on their quality of life over time as their ability to communicate	Evidence suggests that the ability of people to access hearing aid aftercare and other services, such as ear wax removal, depends to a large extent on where they live. For example, our Under Pressure report found that only half (49%) of NHS audiology services offer patients face-to-face follow-up appointments and less than half (43%) offer hearing aid aftercare in care home settings. NICE’s Hearing Loss in Adults Guideline1 notes that in some areas, GP surgeries do not treat uncomplicated ear wax and instead only prescribe long courses of ear drops which, used on their own, are ineffective. Evidence also suggests that people with learning disabilities may struggle to access ongoing hearing aid support. For example, research shows that 70% of people with learning disabilities have been seen by audiologist at some point in their lifetime, but only 24% receive on-going hearing aid support. Evidence suggests hearing loss is often overlooked during the day-to-day management of care homes and other care settings. Our World of Silence26 report found that processes for managing hearing loss and looking after hearing aids in care

			and participate in everyday situations declines.”	homes are not always consistently followed and are sometimes de-prioritised compared to other long-term conditions. For example, some care staff who were interviewed as part of the study said that they relied on family members or older people themselves to notify them if hearing aid batteries or tubing needed replacing. Other staff reported that checks for ear wax were not carried out on a regular basis. These findings are supported by similar research exploring the experiences of people with learning disabilities living in care homes or sheltered accommodation. For example, one study found that care staff working with people with learning disabilities did not know about hearing loss and lacked the know how to carry out basic hearing aid maintenance.

75	ADASS	Recognising signs of the onset of dementia and provision of support and training for staff and family carers	People with LD are more at risk of developing dementia at an earlier age. Earlier diagnosis will help to tailor care and support plans, and ensure greater access to mainstream dementia services	Some useful checklists that carers could be trained in may be useful such as the PASADD checklist or similar. This may be useful for picking up other changes that could contribute to diagnostic overshadowing. Other important checks such as thyroid function are also important. Local NHS provider trusts should be using clear pathways so that referrals are addressed consistently.
76	ADASS	Ensuring annual health checks are carried out for people with LD, with increasing frequency over 65	Preventative screening for disease or illness to ensure earlier diagnosis and treatment	Evidence for SAF of variable take up of annual health checks?

77	British Dietetic Association	We recommend a quality statement on Nutritional care for people growing older with a learning disability – Provision of support for those growing older with learning disabilities and their carers.	People with a diagnosis of learning disability are at higher risk of obesity, malnutrition and dysphagia than the general population, in addition people with a learning disability are known to die at a younger age (13-20years younger than the general population). There are significant health inequalities in this group. Difficulties with eating, drinking and swallowing have a significant impact on health and wellbeing. 40% of people with learning disabilities with dysphagia experience recurrent respiratory tract infections, further physical health consequences include: asphyxia, dehydration, poor nutritional status and urinary tract infections. The most frequent cause of death in people with learning disabilities is respiratory infection which is often linked with difficulties with eating, drinking and swallowing. People with learning disabilities are often dependent on others to provide or support them in eating a healthy diet for them; carers often lack the nutritional knowledge to provide this.	Training on the importance of good nutrition in learning disabilities for carers and health professionals supporting people growing older with learning disabilities is variable, with many not having access to this type of training. Provision of dietetic services to support those growing older with learning disabilities and their carers is poor and variable across the county.

78	Foundation for People with Learning Disabilities	Mental health commissioners should develop protocols to ensure that people with learning disabilities, including people in later old age, have access to mainstream mental health services for older people, including dementia support.	The mental health needs of people with learning disabilities are not well supported in old age. Early evidence from the McIntyre Charity work on Learning disability and dementia indicates the need for training of staff to recognise changes in people they support and ensure that support is person centred and supports people to lead as normal to them a life as possible.	https://www.macintyrecharity.org/ new report on dementia and training for support staff also see outcomes from research on what people say. https://www.mentalhealth.org.uk/sites/default/files/feeling-down-report-2014.pdf guides are available that can support understanding of the complexity of recognising the mental health needs of people and ensuring that they are supported by the best practitioners. Support staff are equipped to listen and support but are not psychologist, counsellors etc. the best practitioners might be in mainstream.
79	Local Government Association (LGA)	Support to staff and families to recognise the onset of dementia in people with a learning disability and reasonable adjustments to dementia services.	There is an evidence base that shows that people with a learning disability are more at risk of developing dementia at an earlier age. Specific age-related services, such as dementia services, need to be able to meet the needs of older people with a learning disability. Support to staff and family members will help with care and support planning.	There is lots of guidance and good practice relating to reasonable adjustments to dementia services for people with a learning disability. The IHAL research includes evidence, research and best practice.
80	Local Government Association (LGA)	Improved health outcomes for people through increased take up of annual health checks.	This is not exclusive to older people with a learning disability, but a commitment to the increase in take up of annual health checks needs to also apply to those over the age of 65.	There is a significant evidence base relating to the health in equalities faced by people with a learning disability. Annual health checks can lead to earlier diagnosis and

				treatment, preventing ill-health and behaviours that may challenge services where this are as a result of an undiagnosed health condition. SCIE has examined health-related literature on aging and learning disability, focused on age-associated health risk factors.
81	National Development Team for Inclusion	Living well with Dementia and a learning disability	People with Down syndrome are at greater risk of Dementia, and earlier than the general population. Those with other learning disabilities may not receive the diagnosis due to diagnostic overshadowing.	
82	National Development Team for Inclusion	Health changes as people age- prevention and good support is needed.	As people age with our without a learning disability, health risks and issues increase. Good planning and support and close working with GPs and specialist health services is essential throughout life but especially as people get older. This includes the need for good sensory impairment testing- hearing and sight loss often go undiagnosed, reducing the person's communication and quality of life.	Improving health and lives has looked at what it takes to ensure people access screening and health interventions. Reasonable adjustments in health services can be made to support people to have equal access to good health support, which is essential as they get older.
83	NHS England (NCD)	Annual health checks but also accessible, reasonably adjusted or even targetted health promotion/self management opportunities esp now with growth of digital innovations		

84	NHS England (NCD)	Medicines optimisation		
85	OLM Group	Annual health checks for the individual need to be promoted and explained in a way they understand. They should have access to the same professional in the primary care settings. Where the person has dementia this should be 1-6 times per year depending on deterioration (hidden in plain sight).	People with learning disabilities are entitled to the same routine screenings as all older people without learning disabilities. Annual health checks will allow for proactive planning to take place and avoid early mortality where the required referrals are made effectively.	Annual health checks are not always followed up by prompt referral to specialists when required. This has led to delays in treatment and support. The Hidden in Plain Sight report highlights that people over 65yrs with downs syndrome will double by 2020 and that over a third of people with learning disabilities will be over the age of 50. People with learning disabilities are 3x more likely to develop dementia. The learning disability mortality review 2017 found that the main causes of death were respiratory (aspiration) circulatory and cancer. It also evidences that better communication and coordination of care was required. There is a 20 year gap at the age of death for people with a learning disability and those without. This higher mortality rate is an outcome of health inequality. Public Health England found that 43% of deaths were considered premature. They also found that annual health checks carried out on eligible people in 2014-2015 was 63.2% There are still about 77% of people not identified on the GP's

				registered as having a learning disability. NICE guidance is that GPs hold a register of people with learning disabilities.
86	Royal College of General Practitioners	Proactive annual health checks that focus on hearing, vision, foot care and dental care	Older adults with learning disabilities are a heterogeneous group of patients and have health conditions and factors affecting their health that can vary in kind, manifestation, severity, or complexity from those of others in the community. They require approaches to care and interventions that are adapted to their needs.	The RCGP annual health checks tool kit http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx Primary care of adults with intellectual and developmental disabilities 2018 Canadian consensus guidelines http://www.cfp.ca/content/cfp/64/4/254.full.pdf
87	Royal College of Speech and Language Therapists	All individuals with learning disabilities who are ageing and have swallowing difficulties should have regular re-assessment and appropriate intervention planning with the multi-disciplinary team.	Dysphagia (difficulties with swallowing) is common in adults with learning disabilities (Chadwick and Joliffe, 2008) and the ageing individual is also susceptible to age-related changes in dysphagia (Sura et al., 2012). If an individual has communication difficulties too then they may be unable to express discomfort with feeding and drinking.	All individuals with learning disabilities who are ageing and have swallowing difficulties should have regular re-assessment and appropriate intervention planning with the multi-disciplinary team.
88	SCM2	Diagnostic Overshadowing (1.3.4)	There is good evidence that when someone with a Learning Disabilities health status changes that a full investigation rather than assuming is their LD is highly beneficial	If a health status change is not properly investigated this can significantly foreshorten a person's life

89	SCM2	Training in recognising changes and managing age related conditions (1.5.6)	Many people’s changing health needs are often over looked or conflated with their learning disability. If carers are given training in what to be alert to then this can be extremely beneficial	Cares need to be helped to recognise changes in a person’s health status especially if that individual has communication problems.
90	SCM3	Access to primary and hospital health services	There is extensive and consistent evidence that people with learning disabilities die younger and have poorer health experiences than the general population	People with learning disabilities die younger than the general population for reasons unrelated to their learning disability. There is evidence to show the failure of services to make reasonable adjustments leads to undiagnosed conditions, over-shadowing and premature death
91	SCM4	If you have the right care and support	If they didn’t check, you could be really ill and they wouldn’t know. This could lead to serious problems. It should be someone who knows you well because I don’t like working with strangers. It makes me feel uncomfortable and like I can’t say what I want or need. There is more to me than a learning disability. There could be something else really wrong and not just my learning disability. Getting the right support is really important. Carers need support too. People with learning disabilities can also be carers and they would need a different type of support.	
92	SCM4	Keeping well	You should have someone who knows you well and who looks after your health. They should also know about learning disabilities. You should have extra time at the doctors	

			or appointments if you need it. Sometimes you don't have the time to get out all you want to say or other people might find it hard to say how they feel. They should know about learning disabilities and understand how to communicate with you. Seeing someone who knows you well is important because they would notice any changed in your behaviour or appearance. They also know how to talk to you and I would trust them. We would have a relationship. I don't feel comfortable working with strangers. I should be included in my health. It is mine and I should know what is going on or someone should explain it to me in a way that I can understand. You should always feel comfortable with a doctor or a nurse otherwise it might stop you seeing them/having examinations or tests. Anyone who is giving you care or support should know what a learning disability is and how they should support you. They shouldn't assume things just because you have a learning disability or because you can't communicate in the same way. Having your learning disability on your record would be a good thing but it doesn't always happen and nurses don't always have the time to read it.'	
93	SCM5	Annual health check	Morbidity rates higher for these people	Currently not mandatory

94	SCM6	Health checks	The opportunity for people with learning disability to have an annual health check is patchy across the country .Most people with learning disabilities have poorer health than the rest of the population and are more likely to die at a younger age.	There is clear evidence that their access to the NHS is often poor and characterised by problems that undermine personalisation, dignity and safety. at worst, reports have identified abuse, undiagnosed illness and, in some cases, avoidable death.
95	SCM7	Having checkups	Because that's when they find out if something is wrong	
96	SCM8	Monitoring and detecting dementia in people with learning disabilities	It is widely recognised that people with a learning disability are 3 times more likely to develop dementia - including Alzheimer's in people with Downs syndrome. It is however an area that can remain undetected in people with a learning disability	The report Hidden in Plain Sight- Dementia and learning disability describes the statistical gap in national dementia statistics - not recognising people with a learning disability. This indicates that more must be done to set the standard in detection and monitoring in this group. The root cause may be the lack of a consistent GP register of learning disability. This would benefit from being built into the quality standards (a starting point only into surveillance re dementia). In addition, further work is needed to up-skill the social care workforce in understanding and recognising the likelihood and early signs of different dementias, to enable them to report and seek specialist input. In addition, development is needed in the skills and knowledge of health care professionals in the needs of people

				with a learning disability and to avoid diagnostic over-shadowing.
97	SCM8	Access to health surveillance and screening for age related conditions	Whilst developing the NICE guideline and from my own experience, it is clear that this is an area that requires more attention.In particular: - Recognising the potential for diagnostic overshadowing – particularly in dementia, age-related sensory loss and Menopause - Health professionals' understanding how a learning disability may impact ability to recognise and report symptoms of ill health - Both social care staff and health professionals' understanding the value of social care staff's knowledge of the person with a learning disability,to support health reporting and access to appointments - Working together with family carers to tap into their knowledge of the person	People with a learning disability are more likely to die prematurely than the general population. People with a learning disability in general and therefore those who are aging, are not always accessing the required Annual Health checks Social care staff are not always fully knowledgeable of age- related health conditions and this must now be a key focus given the aging population. From my own experience, social care staff are not always confident in their discussions with health care professionals and require to develop skills in working collaboratively with GPs, consultants and others Health care professionals are not always knowledgeable nor confident in dealing with their patients with a learning disability and therefore are not aware of the reasonable adjustments required to enable good access

98	SCM9	Improved uptake of Annual Health Checks (and Health Action Planning)	There is evidence that people with a learning disability are not all accessing / offered Annual Health checks and associated health screening. While there is limited evidence of the impact of health checks and screening there is evidence that early detection of health issues improves chances of successful treatment and reduces long term impact on services	Confidential Inquiry into premature deaths of people with learning disabilities (CIPLOD) Final Report Made the recommendation "Standardisation of the Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans" LeDeR Report 2016-7 identified 3 main learning points one being; "Interagency and collaboration" This report also recommended "Health Action Plans developed as part of the Learning Disability Annual Health Checks should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate Mental Capacity Act decision making process)"
99	St Anne's Community Services	Dydphagia awareness	Thorough information/training resources is needed re. dysphagia – as more people with learning disabilities die of respiratory issues than the general population. We think that identification and treatment of swallowing conditions especially with relation to dementia and aspiration risk needs a greater publicity campaign	Please see: https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/swallowing-difficulties-dysphagia

100	St Anne’s Community Services	Development of epilepsy in older age	Support workers and families need greater awareness of the likelihood of epilepsy and what to do if the person they care for develops epilepsy. Training resources, more epilepsy specialist nurses going out to visit in their homes etc. This can in turn prevent hospital admissions, empower people with learning disabilities to be able to stay at home/in their current accommodation rather than needing nursing care due to a lack of awareness and knowledge.	
101	St Anne’s Community Services	Constipation	Identification and treatment of constipation is vital, and tools are needed to help identify this as are signs and symptoms. More knowledge and awareness is needed around the causes of constipation and why it can affect people with learning disabilities – e.g. polypharmacy, limited mobility, reduced fluid intake etc.	

102	The Down's Syndrome Association	To celebrate the fact that individuals with a learning disability have an increased life expectancy, but acknowledge that there are increased risks of developing additional health issues in older age for many people with a learning disability	For individuals with Down's syndrome there is a significantly higher risk of developing dementia at a much earlier age. Increased focus on annual health checks for people with a learning disability are warranted 1. including adoption of the British Psychological Society guidance on baseline assessments for adults with a learning disability https://www1.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf It is of paramount importance that appropriately qualified and trained staff conduct a differential diagnosis when assessing whether an older person with a learning disability may be developing dementia and ascertain whether the changes in their cognitive function are due to dementia, or some other, treatable, health condition.	

103	The Faculty of General Dental Practice	Oral care	One of these specific aspects is oral health - people with ID have poorer oral hygiene than the general population. There is also a higher prevalence of periodontal disease among the population with ID, with greater severity. The incidence of dental caries in people with ID is the same as, or lower than, the general population; however, the rates of untreated caries are consistently higher. Two subgroups at especially high risk for oral health problems are those with Down syndrome, and those unable to cooperate to receive routine dental care. Good oral health is important for health and wellbeing, bringing benefits in terms of self-esteem, dignity, social integration and nutrition. Poor oral health can lead to pain, which patients with ID may have difficulty articulating, and tooth loss. It can also negatively affect self-esteem and the ability to eat, laugh and smile.	Healthcare professionals caring for patients with ID should be aware that their patients are at risk of poor oral health, and understand the importance of oral health to a patient’s quality of life and wider health, particularly as they grow older. Healthcare professionals caring for patients with ID should therefore ensure that their patients’ oral health is assessed and treated, making referrals as necessary to general / community / special care dental services according to each patient’s needs.
104	Thera Trust	Early detection of Dementia	• Health professionals’ assess using the knowledge and expertise of family or social care staff • Use of learning disability specific assessment tools • Ruling out of other causes of symptoms • Avoiding diagnostic overshadowing	

105	SCM4	Caring for a health problem	Living a healthy life also means being active and being out and about. People involved in my care should work together with me to make sure I am getting what I need to keep me well or to look after me when I am poorly. Giving me information in a way that I can understand is important. I want to be included in my health and understand what tests are for/ medication is for. I want to know how to keep myself healthy. It is important that friends, families and carers have information too. If you go to hospital they should be able to come and stay with you. They know you and can help you get the best care. Nurses don't always have time to read your passports or notes and they might not understand learning disabilities. Everyone involved in your care and support needs to work together to support you when you come out of hospital even if that means waiting until your house is ready to go back to (reasonable adjustments) so you can keep your independence as long as possible.	
106	SCM5	Identified support worker in General Hospitals (or support worker allowed to stay with them)	Admission is frightening	Personal experience

107	The Royal College of Psychiatrists	Nursing care and support during hospital admissions and rehabilitation from qualified general and learning disability qualified nurses who understand the complex needs of older people with learning disability and autism	Hospital care with adequate reasonable adjustments including communication needs.	As above
108	The Royal College of Psychiatrists	Aftercare following discharge – Follow up support preferable at home by trained professionals for older people with learning disability	After care provided with appropriate information which may need to be repeated time and again, monitoring and contact by trained professionals	As above
End of life care				
109	ADASS	A stronger focus on end of life planning if needed including hospice care access if needed with effective pain relief.	Not sure what the evidence is about access to hospice care and palliative care for people who have a learning disability but equality of access is an important aspect of care as people grow older and/or terminal health needs.	Can we measure and compare the access to palliative care services for people who have a learning disability compared to the wider population? People should also have access to effective end of life planning and effective pain relief. Also bereavement support for staff , friends and families is important.Plymouth have done some good work on this.
110	British Dietetic Association	We recommend a quality standard linked to end of life needs including mental capacity		

111	Mencap	End of life care	It is important that people with a learning disability are able to access palliative care services. Social care staff must have the training they need to support people at the end of their lives.	Research shows people with a learning disability have poorer experiences of end of life care (NHS England 2017). CIPOLD (2013) found a number of areas which could lead to a person with a learning disability experiencing a poorer quality death. The 2018 LeDeR report showed a much higher number of older people with a learning disability had died in hospital than reported in the general population. CIPOLD (2013) found evidence which suggested that people with a learning disability were offered suboptimal pain relief – particularly those who were not able to verbally describe their pain – and there were several examples of this in the LeDeR report.
112	SCM2	An end of life plan (1.6.4)	An end of life plan can help the individual and their carers think about the future and plan accordingly	

113	SCM4	Care near the end of life	Checking who you want to be involved in your care or what you want to happen is really important because you might change your mind. It is my life and my choice so I should get to make the decision. Someone might not be in your life or they might die so you would need to update your plan. It is important to have a plan. I don't have one because I said I was too young and didn't want to think about it but I understand why it is important. It should be done by someone who knows you well. It is my choice about what happens to me and my voice should be at the centre. People with learning disabilities aren't always asked what they want and are told what they are doing. Listening to me/family/carers is really important because they know me and what I want. If I can't tell people myself I want someone who knows me to say what I would want. It is really important to be surrounded by people you love and who know you when you are at the end of your life.	
114	SCM6	End of life care for people with a learning disability	There is a lack of planning with people and their families about future plans and end of life care.	NICE's guideline on care of dying adults in the last days of life.
115	SCM7	Care near the end of life	Because if I am ever in a coma, I don't want a gastric tube. A person might not want to be in a hospital, they might want to be in a hospice or their own home.	

Additional areas				
116	Action on Hearing Loss	Improving the accessibility of health and social care services	Aside from information in accessible formats, such as Easy Read or advocacy support, people with learning disabilities who are deaf or have hearing loss may need a range of support to communicate well. This could include: • Many people who are deaf or have hearing loss will find it difficult or impossible to use the telephone and may benefit from alternative contact options such as email, Text messages, Next Generation Text Relay (NGTR) or BSL Video Relay Services (VRS) • For face-to-face contact, people with hearing loss may need other people to follow simple communication tips such as speaking clearly and avoid obstructing their lip movements with hand gestures or other objects. People who use hearing aids may benefit from hearing loop systems that make speech clearer by reducing background noise. • Some people who are deaf or have hearing loss will need support from a communication professional to follow conversations, such as a British Sign Language (BSL) interpreter or Speech-To-Text-Reporter (STTR). • English may not be the first or preferred language of people who are deaf, so information should be written in Plain	Despite the legal requirements of NHS England's Accessible Information Standard, our Good Practice? report shows that many people who are deaf or have hearing loss are still experiencing barriers to communication when visiting or contacting GP surgeries: • Nearly two-thirds (64%) feel unclear about the information they've been given at GP appointments, at least some of the time. • More than half of people with hearing loss (52%) said doctors or nurses spoke too quickly – or didn't check whether they'd been understood. • More than half of people are deaf (57%) were unclear about their health advice because a sign language interpreter was unavailable. • One-quarter (26%) said they ask other people to call their GP surgery on their behalf, although fewer than one in 12 (7%), want to have to do this. • Two-fifths (43%) said staff at their GP surgery still let them know when it's their turn to be seen, by calling

			English. While many people who are deaf can read and write English, some cannot, so services should consider producing BSL videos of key documents or other information and promote these to the Deaf community. Poor communication may cause considerable stress and anxiety for people who are deaf or have hearing loss and may lead to missed appointments and ineffective care. Improving the accessibility of care settings will also save the NHS money: • NHS England estimates that the cost of people with hearing loss missing appointments – because they didn't hear their name being called in the waiting room – could be as high as £15m every year. • The Ear Foundation estimates that, because of communication difficulties, people with hearing loss cost the NHS £76m in extra GP visits every year. • SignHealth estimates that missed diagnosis and poor treatment of people who are deaf costs the NHS £30m every year.	their name. These findings are supported by NHS England's post-implementation review of the Accessible Information Standard, which showed that, although there was widespread support for the Standard, significant challenges remained in terms of its implementation. For example, more than half (53%) of patients who responded to NHS England's survey said they had not experienced any improvement in getting accessible information or communication support over the last six months. Taken together, these findings suggest that the Standard isn't being implemented in a consistent way. More work is needed to gain a national picture of current service provision and identify areas of poor performance.
117	Action on Hearing Loss	Additional developmental areas of emergent practice	The National Lottery funded UK Hear to Inform and Connect project will expand Action on Hearing Loss' face-to-face information provision for older people with hearing loss in Scotland, Northern Ireland and London and South East	

			England. The project aims to ensure older people feel better informed about how to seek help for their hearing loss, manage their hearing loss better and stay in touch with their family and friends and local community. Trained staff and volunteers provide information and advice on hearing loss, hearing aids and other forms of support people with hearing loss may need, such as assistive equipment and employment support. Talks and presentations are being delivered to local health, social care and voluntary organisations, with the aim of empowering them to make their services more accessible for older people with hearing loss. There will be a particular focus on ensuring ‘harder to reach’ groups and communities have increased access to information about deafness, hearing loss and tinnitus, including people with learning disabilities. The project evaluation will explore the long-term impact of face-to-face information provision, including whether it leads to more older people accessing hearing aids.	

118	British Association of Social Work (BASW)	Professionals working with adults growing older with learning disabilities should have the same understanding of wellbeing.	Improving the wellbeing of people with care and support needs is the cornerstone of the Care Act 2014. Professionals should be capable of applying the principle of wellbeing to the judgements they are required to make in undertaking assessments of need, care and support planning. There should be transparency in how these judgements are made.	Practice would be improved by greater clarity in how this concept can best be applied to the health and social care needs of older with learning disabilities. This can be achieved through improved definition and BASW advocates for the use of the United Nations Convention of the Rights of Disabled Persons standard of independent living to be applied as the necessary standard of wellbeing. Work is also required on developing good practice guidance, that will support social workers in their decision-making and contribute to greater transparency.
119	British Geriatrics Society	1.1.3 Service providers and commissioners must make reasonable adjustments to health, social care and housing services to ensure they are fully accessible to older people with learning disabilities and their family members and carers, in line with the Equality Act 2010.	This is a legal requirement, but unlike physical disabilities, Learning Disability may not be recognized and so these adjustments fail to be met. NHS England Liaison and Diversion Manager and Practitioner Resources: Learning Disability states that people with LD may be unknown to services. Public Health England's 2015 report on People with Learning Disabilities estimated there were 1,087,100 people with LD in England, but only 252,446 were recorded as such on GP registers.	Cognitive screening is routine for older adults admitted to hospital and in contact with outpatient Medicine of the Elderly services. This provides an opportunity to screen for and then identify older adults with LD which has hitherto been unrecognized.

120	Foundation for People with Learning Disabilities	People with learning disability get the same care and support as everyone else. In line with the Equality Act 2010. Evidence suggests that people with learning disabilities are not afforded respect and choice when deciding where and how they want to live. Changes are made by providers without adequate support to understand their wishes. Changes in the Mental Capacity Act suggesting that home managers support the capacity of residents acts against their rights.	The LEDER Report 2018 suggests that this is not happening people are dying prematurely from preventable diseases. Variation in the type and style of support offered.	See Leder Report https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2017/ https://www.equalityhumanrights.com/sites/default/files/research-report-114-housing-and-disabled-people-experiences-in-britain.pdf
121	People First	1948 the NHS was formed moving forward there needs to be a social care system on a similar model so that no matter where you are in the country you are entitled to the same level of social care support		
122	SCM1	Decision Making, Capacity and Consent	A greater awareness of the MCA is required, both across professionals and individuals and their families. Work is required to reduce the stigma and fear associated with being unable to make decisions to ensure that families request support and know how to access this when required. All professionals, including health, should be aware of their powers to undertake a capacity assessment and how to do this, without an automatic referral to social care in every case.	

123	SCM3	People with learning disabilities have the right to the same quality of care and support as everyone, in accordance with the Equality Act 2010	25% of people with learning disabilities have no contact with social care services until a crisis arises. Many families need preventive intervention to help sustain the caring relationship. Constraints on resources means that this is often non-existent.	People with learning disabilities and their family carers are excluded from many mainstream services and receive inadequate support from specialist services. Older people and families of people with learning disabilities have been most reluctant to take on the responsibilities of a personal budget.
124	Skills for Care	Making dementia services suitable for people with LD.		
125	The Challenging Behaviour Foundation	Safeguarding	People with learning disabilities are at risk of abuse. It is important that robust systems are in place to prevent and identify abuse of this group, with all areas working effectively, in coordination and communicating effectively to prevent abuse being missed.	There is much evidence demonstrating how people with learning disabilities have a poor experience of safe guarding. Panorama revealed shocking abuse of people with learning disability at Winterbourne View Hospital in 2011. Since then safeguarding has continued to fail people with a learning disability. People with a learning disability are sectioned inappropriately, spending many years in units, experiencing abuse and neglect, including overuse of restrictive practices, not receiving any proper ‘assessment or treatment’ and not being able to get out and live a fulfilling life, with the right support in their local community. Evidence of this can be found in Mencap and the Challenging Behaviour Foundations

				‘Out of Sight’ report, the report ‘Winterbourne View: the Scandal Continues’, and the Care Quality Commission and Challenging Behaviour Foundation’s ‘Three Lives’ report. There is wide recognition that people with a learning disability are being overmedicated in all settings. NHS England launched the Stopping the over medication of people with a learning disability, autism or both (STOMP) programme to help tackle this. There are many examples which highlight the poor experience of safeguarding for people with learning disabilities; the terrible abuse at Mendip House uncovered this year provides a recent example.
126	The Royal College of Psychiatrists	We need quality standards for access to both physical and mental health care needs in the older population with learning disabilities as co-morbidity is common.	It is known that older people with learning disabilities often do not get the same standard of quality health care available to other individuals. Reasonable adjustments need to be made to for people with learning disabilities to avail of health care including the areas stated in the previous column.	Death by indifference – Mencap report https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf CIPOLD report: Confidential Inquiry into premature deaths of people with learning disabilities https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

127	The Royal College of Psychiatrists	Easier and prompt access for mental and physical healthcare including GP assessments, hospital appointments, phlebotomy and investigations such as X-rays that could be done at home or near home.	Easier and prompt access for mental and physical healthcare including GP assessments, hospital appointments, phlebotomy and investigations such as X-rays that could be done at home or near home. Access to care for proper examinations and investigations.	As above
128	Thera Trust	Improved access to Health Care	• Annual health check as a minimum standard • Accessible information about appointments, examinations, health conditions, healthy lifestyles • Accessible appointments – length of time, appointment timings to reduce fear/behavioural challenges as a result of unfamiliar environment/ activity, support from social care staff/ family • Knowledge required of health professionals re learning disability including communication	
129	Mencap	Training for staff around the changing needs of older people.	It is important that social care and health staff are trained in the specific needs of people with a learning disability as they grow older. This is particularly important as some of the conditions that affect older people – for example, dementia, can present differently in people with a learning disability.	The LeDeR report (2018) recommends that training be improved for health and social care staff to understand the health needs of people with a learning disability as they get older – including how to recognise the signs of deterioration in health.

130	Royal College of General Practitioners	Staff receive specific training in caring for older people with learning disabilities, including end of life care and recognising when someone may be approaching end of life	Staff have up to date training in Mental Capacity, Deprivation of Liberty Safeguards. • There is a policy on implementing the end of life care pathway, and there is evidence that some older people with learningdisabilities have used the pathway. • Staff are aware of people's rights to continuing healthcare funding, and work to ensure that eligible people receive it. • Staff routinely signpost older people with learning disabilities and family carers to appropriate information including bereavement support. In addition, staff have training on understanding different cultural attitudes to death, and work with palliative care services to ensure that people with learning disabilities have a good death. • In addition to up to date training, staff have access to a range of resources to enable them to implement the MCA appropriately. • People with learning disabilities who are nearing the end of their lifeare routinely put on an agreed end of life pathway. • Older people with learning disabilities who are nearing the end of their life and their families are routinely given	Turner S Bernard C. Supporting older people with learning disabilities: a toolkit for health and social care commissioners BILD 2014 www.bild.org.uk/EasySiteWeb/GatewayLink.aspx?alId=5313

			information in appropriate formats on continuing healthcare funding, and allpeople eligible for this receive it in a timely fashion. • In both care settings and in the community, people growing olderwith learning disabilities and their families are supported to talk about dying, and what they need and want. • Older people are able to make plans for their own funerals, and are supported to make a will.	
131	SCM3	Health and social care professionals need training to respond appropriately to the needs of people with learning disabilities as they age.	There are growing numbers of people with learning disabilities living into old age. Most are living with a family carer who is also ageing. The caring relationship is increasingly fragile and families need support. Workers in the learning disability field have little or no experience of working with older people; those in the ageing sector have no knowledge of learning disability.	Without training workers can make interventions which are at best inappropriate and at worst life threatening.
132	SCM6	Managers in health and social care services should ensure that staff in older people's services have the expertise to support people growing older with learning disabilities from a wide range of backgrounds	The care sector is under pressure to attract and recruit people with appropriate skills to meet the needs of people with a learning disability.	Skills for care

133	SCM8	Social care staff’s skills in recognising age related health conditions	In addition to the vital knowledge and the understanding well, of the older person with a learning disability, social care workers supporting people on a day-to-day basis, need to be more knowledgeable in recognising the symptoms of a range of age related illnesses including – dementia, cancer, diabetes, sensory loss, high blood pressure and cholesterol, osteoporosis, menopause and others, as these can go undetected until an annual health check, or are under reported when a verbal history is given.	“The number of people with learning disabilities aged over 60, in England, is predicted to increase by over a third between 2001 and 2021 (Emerson and Hatton 2008). Recent evidence suggests that older people are one of the fastest growing groups of the learning disabled population (Emerson and Hatton 2011). The most recent predictions suggest that by 2030 the number of adults aged over 70 using services for people with learning disabilities will more than double”. British Institute of Learning Disability The increase in population of people with a learning disability who are aging, means that the social care profession needs to up-skill in this area – marrying their knowledge and expertise in learning disability, with that of the conditions of aging- current basic training covers mental health conditions, dementia and learning disability, safeguarding and rights, but doesn’t cover the specifics of aging and how that impacts a person with a learning disability.

134	SCM8	Social care staff’s expertise in supporting end-of-life care	To ensure consistency of end-of-life care to people with a learning disability in their own home should they choose, and reduce the need for hospital admission or admission into nursing home provision	Social care teams are skilled and motivated to continue to support people at home but require health professionals’ input to deliver on specific health care needs and/or to train, advise and monitor the delivery of appropriately delegated tasks. From the research reviewed when developing the guideline “McCarron (2010) reported that most learning disability staff agreed the ideal place for end of life care was a person’s own home although they recognised this is not always possible because staff sometimes lack specialist knowledge and specialist palliative professionals said the person with learning disabilities should have the option to die in their familiar place of care McLaughlin et al(2014)”.From my own experience, there are examples of excellent care for people at the end of their life, where they are supported in the place they are familiar, cared for by people they know and trust, alongside the appropriate health care professional.

135	SCM9	Raising awareness of the needs of people with a learning disability across health and social care professionals	Health professional to understand communication can be through behaviour which may indicate pain / distress and need to make reasonable adjustments Social care staff do not understand health conditions / risks for people with learning disabilities i.e. increased risk re respiratory conditions	LeDeR Report 2016-7 identified 3 main learning points one being; "Awareness of the needs of people with learning disabilities" This report also recommended "Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families"
136	SCM9	Awareness of and adherence to the Mental Capacity Act so that all professionals ensure that people with a learning disability are central to decisions made concerning them		Confidential Inquiry into premature deaths of people with learning disabilities (CIPLOD) Final Report Made the recommendation "Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health and social care" LeDeR Report 2016-7 identified 3 main learning points one being; "The understanding and application of the Mental capacity Act" This report also recommended "Local services strengthen their governance in relation to adherence to the Mental Capacity Act and provide training and audit of compliance on the ground so that professionals fully appreciate the

				requirements of the Act in relation to their own role”
137	Skills for Care	Staff (and / or family / community) skills need to change with the needs of the person as they change – a big issue will be engaging with and working in partnership with health services which older people use much more		
138	The Challenging Behaviour Foundation	Specialist skills for the workforce	People with learning disabilities and complex needs face a wide range of issues. To meet these needs effectively, staff working with people learning disabilities and behaviours that challenge need to be appropriately skilled.	There is much evidence indicating that the care of people with severe learning disabilities and behaviours that challenge is currently inadequate. Despite the national transforming care programme recognising that people with learning disabilities and behaviours that challenge should be able to get the right support in the community, this is not being provided. Individuals with learning disabilities and behaviour perceived as challenging are likely to: • Live in places or with people they don’t like, often a long way from their family home. • Be given too much medication, or inappropriate medication. • Be subjected to restraint. • Be secluded and have their movement restricted. Many people with a learning disability have ended up in an

				inpatient unit due to a failure to provide or develop the right support and services in the local community. At the end of January 2018 there were 2,465 people with a learning disability in inpatient services. This issue is a finding of the 2017 National Audit Office report which concluded that there is a lack of a workforce with the right skills to support people with learning disabilities in the community.
139	Thera Trust	Development of social care staff skills and knowledge	• Increase in staff knowledge and confidence to recognise and report age-related health conditions and provide appropriate social care support • Increase in skills to assess needs in relation to aging – both care providers and care managers • Promotion of collaborative working with health care professionals	
140	Action on Hearing Loss	Improving the availability and quality of social care	Older people with learning disabilities who are deaf or have hearing loss may benefit from assistive equipment and rehabilitation support (usually provided or funded by local authority sensory services) to help them communicate with other people, manage their hearing loss better, get out and about, and live safely and independently in their own homes or in care homes. This could include: • Assistive equipment such as flashing smoke alarms, amplified telephones and	Despite the benefits of social care, our FOI research suggests that people who are deaf or have hearing loss may face difficulties accessing assistive equipment and rehabilitation support in some areas due to informal eligibility criteria or local authorities incorrectly applying the Care Act. A small number of local authorities in England told us that they only

			personal listeners. • Peer support groups such as hearing loss or Deaf clubs. • Information and advisory services to help people get information on hearing loss, use local services and apply for benefits. People who are deaf may benefit from information and advice in British Sign Language (BSL). • Mobility training and Communicator Guides to help people with sight loss and people who are Deafblind move around safely. Lipreading classes teach people with hearing loss to recognise lip shapes and patterns and how to use context and facial expressions to help them make sense of conversations. Lipreading support is a valuable skill that can reduce feelings of loneliness at home or in the workplace. Lipreading classes provide a valuable opportunity for people with hearing loss to meet, support each other and share their experiences. Our Not Just Lip Service report identified a range of benefits lipreading classes can bring for people with hearing loss, such as improvements in people's ability to communicate and talk confidently to others about their hearing loss. People who are deaf with multiple or complex needs may require specialist care and support that recognises the	provide equipment and rehabilitation support to people with moderate or severe hearing loss. Others said that they only fund assistive equipment for the home if the person cannot afford to buy it themselves. We have also received reports of variations between areas in terms to types of assistive equipment and rehabilitation support offered by local authorities. The Department of Health's Care and Support Statutory Guidance clearly states that assistive equipment and rehabilitation support should be offered to all people who are deaf or have hearing loss with social care needs, whether their needs meet the Care Act's national eligibility criteria for social care or not. However, a small number of local authorities who responded to our FOI request told us that they apply the Care Act's national eligibility criteria for the provision of equipment and rehabilitation support. Evidence suggests that there is unmet need for peer support groups and other forms of rehabilitation support. Participants in focus groups carried out to support the development of our 2018 – 23

			importance of good communication and takes account of the unique values and culture of the Deaf community. For example, people who are deaf with multiple or complex needs may require a specialist support worker who is trained to communicate in British Sign Language (BSL). As a member of the Think Local Act Personal partnership, we produced guidance for local authorities on personalising social care services for people with sensory loss. To find out more, please visit https://www.thinklocalactpersonal.org.uk/Latest/Making-it-Real-for-people-with-sensory-impairment/. Without access assistive equipment and rehabilitation support, people who are deaf or have hearing loss will be at risk of deteriorating health and reduced personal independence. For example, unaddressed hearing loss can be a major barrier to employment; it is estimated that the UK economy lost £24.8 billion in potential economic output because too many people with hearing loss were unable to work. People who are deaf with multiple or complex needs may be at risk of loneliness and reduced wellbeing if they are unable to communicate in a meaningful way with care staff or other people. Evidence suggests that if people	strategy reported that community groups and local authority disability services in their area had closed down or they had to pay for services that had previously been free, such as lipreading classes. All focus group participants agreed that community groups such as deaf clubs or hearing loss clubs were a valuable source of support, but many reported that these services were unavailable or only aimed at older age groups. Our Not Just Lip Service35 report shows that rising course fees and reduced availability in some areas have deterred some people from attending lipreading classes. Our Managing Hearing Loss When Seeking or in Employment report also shows that seven out of 10 (70%) of survey respondents have not used lipreading classes, even though a similar proportion (68%) said they would find it useful to attend group lipreading sessions. Improving the availability and quality of assistive equipment and other forms of rehabilitation support has been identified by NHS England as a national priority. NHS England's Action Plan on Hearing Loss15 identified improving access to choice of support to help people manage

			who are deaf with multiple or complex needs cannot communicate in BSL in a meaningful way, this can result in reduced signing skills and loss of cultural identity.	their hearing loss better as key outcome measure for quality improvement.
141	People First		• What needs to change the most? I think services and all local authorities first question should be what support does older and younger disabled people need to access society in the same way that parents and brothers and sisters already do because moving forward it must be person centred Building services fit to meet disabled and older disabled peoples needs in local areas must be first thing done. A Wise person said to me once you don't realise what you've got till you lose it I think that services wont realise what they've broken over the last 10 years until they started to try and rebuild it. With the right support anything is possible that needs to be at the heart of every local authority policy. If a local authority has a consultation group with the name learning disability in it then that group needs to be made up of 100% of people with learning difficulties if it is to be taken seriously because tokenism is never taken seriously. • How can services be made better for people with a learning disability as they	

			get older. Older disabled people will have strong views on this point it will be based on whether the local authority or services have met their support needs as a Person growing up. Services will need to be adaptable to meet peoples access needs and ambitions. Out sourcing must be stopped look at what the UN Convention on the rights of persons with disability said around family life and support and use that as a benchmark to develop your services. • What would make the biggest difference? Putting everything that I have said into a business plan with targets to meet them and consequences when you don't.	
142	Royal College of Nursing	This is just to let you know that there are no comments to submit on behalf of the Royal College of Nursing in relation to the stakeholder engagement exercise for the Care and support of people growing older with learning disabilities quality standard. Thank you for the opportunity to participate.		