## Appendix A How this guideline was developed

This guideline was developed in accordance with the process and methods set out in the NICE social care guideline manual.

## Search strategies

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches, following the methods described in the NICE social care guideline manual. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee (GC) and NICE Collaborating Centre for Social Care.

A single search strategy was developed for the all the review questions, by the NICE Collaborating Centre for Social Care. The research questions were translated into a framework of two concepts of: a) older people, ageing, future planning, or aged care services and b) intellectual or learning disabilities. An additional strategy was developed for the review questions on end of life care replacing concept a) with the concept of a) end of life care, terminal illness, or advance care planning.

These concepts were translated into search strategies using subject heading and free text terms. The strategies were run across a number of databases. The search was restricted to studies published from 1999 onwards, and was later restricted to 10 years from 2005 to 2015 following agreement with the GC, as it would capture evidence relevant to current practice and ensure important and relevant studies would be identified. Citations published nonEnglish language were limited within several databases (CINAHL, EMBASE, MEDLINE, PsycINFO and SSCI). The number of records obtained from the database searches both with and without English language is given in the database search history. Additional searches of websites of relevant organisations, and trials registries were undertaken to capture literature that might not have been found from the database searches.

Economic evidence was searched for as part of the single search strategy, and included searching within the economic databases: NHS Economic Evaluation Database (NHS EED) and Econlit.

GC members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

The main searches of the bibliographic databases were undertaken during January 2016 and update searches were undertaken during February 2017. Websites, trials registries and other resources were searched during April 2016. The bibliographic database searches for the review questions on end of life care were undertaken during February 2017 and websites and other resources relating to this topic were searched during March 2017. References were checked from two systematic reviews, and research citations were also collected from the scoping work for the Guideline and from some members of the GC.

## Main searches

The following sources were searched for the topics presented in the sections below.

## Bibliographic databases

Abstracts in Social Gerontology (EBSCOhost)
Ageline (EBSCOhost)
ASSIA(Proquest)
British Nursing Index (HDAS)
CENTRAL (Cochrane Library)
CINAHL (EBSCOhost)
Cochrane Database of Systematic reviews (Cochrane Library)
Database of Abstracts of Reviews of Effects (CRD)
Econlit (EBSCOhost)
EMBASE (OVID SP)
Family and Society Studies Worldwide (EBSCOhost)

Health Management Information Consortium (OVID SP)
HTA (CRD)
Medline - Pubmed (Web of Knowledge)
Medline (OVID SP)
NHS Economic Evaluation Database (CRD)
PsycINFO (EBSCOHost)
Social Policy and Practice (OVID SP)
Social Sciences Citation Index and Conference Proceedings Citation Index -
Social Science and Humanities (Web of Knowledge)
Social Services Abstracts (Proquest)
Social Work Abstracts (OVID)
SocIndex (EBSCOhost)

Allied and Complementary Medicine (AMED) was searched for the review questions on end of life care.

## Websites, trials registries and other resources

The following websites, trials registries and other databases were searched and browsed during April 2016, unless indicated:

Age UK (searched September 2016)
Agency for Healthcare Research and Quality (AHRQ)
Alzheimer's Society (searched September 2016)
ASCOF Interventions Database (AID)
British Institute of Learning Disabilities
Campbell Collaboration Library

## Care and Repair England

Center on Knowledge Translation for Disability and Rehabilitation Research (KTDRR) registry of systematic reviews

Centre for Intellectual and Developmental Disabilities - University of Ulster http://www.science.ulster.ac.uk/inhr/cidd/publications.php
Database of Promoting Health Effectiveness Reviews (DoPHER)

Foundation for People with Learning Disabilities
Google (focussed search)
Google scholar (focussed search)
Growing Older with a Learning Disability)
Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing International Association for the Scientific Study of Intellectual and

Developmental Disabilities (IASSID)
ISCTRN REGISTER
Learning Disabilities Elf
Learning Disabilities Observatory
National Autistic Society (searched September 2016)
National Development Team for Inclusion
NHS Evidence
Norah Fry Research Centre (Bristol University)
Online Research Base older people (Northern Ireland)
OPENgrey (European grey literature) (focussed search)
PSSRU Discussion Papers
Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD)

Royal College of Psychiatrists
Social Policy Research Unit
Trials Register of Promoting Health Interventions (TRoPHI)
UCL Centre for Intellectual \& Developmental Disabilities Research (CIDDR) Unit for Development in Intellectual Disabilities (UIDID) (University of South Wales)

UK Clinical Trials Gateway
WHO ICTRP register

The following websites were searched and browsed during March 2017 for the end of life care review questions:

European Association for Palliative Care
Google (focussed search)

Google Scholar (focussed search)
Learning Disabilities and Palliative Care Project
Marie Curie (research-related pages)
National End of Life Care Intelligence Network

## NHS Evidence

Palliative Care for People with Learning Disabilities Network

References from the following systematic reviews were checked:

Robertson J, et al. (2015) Systematic Reviews of the Health or Health care of People with Intellectual Disabilities: A Systematic Review to Identify Gaps in the Evidence Base. Journal of Applied Research in Intellectual Disabilities, DOI: 10.1111/jar. 12149

Innes et al. (2012) Caring for older people with an intellectual disability: A systematic review. Maturitas

## Review questions and objectives

## Review Protocols

Individual review protocols were produced for each question, protocols for questions 1-9 (including the update search), were quality assured by a second Information Specialist and approved by the GC members and NICE. The review protocols contained a test search on MEDLINE which provided the details of the sources, terms and syntax intended for use. The formulation of the review protocol was two-fold, firstly the included studies from the scope where consulted to obtain information on terms and sources used and secondly additional google searches for each question were combined with the term 'search strategy' to check for existing searches on the topic to inform development.

| Q <br> number | Questions | Objectives of review | Criteria for considering studies <br> for review |
| :--- | :--- | :--- | :--- |
| 1 | What are the views <br> and experiences of <br> older people with | To describe the self- <br> reported views and <br> experiences of adults, their | Population: Older people with <br> learning disabilities and care <br> and support needs, their |

$\left.\begin{array}{|l|l|l|}\hline & \begin{array}{l}\text { learning disabilities } \\ \text { and their carers } \\ \text { about how care and } \\ \text { support needs are } \\ \text { identified, assessed } \\ \text { and reviewed? }\end{array} & \begin{array}{l}\text { families, carers and } \\ \text { supporters about the } \\ \text { identification, assessment } \\ \text { and review of care and } \\ \text { support needs, including } \\ \text { what works and what does } \\ \text { not work well. }\end{array} \\ & \begin{array}{l}\text { families, supporters and carers. } \\ \text { Self-funders and people who } \\ \text { organise their own care or have } \\ \text { help doing so. In addition, the }\end{array} \\ \text { EIA sets out protected } \\ \text { characteristics and other specific } \\ \text { groups of the population which it } \\ \text { is understood often face } \\ \text { particular difficulties. The review } \\ \text { learning disabilities, their } \\ \text { process will both include and } \\ \text { seek evidence of any } \\ \text { considerations specific to these } \\ \text { families and supporters } \\ \text { groups of people. }\end{array}\right\}$

|  |  |  | control over daily life; capability to achieve desired personcentred outcomes; user and carer satisfaction; continuity of care; health and social care related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). <br> The study designs relevant to this question are likely to include: <br> Systematic reviews of qualitative studies on this topic; <br> Qualitative studies of user and carer views of social and integrated care; <br> Qualitative components of effectiveness and mixed methods studies; <br> Observational and crosssectional survey studies of user or carer experience. |
| :---: | :---: | :---: | :---: |
| 2 | What are the views and experiences of health, social care and other practitioners about how the health and social care needs of older people with learning disabilities and their carers are identified, assessed and reviewed? | To identify emerging models and approaches to identification, assessment and review of the needs of older people with learning disabilities. <br> To describe the views and experiences of people delivering, organising and commissioning social care, health and housing services about the identification, assessment and review of care and support needs, including what works and what does not work well. | Population: Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support to older people with learning disabilities; personal assistants engaged by people with care and support needs and their families. General practice and other community-based healthcare practitioners, including GPs, therapists and community/ district nurses; hospital ward staff. |




|  |  | their families, carers and advocates. Includes views on what works and what does not work well. | Setting: People's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, including KeyRing Network and Shared Lives schemes; specialist accommodation or accommodation with a housing scheme manager such as extra care housing and residential and nursing care homes (including hospices). Day services including leisure services, centres for education and employment support schemes. Primary healthcare, outpatients and day hospitals, acute (general and mental health) and community hospitals. <br> Outcomes: Person focussed outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care related quality of life, including carer quality of life; years of life saved) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and readmissions; admission to care homes; length of stay in hospital and care homes). <br> The study designs relevant to the 'effectiveness and cost effectiveness' part of this question are likely to include: <br> Systematic reviews of studies of interventions to provide information, advice and training for older people with learning disabilities, their families, carers and advocates; |
| :---: | :---: | :---: | :---: |


|  |  |  | Randomisedcontrolled trials of interventions to provide information, advice and training for older people with learning disabilities, their families, carers and advocates <br> Economic evaluations; <br> Quantitative and qualitative evaluations of different approaches; <br> Observational \& descriptive studies of process; <br> Cohort studies, case control and before and after studies; <br> Mixed methods studies. <br> The study designs relevant to the views and experiences parts of this question are likely to include: <br> Systematic reviews of qualitative studies on this topic; <br> Qualitative studies of user, carer and practitioner views of to provide information, advice and training for older people with learning disabilities, their families, carers and advocates; Qualitative components of effectiveness and mixed methods studies; Observational and crosssectional survey studies of user or carer experience. |
| :---: | :---: | :---: | :---: |
| 4 (a) <br>  <br>  <br>  <br>  <br> 4 (b) | What is the acceptability, effectiveness and cost effectiveness of providing information, advice, training and support to families, carers and advocates of older people with learning disabilities? <br> What are the views and experiences of older people with learning disabilities and their carers | To identify the acceptability, effectiveness and cost effectiveness of providing information, advice and training to older people with learning disabilities, their families, carers and advocates. <br> To identify emerging models and approaches to improving information, advice and training for older people with learning disabilities, their families, carers and advocates and the associated outcomes. | Population: Older people with learning disabilities and care and support needs, their families, carers and advocates. Self-funders and people who organise their own care or have help doing so. In addition, the EIA sets out protected characteristics and other specific groups of the population which it is understood often face particular difficulties. The review process will both include and seek evidence of any considerations specific to these groups of people. |


| 4 (c) | about information, advice, training and support provided to families, carers and advocates? <br> What are the views and experiences of health, social care and other practitioners about information, advice, training and support for families, carers and advocates? | To describe the selfreported views and experiences of older people with learning disabilities, their families, carers and advocates about information, training and advice available to them, including what works and what does not work well. <br> To describe the views and experiences of people delivering, organising and commissioning social care, health and housing services about information, training and advice available to older people with learning disabilities, their families, carers and advocates. Includes views on what works and what does not work well. | Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities; personal assistants engaged by people with care and support needs and their families. General practice and other community-based healthcare practitioners, including GPs, therapists and community/ district nurses; hospital ward staff. <br> Intervention: Information, advice and training for older people with learning disabilities, their families, carers and advocates. <br> Setting: People's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, including KeyRing Network and Shared Lives schemes; specialist accommodation or accommodation with a housing scheme manager such as extra care housing and residential and nursing care homes (including hospices). Day services including leisure services, centres for education and employment support schemes. Primary healthcare, outpatients and day hospitals, acute (general and mental health) and community hospitals. <br> Country: Must be UK or other OECD. <br> Outcomes: Person focussed outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity |
| :---: | :---: | :---: | :---: |





|  |  |  | Quantitative and qualitative evaluations of different approaches; <br> Observational \& descriptive studies of process; <br> Cohort studies, case control and before and after studies; Mixed methods studies. <br> The study designs relevant to the views and experiences parts of this question are likely to include: <br> Systematic reviews of qualitative studies on this topic; <br> Qualitative studies of user, carer and practitioner views of interventions to improve access and referral to care and support for older people with learning disabilities; <br> Qualitative components of effectiveness and mixed methods studies; <br> Observational and crosssectional survey studies of user or carer experience. |
| :---: | :---: | :---: | :---: |
| 6 (a) | What is the acceptability, effectiveness and cost effectiveness of care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology? <br> What are the views and experiences of older people and their carers in relation to support for | To identify the acceptability, effectiveness and cost effectiveness of care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology. <br> To identify emerging models and approaches to maintaining relationships with family, friends and local communities and improving access to volunteering, employment and adult learning, social and leisure activities, transport and technology. | Population: Older people with learning disabilities and care and support needs, their families, carers and advocates. Self-funders and people who organise their own care or have help doing so. In addition, the EIA sets out protected characteristics and other specific groups of the population which it is understood often face particular difficulties. The review process will both include and seek evidence of any considerations specific to these groups of people. <br> Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities; personal assistants engaged by |


| 6 (c) | developing and maintaining relationships with family, friends and the local community and improving access to volunteering, employment and adult learning, social and leisure activities, transport and technology? <br> What are the views and experiences of health, social care and other practitioners about support for older people with learning disabilities to develop and maintain relationships with family, friends and the local community and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology? | Also, to identify outcomes associated with these emerging models. <br> To describe the selfreported views and experiences of older people with learning disabilities, their families, carers and advocates about care planning and support to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology, including what works and what does not work well. <br> To describe the views and experiences of people delivering, organising and commissioning social care, health and other services about care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology. Includes views on what works and what does not work well. | people with care and support needs and their families. Practitioners involved in enabling access to volunteering, education, employment, leisure and transport. General practice and other community-based healthcare practitioners, including GPs, therapists and community/ district nurses; hospital ward staff. <br> Intervention: care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology. <br> Setting: People's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, including KeyRing Network and Shared Lives schemes; specialist accommodation or accommodation with a housing scheme manager such as extra care housing and residential and nursing care homes (including hospices). Day services including leisure services, centres for education and employment support schemes. Primary healthcare, outpatients and day hospitals, acute (general and mental health) and community hospitals. <br> Country: Must be UK or other OECD. <br> Outcomes: Person focussed outcomes (independence, choice and control over daily life; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care |
| :---: | :---: | :---: | :---: |



\begin{tabular}{|c|c|c|c|}
\hline \& \& \& \begin{tabular}{l}
Systematic reviews of qualitative studies on this topic; \\
Qualitative studies of user, carer and practitioner views of care planning and support for older people with learning disabilities to maintain relationships with family, friends and local communities and improve access to volunteering, employment and adult learning, social and leisure activities, transport and technology; \\
Qualitative components of effectiveness and mixed methods studies; \\
Observational and crosssectional survey studies of user or carer experience.
\end{tabular} \\
\hline 7 (a)

7

(b) \& \begin{tabular}{l}
What is the acceptability, effectiveness and cost effectiveness of care and support at home for older people with learning disabilities? <br>
What are the views and experiences of older people with learning disabilities and their carers in relation to care and support at home?

 \& 

To identify the effectiveness and cost effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities. <br>
To identify emerging models and approaches to care and support at home for older people with learning disabilities and associated outcomes.
\end{tabular} \& Population: Older people with learning disabilities and care and support needs, their families, supporters and carers. Self-funders and people who organise their own care or have help doing so. In addition, the EIA sets out protected characteristics and other specific groups of the population which it is understood often face particular difficulties. The review process will both include and seek evidence of any considerations specific to these groups of people. <br>

\hline 7 (c) \& What are the views and experiences of health, social care and other practitioners about care and support at home for older people with learning disabilities? \& | To describe the selfreported views and experiences of older people with learning disabilities, their families and supporters about the care and support received at home, including what works and what does not work well. |
| :--- |
| To consider specifically whether older people with learning disabilities, their families and supporters | \& Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and social care commissioners involved in delivering care and support at home to older people with learning disabilities; personal assistants engaged by people with care and support needs and their families. General practice and other community-based healthcare practitioners, including GPs, therapists and community/ district nurses; hospital ward staff. <br>

\hline
\end{tabular}



|  |  |  | older people with learning disabilities; <br> Randomised controlled trials of care and support at home for older people with learning disabilities; <br> Economic evaluations; <br> Quantitative and qualitative evaluations of different approaches; <br> Observational \& descriptive studies of process; <br> Cohort studies, case control and before and after studies; <br> Mixed methods studies. <br> The study designs relevant to the views and experiences parts of this question are likely to include: <br> Systematic reviews of qualitative studies on this topic; <br> Qualitative studies of user, carer and practitioner views of care and support at home; <br> Qualitative components of effectiveness and mixed methods studies; <br> Observational and crosssectional survey studies of user or carer experience. |
| :---: | :---: | :---: | :---: |
| 8(a) $8(b)$ | What is the acceptability, effectiveness and cost effectiveness of end of life care for older people with learning disabilities? | To identify the effectiveness and cost effectiveness of interventions or approaches to improve end of life care for older people with learning disabilities. | Population: Older people with learning disabilities and care and support needs, their families, supporters and carers. Self-funders and people who organise their own care or have help doing so. In addition, the EIA sets out protected |
| 8 (b) | What are the views and experiences of older people with learning disabilities and their carers about end of life care? | To identify emerging models and approaches to improving end of life care for older people with learning disabilities and associated outcomes. | characteristics and other specific groups of the population which it is understood often face particular difficulties. The review process will both include and seek evidence of any considerations specific to these groups of people. |
| 8 (c) | What are the views and experiences of health, social care and other | To describe the selfreported views and experiences of older people with learning disabilities, their families | Social care practitioners (providers, workers, managers, social workers), housing practitioners and health and |


| practitioners about end of life care for older people with learning disabilities? | and supporters about end of life care, including what works and what does not work well. <br> To describe the views and experiences of people delivering, organising and commissioning social care, health and housing services about end of life care for older people with learning disabilities. Includes views on what works and what does not work well. | social care commissioners involved in delivering care and support at home to older people with learning disabilities; personal assistants engaged by people with care and support needs and their families. General practice and other community-based healthcare practitioners, including GPs, therapists and community/ district nurses; hospital ward staff. <br> Intervention: End of life care for older people with learning disabilities. <br> Setting: People's own homes, family homes and temporary accommodation such as hostels and respite arrangements; supported living, including KeyRing Network and Shared Lives schemes; specialist accommodation or accommodation with a housing scheme manager such as extra care housing and residential and nursing care homes (including hospices). Acute (general and mental health) and community hospitals. <br> Country: Must be UK or other OECD. <br> Outcomes: Person focussed outcomes (independence, choice and control; capability to achieve desired person-centred outcomes; user and carer satisfaction; continuity of care; health and social care related quality of life, including carer quality of life) and service outcomes (use of health and social care services and housing support; need for support from health and social care practitioners and carers; delayed transfers of care from hospital; hospital admissions and |
| :---: | :---: | :---: |


|  |  | readmissions; admission to care <br> homes; length of stay in hospital <br> and care homes). <br> Additional outcomes specific to <br> this review question: pain and <br> other symptoms, emotional and <br> cognitive symptoms, spirituality, <br> survival time and <br> aggressiveness of care, <br> advance care planning. |
| :--- | :--- | :--- |
|  | The study designs relevant to <br> the 'effectiveness and cost <br> effectiveness' part of this <br> question are likely to include: <br> Systematic reviews of studies of <br> interventions to improve end of <br> life care for older people with <br> learning disabilities; <br> Randomised controlled trials of <br> interventions to improve end of <br> life care for older people with <br> learning disabilities; <br> Economic evaluations; <br> Quantitative and qualitative |  |
| evaluations of different |  |  |
| approaches; |  |  |


| 9 | What are the views <br> and experiences of <br> older people with <br> learning disabilities <br> and their carers <br> about care and <br> support in health <br> settings? | To describe the self- <br> reported views and <br> experiences of adults, their <br> families, carers and <br> supporters about care and <br> support in health settings, <br> including what works and <br> what does not work well. | Population: Older people with <br> learning disabilities and care <br> and support needs, their <br> families, supporters and carers. <br> Self-funders and people who <br> organise their own care or have <br> help doing so. In addition, the <br> EIA sets out protected <br> characteristics and other specific <br> groups of the population which it <br> is understood often face <br> particular difficulties. The review <br> process will both include and <br> seek evidence of any <br> considerations specific to these <br> groups of people. |
| :--- | :--- | :--- | :--- |
|  | To consider specifically <br> whether older people with <br> learning disabilities, their <br> families and supporters <br> think that care and support <br> in health settings is <br> delivered in a way that is <br> person centred, dignified <br> and promotes the best <br> possible outcomes. | Intervention: Primary, <br> secondary and community <br> based health care provided to <br> older people with learning <br> disabilities. |  |
|  |  |  | Setting: Primary, secondary <br> and community based health |
| settings. |  |  |  |


|  |  | Qualitative studies of user and <br> carer views; <br> Qualitative components of <br> effectiveness and mixed <br> methods studies; <br> Observational and cross- <br> sectional survey studies of user <br> and carer experience. |  |
| :--- | :--- | :--- | :--- |
|  |  |  |  |

## Excluded studies

## Research questions 1 and 2

## Studies excluded on second screening on duplicate

| No. | Study details |
| :--- | :--- |
| 1 | Strnadova I, and Evans D (2015) Older women with intellectual <br> disabilities: overcoming barriers to autonomy. Journal of Policy and <br> Practice in Intellectual Disabilities 12:12-9. |

Studies excluded on second screening on population

| No. | Study details |
| :--- | :--- |
| 1 | Cott CA, Tierney MC (2013) Acceptable and unacceptable risk: <br> balancing everyday risk by family members of older cognitively <br> impaired adults who live alone. Health, Risk and Society 15:402-15. |
| 2 | Fitzroy Transforming Lives (2015) "Who will care after I'm gone?" <br> An insight into the pressures facing parents of people with learning <br> disabilities. |
| 3 | Hewitt A, Lightfoot E, Bogenschutz M et al (2010) Parental <br> caregivers' desires for lifetime assistance planning for future <br> supports for their children with intellectual and developmental <br> disabilities. Journal of Family Social Work 13:420-34. |
| 4 | Mansell I, Wilson C (2010) 'It terrifies me, the thought of the future': <br> listening to the current concerns of informal carers of people with a <br> learning disability. Journal of Intellectual Disabilities 14:21-31. |
| 5 | Williams V, Robinson C (2001) 'He will finish up caring for me': <br> people with learning disabilities and mutual care. British Journal of <br> Learning Disabilities 29:56-62. |

## Studies excluded on second screening on topic

| No. | Study details |
| :--- | :--- |


| 1 | Clute MA, Kobayashi R (2012) Looking within and reaching out: bereavement counselor perceptions of grieving adults with ID. American Journal of Hospice and Palliative Medicine 29:583-90. |
| :---: | :---: |
| 2 | Coyle CE, Putman M, Kramer J et al (2016) The role of aging and disability resource centers in serving adults aging with intellectual disabilities and their families: findings from seven states. Journal of Aging and Social Policy 28:1-14. |
| 3 | Davys D, Mitchell D, Haigh C (2015) Futures planning—adult sibling perspectives. British Journal of Learning Disabilities 43:21926. |
| 4 | Kramer J, Hall A, Heller T (2013) Reciprocity and social capital in sibling relationships of people with disabilities. Intellectual and Developmental Disabilities 51:482-95. |
| 5 | Lehmann BA, Bos AE, Rijken M et al (2013) Ageing with an intellectual disability: the impact of personal resources on wellbeing. Journal of Intellectual Disability Research 57:1068-78. |
| 6 | McCallion P, Nickle T, McCarron M (2005) A comparison of reports of caregiver burden between foster family care providers and staff caregivers in other settings. Dementia: the International Journal of Social Research and Practice 4:401-12. |
| 7 | McEvoy J, Machale R, Tierney E (2012) Concept of death and perceptions of bereavement in adults with intellectual disabilities. Journal of Intellectual Disability Research 56:191-203. |
| 8 | Newberry G, Martin C, Robbins L (2015) How do people with learning disabilities experience and make sense of the ageing process? British Journal of Learning Disabilities 43:285-92. |
| 9 | Regnard C, Reynolds J, Watson B et al (2007) Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). Journal of Intellectual Disability Research 51:277-92. |
| 10 | Ryan A, Taggart L, Truesdale-Kennedy M et al (2014) Issues in caregiving for older people with intellectual disabilities and their |


|  | ageing family carers: a review and commentary. International <br> Journal of Older People Nursing 9:217-26. |
| :--- | :--- |
| 11 | Strnadova I, Evans D (2012. Subjective quality of life of women <br> with intellectual disabilities: the role of perceived control over their <br> own life in self-determined behaviour. Journal of Applied Research <br> in Intellectual Disabilities 25:71-9. |
| 12 | Strydom A, Lee L, Jokinen N et al. (2009) Dementia in older adults <br> with intellectual disabilities: a report on the state of science on <br> dementia in older adults with intellectual disabilities by the IASSID <br> Special Interest Research Group on Ageing and Intellectual <br> Disabilities. |
| 13 | Webber R, Bowers B, Bigby C (2014) Residential aged care for <br> people with intellectual disability: a matter of perspective. <br> Australasian Journal on Ageing 33:E36-40. |

## Studies excluded on second screening on outcomes

| No. | Study details |
| :--- | :--- |
| 1 | Grossman BR, Webb CE (2016) Family support in late life: A |
| review of the literature on aging, disability, and family caregiving. |  |
|  | Journal of Family Social Work 19:348-95. |

Studies excluded on second screening on evidence type

| No. | Study details |
| :--- | :--- |
| 1 | Campbell A, Bell D (2011) 'Sad, just sad': a woman with a learning <br> disability experiencing bereavement. British Journal of Learning <br> Disabilities 39:11-6. |
| 2 | Kalsy S, McQuillan S, Adams D et al (2005) A proactive <br> psychological strategy for determining the presence of dementia in <br> adults with Down Syndrome: preliminary description of service use <br> and evaluation. Journal of Policy and Practice in Intellectual <br> Disabilities 2:116-25. |


| 3 | McCarthy M (2002) The menopause and women with learning <br> disabilities. Updates 3. |
| :--- | :--- |
| 4 | Slevin E, Taggart L, McConkey R et al (2011) A rapid review of <br> literature relating to support for people with intellectual disabilities <br> and their family carers when the person has: behaviours that <br> challenge and/or mental health problems; or they are advancing in <br> age. Belfast, Northern Ireland: University of Ulster. |
| 5 | Sciscione P (2015) The experience of having primary caregiving <br> responsibilities for an adult sibling with Down syndrome. Seton Hall <br> University Dissertations and Theses (ETD). Paper 1932. New <br> Jersey, USA. |

## Studies excluded on second screening on publication type

| No. | Study details |
| :--- | :--- |
| 1 | McCallion P, Nickle T (2008) Individuals with developmental <br> disabilities and their caregivers. Journal of Gerontological Social <br> Work 50 (Suppl 1):245-66. |

## Research question 3

## Studies excluded on second screening on publication date

| No. | Study details |
| :--- | :--- |
| 1 | Heller T, Miller A, Hsieh K et al (2000) Later-life planning: <br> promoting knowledge of options and choice-making. Mental <br> Retardation 38:395-406. |
| 2 | Lifshitz H (2002) Later Life Planning Training Program: A pre-test <br> assessment in Israel. Journal of Gerontological Social Work 37:87- <br> 103. |
| 3 | McCarthy M (2002) Going through the menopause: perceptions <br> and experiences of women with intellectual disability. Journal of <br> Intellectual and Developmental Disability 27:281-95. |


| 4 | McCarthy M (2002) Responses to women with learning disabilities <br> as they go through the menopause. Tizard Learning Disability <br> Review 7:4-12. |
| :--- | :--- |
| 5 | McCarthy M, Millard L (2003) Discussing the menopause with <br> women with learning disabilities. British Journal of Learning <br> Disabilities 31:9-17. |

## Studies excluded on second screening on population

| No. | Study details |
| :--- | :--- |
| 1 | Bruce M, Collins S, Langdon P et al (2010) Does training improve <br> understanding of core concepts in cognitive behaviour therapy by <br> people with intellectual disabilities? A randomized experiment. The <br> British journal of clinical psychology / the British Psychological <br> Society 49:1-13. |
| 2 | Dowling S, Hubert J, White S et al (2006) Bereaved adults with <br> intellectual disabilities: a combined randomized controlled trial and <br> qualitative study of two community-based interventions. Journal of <br> Intellectual Disability Research 50:277-87. |
| 3 | Gill J, Fazil Q (2013) Derogation of "duty of care" in favour of <br> "choice"? Journal of Adult Protection 15:258-70. |
| 4 | Gilrane-McGarry U, Taggart L (2007) An exploration of the support <br> received by people with intellectual disabilities who have been <br> bereaved. Journal of Research in Nursing 12:129-144. |
| 5 | Heller T, Caldwell J (2006) Supporting aging caregivers and adults <br> with developmental disabilities in future planning. Mental <br> Retardation 44:189-202. |
| 6 | Hemmings C, Obousy S, Craig T (2013) Mental health crisis <br> information for people with intellectual disabilities. Advances in <br> Mental Health and Intellectual Disabilities 7:135-42. |
| 7 | Marks B, Sisirak J, Chang Y (2013) Efficacy of the HealthMatters <br> program train-the-trainer model. Journal of Applied Research in <br> Intellectual Disabilities 26:319-34. |
| 6 |  |


| 8 | Sundblom E, Bergström H, Ellinder L (2015) Understanding the <br> implementation process of a multi-component health promotion <br> intervention for adults with intellectual disabilities in Sweden. <br> Journal of Applied Research in Intellectual Disabilities 28:296-306. |
| :--- | :--- |

## Studies excluded on second screening on topic

| No. | Study details |
| :--- | :--- |
| 1 | De Vreese LP, Mantesso U, De Bastiani E et al (2012) Impact of <br> dementia-derived nonpharmacological intervention procedures on <br> cognition and behavior in older adults with intellectual disabilities: A <br> 3-year follow-up study. Journal of Policy and Practice in Intellectual <br> Disabilities 9:92-102. |
| 2 | McEvoy J, Smith E. (2005) Families perceptions of the grieving <br> process and concept of death in individuals with intellectual <br> disabilities. British Journal of Developmental Disabilities 51:17-25. |

## Studies excluded on second screening on outcome

| No. | Study details |
| :--- | :--- |
| 1 | McVilly K, McGillivray J et al (2014) Diabetes in people with an <br> intellectual disability: a systematic review of prevalence, incidence <br> and impact. Diabetic Medicine 31:897-904. |

Studies excluded on second screening on evidence type

| No. | Study details |
| :--- | :--- |
| 1 | Hahn JE, Aronow HU (2005) A pilot of a gerontological advanced |
| practice nurse preventive intervention. Journal of Applied Research |  |
| in Intellectual Disabilities 18:131-42. |  |

## Research question 4

## Studies excluded on second screening on publication date

| No. | Study details |
| :--- | :--- |
| 1 | Llewellyn G, Gething L, Kendig H et al (2004) Older parent <br> caregivers' engagement with the service system. American Journal <br> of Mental Retardation 109:379-96. |

## Studies excluded on second screening on population

| No. | Study details |
| :--- | :--- |
| 1 | Cairns D, Tolson D, Darbyshire C et al (2013. The need for future <br> alternatives: an investigation of the experiences and future of older <br> parents caring for offspring with learning disabilities over a <br> prolonged period of time. British Journal of Learning Disabilities <br> $41: 73-82$. |
| 2 | Chadwick DD, Mannan H, Garcia I et al (2013) Family voices: life <br> for family carers of people with intellectual disabilities in Ireland. <br> Journal of Applied Research in Intellectual Disabilities 26:119-32. |
| 3 | Gill J, Fazil Q (2013) Derogation of "duty of care" in favour of <br> "choice"? Journal of Adult Protection 15:258-70. |
| 4 | Hatton C, Emerson E, Kirby S et al (2010) Majority and minority <br> ethnic family carers of adults with intellectual disabilities: <br> perceptions of challenging behaviour and family impact. Journal of <br> Applied Research in Intellectual Disabilities 23:63-74. |
| 5 | Heller T, Caldwell J (2006) Supporting aging caregivers and adults <br> with developmental disabilities in future planning. Mental <br> Retardation 44:189-202. |
| 6 | Heller T, Gibbons HM, Fisher D (2015) Caregiving and family <br> support interventions: crossing networks of aging and <br> developmental disabilities. Journal of Intellectual and <br> Developmental Disabilities 53:329-45. |


| 7 | Jenkins R, Davies R, Sardi I et al (2009) Adults with learning <br> disabilities presenting with dementia. Pontypridd: University of <br> Glamorgan. |
| :--- | :--- |
| 8 | Perkins EA, LaMartin KM (2012) The Internet as social support for <br> older carers of adults with intellectual disabilities. Journal of Policy <br> and Practice in Intellectual Disabilities 9:53-62. |
| 9 | Sundblom E, Bergström H, Ellinder L (2015) Understanding the <br> implementation process of a multi-component health promotion <br> intervention for adults with intellectual disabilities in Sweden. <br> Journal of Applied Research in Intellectual Disabilities 28:296-306. |

## Studies excluded on second screening on topic

| No. | Study details |
| :--- | :--- |
| 1 | Carling-Jenkins R, Torr J, lacono T et al (2012) Experiences of <br> supporting people with Down syndrome and Alzheimer's disease in <br> aged care and family environments. Journal of Intellectual and <br> Developmental Disability 37:54-60. |
| 2 | Perera BD, Standen PJ (2014) Exploring coping strategies of <br> carers looking after people with intellectual disabilities and <br> dementia. Advances in Mental Health and Intellectual Disabilities <br> $8: 292-301$. |

## Studies excluded on second screening on outcome

| No. | Study details |
| :--- | :--- |
| 1 | Ryan A, Taggart L, Truesdale-Kennedy M et al (2014) Issues in |
| caregiving for older people with intellectual disabilities and their |  |
| ageing family carers: a review and commentary. International |  |
| Journal of Older People Nursing 9:217-26. |  |

## Studies excluded on second screening on evidence type

| No. | Study details |
| :--- | :--- |


| 1 | Thompson A, Taggart L (2014) Planning for the future for family <br> carers of adults with intellectual disabilities (ID): training-the- <br> trainers: a pilot study. Journal of Applied Research in Intellectual <br> Disabilities 27:348. |
| :--- | :--- |
| 2 | Zendell AL (2010) Decision-making processes among siblings <br> caring for adults with intellectual or developmental disabilities. <br> Dissertation no. AAI3402568. State University of New York at <br> Albany, US. |

## Research question 5

## Studies excluded on second screening on publication date

| No. | Study details |
| :--- | :--- |
| 1 | *Bent S, McShea L, Brennan S (2015) The importance of hearing: <br> a review of the literature on hearing loss for older people with <br> learning disabilities. British Journal of Learning Disabilities 43:277- <br> 84. |
| 2 | *Heller T, Sorensen A (2013) Promoting healthy aging in adults <br> with developmental disabilities. Developmental Disabilities <br> Research Reviews 18:22-30. |
| 3 | *Strydom A, Lee L, Jokinen N et al (2009) Dementia in older adults <br> with intellectual disabilities. Report on the state of science on <br> dementia in older adults with intellectual disabilities by the IASSID <br> Special Interest Research Group on Ageing and Intellectual <br> Disabilities, 49p. |
| 4 | *Willis D, Kennedy C, Kilbride L (2008) Breast cancer screening in <br> women with learning disabilities: current knowledge and <br> considerations. British Journal of Learning Disabilities 36:171-84. |
| NB | *Systematic reviews in which fewer than 80\% of the included <br> studies were published after 2005. |

## Studies excluded on second screening on duplicate

| No. | Study details |
| :--- | :--- |
| 1 | Wark S, Hussain R, Edwards H (2013) Rural and remote area <br> service provision for people aging with intellectual disability. Journal <br> of Policy and Practice in Intellectual Disabilities 10:62-70. |
| 2 | Wark S, Hussain R, Edwards H (2014) Impediments to community- <br> based care for people ageing with intellectual disability in rural New <br> South Wales. Health and Social Care in the Community 22:623-33. |

## Studies excluded on second screening on population

| No. | Study details |
| :--- | :--- |
| 1 | Brolan CE, Boyle FM, Dean JH et al (2012) Health advocacy: a <br> vital step in attaining human rights for adults with intellectual <br> disability. Journal of Intellectual Disability Research 56:1087-97. |
| 2 | Robertson J, Roberts H, Emerson E (2010) Health checks for <br> people with learning disabilities: a Systematic review of evidence. <br> Improving Health and Life: Learning Disabilities Observatory, <br> Department of Health. |
| 3 | Taggart L, Truesdale-Kennedy M, Mcllfatrick S (2011) The role of <br> community nurses and residential staff in supporting women with <br> intellectual disability to access breast screening services. Journal of <br> Intellectual Disability Research 55:41-52. |

## Studies excluded on second screening on topic

| No. | Study details |
| :--- | :--- |
| 1 | Ellison C, White A, Chapman L (2011) Avoiding institutional <br> outcomes for older adults living with disability: the use of <br> community-based aged care supports. Journal of Intellectual and <br> Developmental Disability 36:175-83. |
| 2 | Lalor A, Redmond R (2009) Breast screening for post-menopausal <br> women. Learning Disability Practice 12:28-33. |


| 3 | McCausland D, Guerin S, Tyrrell J et al (2010) Self-reported needs <br> among older persons with intellectual disabilities in an Irish <br> community-based service. Research in Developmental Disabilities <br> $31: 381-7$. |
| :--- | :--- |
| 4 | Parish SL, Swaine JG, Son E et al (2013). Determinants of cervical <br> cancer screening among women with intellectual disabilities: <br> Evidence from medical records. Public Health Reports 128:519-26. |
| 5 | Shaw K, Cartwright C, Craig J (2011) The housing and support <br> needs of people with an intellectual disability into older age. Journal <br> of Intellectual Disability Research 55:895-903. |
| 7 | Slevin E, Taggart L, McConkey R et al (2011) Supporting people <br> with intellectual disabilities who challenge or who are ageing: a <br> rapid review of evidence. Belfast, Northern Ireland: University of <br> Ulster. |
| Strydom A, Hassiotis A, Livingston G (2005) Mental health and <br> social care needs of older people with intellectual disabilities. <br> Journal of Applied Research in Intellectual Disabilities 18:229-35. |  |
| 8 | Watchman K (2008) Changes in accommodation experienced by <br> people with Down syndrome and dementia in the first five years <br> after diagnosis. Journal of Policy and Practice in Intellectual <br> Disabilities 5:65-8. |
| Wikinson JE, Deis CE, Bowen DJ et al (2011) 'It's easier said than <br> done': perspectives on mammography from women with intellectual <br> disabilities. Annals of Family Medicine 9:142-7. |  |
| 9 |  |

## Studies excluded on second screening on evidence type

| No. | Study details |
| :--- | :--- |
| 1 | Corrado DM (2013) The graying of people with intellectual and <br> developmental disabilities: Organizational efforts of community <br> service providers in adapting facilities and programming to meet <br> the needs of older adults. Dissertation number: 3553039. The City <br> University of New York, US. |

## Research question 6

## Studies excluded on second screening on country

| No. | Study details |
| :--- | :--- |
| 1 | Shin IS, Park EY (2012) Meta-analysis of the effect of exercise |
| programs for individuals with intellectual disabilities. Research in |  |
| Developmental Disabilities 33:1937-47. |  |

## Studies excluded on second screening on topic

| No. | Study details |
| :--- | :--- |
| 1 | Bevins S, Dawes S, keyshole A et al (2015) Staff views of a music <br> therapy group for people with intellectual disabilities and dementia: <br> a pilot study. Advances in Mental Health and Intellectual Disabilities <br> $9: 40-8$. |
| 2 | Jenkins R (2012) Meeting the health needs of older people with <br> learning disabilities. British Journal of Nursing 21:468-73. |

## Studies excluded on second screening on outcome

| No. | Study details |
| :--- | :--- |
| 1 | McCausland D, Guerin S, Tyrrell J et al (2010) Self-reported needs |
|  | among older persons with intellectual disabilities in an Irish <br> community-based service. Research in Developmental Disabilities <br> $31: 381-7$. |

Studies excluded on second screening on evidence type

| No. | Study details |
| :--- | :--- |
| 1 | Bigby C, Wilson NJ, Stancliffe RJ et al (2014) An effective program <br> design to support older workers with intellectual disability to |


|  | participate individually in community groups. Journal of Policy and <br> Practice in Intellectual Disabilities 11:117-27. |
| :--- | :--- |
| 2 | Miskimmin C (2014) Age-friendly communities for older persons <br> with mild intellectual disabilities. Dissertation, University of <br> Manitoba, Canada. |

Studies excluded on second screening on publication type

| No. | Study details |
| :--- | :--- |
| 1 | Paterson K, Watson N (2013) Ageing with a lifelong condition: the |
| experiences and perception of older people with cerebral palsy. |  |
| University of Glasgow, Scotland, UK. |  |

## Research question 7

## Studies excluded on second screening on duplicate

| No. | Study details |
| :--- | :--- |
| 1 | Maes B, Van Puyenbroeck J (2008) Adaptation of Flemish services <br> to accommodate and support the ageing of people with intellectual <br> disabilities. Journal of Policy and Practice in Intellectual Disabilities <br> $5: 245-52$. |
| 2 | Webber R, Bowers B, McKenzie-Green B (2010) Staff responses to <br> age-related health changes in people with an intellectual disability <br> in group homes. Disability and Society 25:657-71. |

## Studies excluded on second screening on country

| No. | Study details |
| :--- | :--- |
| 1 | Bai X, Ho DWH, Fung K et al (2014) Effectiveness of a life story |
| work program on older adults with intellectual disabilities. Clinical |  |
| Interventions in Aging 9:1865-72. |  |

Studies excluded on second screening on population

| No. | Study details |
| :---: | :---: |
| 1 | Bowers H, Lockwood S, Eleyand A et al (2013) Widening choices for older people with high support needs. Joseph Rowntree Foundation, London. |
| 2 | Brewer JL, Taber-Doughty T, Kubik S (2010) Safety assessment of a home-based telecare system for adults with developmental disabilities in Indiana: a multi-stakeholder perspective. Journal of Telemedicine and Telecare 16:265-9. |
| 3 | Civis Policy Consulting Research (2008) Research into the effectiveness of floating support services for the Supporting People programme: final report. Department for Communities and Local Government. London: HSMO. |
| 4 | Kozma A, Mansell J, Beadle-Brown J (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. American Journal on Intellectual and Developmental Disabilities 114:193-222. |
| 5 | Niemeijer AR, Frederiks B, Riphagen II et al (2010) Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature. International Psychogeriatrics 22:1129-42. |
| 6 | Niemeijer AR, Depla M, Frederiks B et al (2014) The use of surveillance technology in residential facilities for people with dementia or intellectual disabilities: a study among nurses and support staff. The American Journal of Nursing 114:28-48. |
| 7 | Niemeijer AR, Depla M, Frederiks B et al (2015) The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care. Nursing ethics 22:307320. |
| 8 | Ojasalo J, Suomalainen N, Seppälä H et al (2010) Better technologies and services for smart homes of disabled people: empirical findings from an explorative study among intellectually |


|  | disabled. In: 2nd International Conference on Software Technology <br> and Engineering:V251-9. |
| :--- | :--- |
| 9 | The Mental Health Foundation (2001) The Looking Forward <br> Project: the hopes of people with learning disabilities living with <br> their family ageing carers. Updates 3. |

Studies excluded on second screening on evidence type

| No. | Study details |
| :--- | :--- |
| 1 | Joseph Rowntree Foundation (2004) Support for people with <br> learning difficulties in residential settings who develop dementia. <br> London: Joseph Rowntree Foundation. |
| 2 | Seltzer MM, Krauss MW (2001) Quality of life of adults with mental <br> retardation/developmental disabilities who live with family. Mental <br> Retardation and Developmental Disabilities Research Reviews <br> $7: 105-14$. |

## Research question 8

## Studies excluded on second screening on duplicates

| No. | Study details |
| :--- | :--- |
| 1 | Wagemans A, van Schrojenstein Lantman-de Valk H, Proot I et al <br> $(2013)$ The factors affecting end-of-life decision-making by <br> physicians of patients with intellectual disabilities in the <br> Netherlands: a qualitative study. Journal of Intellectual Disability <br> Research 57:380-9. |

## Studies excluded on second screening on topic

| No. | Study details |
| :--- | :--- |


| 1 | Blackman N (2008) The development of an assessment tool for the bereavement needs of people with learning disabilities. British Journal of Learning Disabilities 36:165-70. |
| :---: | :---: |
| 2 | Clute M, Kobayashi R (2012) Looking within and reaching out: bereavement counselor perceptions of grieving adults with ID. American Journal of Hospice and Palliative Medicine 29:583-90. |
| 3 | Dodd P, Dowling S, Hollins S (2005) A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. Journal of Intellectual Disability Research 49:537-43. |
| 4 | Dodd P, McEvoy J, Guerin S et al (2005) Attitudes to bereavement and intellectual disabilities in an Irish Context. Journal of Applied Research in Intellectual Disabilities 18:237-43. |
| 5 | Dodd P, Guerin S (2009) Grief and bereavement in people with intellectual disabilities. Current Opinion in Psychiatry 22:442-6. |
| 6 | Flood C, Gull N, Thomas B et al (2014) Is knowledge and practice safer in England after the release of national guidance on the resuscitation of patients in mental health and learning disabilities? Journal of Psychiatric and Mental Health Nursing 21:806-813. |
| 7 | Forrester-Jones R (2013) The road barely taken: funerals, and people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 26:243-56. |
| 8 | Gray J, Truesdale J (2015) A Delphi study on staff bereavement training in the intellectual and developmental disabilities field. Journal of Intellectual and Developmental Disabilities 53:394-405. |
| 9 | Jenkins R (2012) Meeting the health needs of older people with learning disabilities. British Journal of Nursing 21:468-73. |
| 10 | MacHale R, McEvoy J, Tierney E (2009) Caregiver perceptions of the understanding of death and need for bereavement support in adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 22:574-81. |


| 11 | Martin G, Lindsay P (2009) Dying and living with learning disability: <br> will health checks for adults improve their quality of life? British <br> Journal of General Practice 59:480-1. |
| :--- | :--- |
| 12 | McEvoy J, Machale R, Tierney E (2012) Concept of death and <br> perceptions of bereavement in adults with intellectual disabilities. <br> Journal of Intellectual Disability Research 56:191-203. |
| 13 | McRitchie R, McKenzie K, Quayle E et al (2014) How adults with <br> an intellectual disability experience bereavement and grief: a <br> qualitative exploration. Death Studies 38:179-85. |
| 14 | Savage T, Moro T, Boyden J et al (2015) Implementation <br> challenges in end-of-life research with adults with intellectual and <br> developmental disabilities. Applied Nursing Research 28:202-5. |
| Tuffrey-Wijne I, Giatras N, Butler G et al (2012) People with <br> intellectual disabilities who are affected by a relative or friend with <br> cancer: A qualitative study exploring experiences and support <br> needs. European Journal of Oncology Nursing 16:512-9. |  |
| 16 | Wicki M (2016) Withholding treatment and intellectual disability: <br> second survey on end-of-life decisions in Switzerland. SAGE open <br> medicine 4. |

## Studies excluded on second screening on evidence type

| No. | Study details |
| :--- | :--- |
| 1 | Barber C (2012) Death, dying and people with a learning disability <br> (2/2). British Journal of Healthcare Assistants 6:74-7. |
| 2 | Barber C (2012) Death, dying, bereavement and people with a <br> learning disability (1/2). British Journal of Healthcare Assistants <br> $6: 24-7$. |
| 3 | Campbell A, Bell D (2011) 'Sad, just sad': A woman with a learning <br> disability experiencing bereavement. British Journal of Learning <br> Disabilities 39:11-6. |


| 4 | Clute M (2007).A grounded theory study of the bereavement <br> experience for adults with developmental disabilities following the <br> death of a parent or loved one: perceptions of bereavement <br> counselors. 19th National Symposium on Doctoral Research in <br> Social Work. Case Western Reserve University, Ohio, US. |
| :--- | :--- |
| 5 | Codling M, Knowles J, Vevers A (2014) End-of-life training for paid <br> carers working with people with learning disabilities. British Journal <br> of Community Nursing 19:170-6. |
| 6 | Dunkley S, Sales R (2014) The challenges of providing palliative <br> care for people with intellectual disabilities: a literature review. <br> International Journal of Palliative Nursing 20:279-84. |
| 7 | Ellison N, Rosielle D (2008) Decision making for adults with <br> developmental disabilities near the end of life (Fast Fact \#193). <br> Journal of Palliative Medicine 11:1263-4. |
| 8 | Goldsmith B, Hendrix C, Gentry J (2006) Providing end-of-life <br> palliative care for the developmentally disabled and their families. <br> Journal of Hospice and Palliative Nursing 8:270-5. |
| 9 | Marriott A, Marriott J, Heslop P (2013) Good practice in helping <br> people cope with terminal illnesses. Learning Disability Practice <br> $16: 22-5$. |
| 10 | Martin G, Lindsay P (2009) Dying and living with learning disability: <br> will health checks for adults improve their quality of life? British <br> Journal of General Practice 59:480-481. |
| 11 | Moro T (2016) Agency staff perceptions of end-of-life care for <br> adults with intellectual and developmental disabilities. Dissertation. <br> University of Chicago, Us. |
| 12 | News in Brief (2010) End of life care services need higher profile to <br> improve equal access. Learning Disability Practice 13:4-4. |
| Olson S (2008) Caring at the End of Life. Exceptional Parent 38:44-- <br> 46. |  |
| 13 |  |


| 14 | Read S, Jackson S, Cartlidge D (2007) Palliative care and <br> intellectual disabilities: individual roles, collective responsibilities. <br> International Journal of Palliative Nursing 13:430-5. |
| :--- | :--- |
| 15 | Read S, Thompson-Hill J (2009) Palliative care nursing in relation <br> to people with intellectual disabilities. British Journal of Nursing <br> $15: 506-10$. |
| 16 | Roberts K, Campbell H (2011) Using the M technique as therapy <br> for patients at the end of life: two case studies. International Journal <br> of Palliative Nursing 17:114-8. |
| 17 | Saunders J (2005) Palliative care for people with learning <br> disabilities. European Journal of Palliative Care 12:117-9. |
| 18 | Tuffrey-Wijne I (2009) The preferred place of care for people who <br> are dying. Learning Disability Practice 12:16-21. |
| 19 | Tuffrey-Wijne I, McEnhill L (2008) Communication difficulties and <br> intellectual disability in end-of-life care. International Journal of <br> Palliative Nursing 14:189-94. |

## Research question 9

## Studies excluded on second screening on publication date

| No. | Study details |
| :--- | :--- |
| 1 | Stuart C, David M (2004) Secondary healthcare and learning <br> disability: results of consensus development conferences. Journal <br> of Learning Disabilities 8:30-40. |

## Studies excluded on second screening on population

| No. | Study details |
| :--- | :--- |
| 1 | Wales Welsh Assembly Government (2006) Costs and benefits of <br> the supporting people programme. 33p. |
| 2 | Carr J (2008) Families of 40-year olds with Down Syndrome. <br> Journal on Developmental Disabilities 14:35-43. |


| 3 | Stewart D (2009) Making it happen for everyone. Mental Health <br> Review Journal 14:1-19. |
| :--- | :--- |
| 4 | Daya A, Dhillon J, Taylor M et al (2011) Thematic analysis of <br> readmission into inpatient units for adults with intellectual <br> disabilities: two case studies. Journal of Intellectual Disabilities <br> $15: 279-88$. |
| 5 | Swaine J, Dababnah S, Parish S et al (2013) Family caregivers' <br> perspectives on barriers and facilitators of cervical and breast <br> cancer screening for women with intellectual disability. Journal of <br> Intellectual and Developmental Disabilities 51:62-73. |

## Studies excluded on second screening on topic

| No. | Study details |
| :--- | :--- |
| 1 | McCarthy M (2002) Responses to women with learning disabilities <br> as they go through the menopause. Tizard Learning Disability <br> Review 7:4-12. |
| 2 | Mason J, Rice D (2008) Does a business-like letter written for a <br> general practitioner meet the standards for patients. Psychiatric <br> Bulletin 32:259-62. |
| 3 | Innes A, McCabe L, Watchman K (2012) Caring for older people <br> with an intellectual disability: a systematic review. Maturitas 72:286-- <br> 95. |
| 4 | Clarke G, Harrison K, Holland A et al (2013) How are treatment <br> decisions made about artificial nutrition for individuals at risk of <br> lacking capacity? A systematic literature review. PloS one <br> $8: e 61475$. |

## Studies excluded on second screening on evidence type

$\square$

| 1 | Davies N, Duff M (2001) Breast cancer screening for older women <br> with intellectual disability living in community group homes. Journal <br> of Intellectual Disability Research 45: 253-7. |
| :--- | :--- |

Figure A1. Flowchart summarising excluded studies and study selection


Notes: Some papers addressed more than one research question.
Some papers were too poor in methodology to contribute to evidence statements.
For each research question we utilised best available evidence.

## Systematic reviews searches

A single search was conducted during January 2016, and was re-run in February 2017 to obtain research citations that were added to the databases since the original searches had been run. The searches were designed to capture research that could answer one or more of the review questions. The strategies for the bibliographic databases are listed below. A separate search was undertaken for review questions on end of life care, during February 2017, and the strategies for these are presented separately, underneath the main searches. The search strategies are presented below.

## Main searches

The strategies for the bibliographic databases are detailed below. They were originally run during Janurary 2016 and re-run during February 2017 to identify research literature added since the original searches.

Search strategy

1. Abstracts in Social Gerontology
(EBSCOhost)
Date searched $\quad 28 / 01 / 2016$
No. of records $\quad 541$
Search modes - Boolean/Phrase

| $\#$ | Query | Results |
| :--- | :--- | :--- |
| S12 | S11 Limiters - Publication Date: 19990101-20161231 | 541 |
| S11 | S7 OR S8 OR S9 OR S10 | 732 |
| S10 | SO ((intellect* and (disab* or disorder* or impair* or handicap* or <br> incapacit* or handicap*)) or (learning and (disab* or disorder* or <br> handicap* or handicap*)) or (mental* and (disab* or handicap* or <br> handicap*)) or ((development* or neurodevelopment*) and disab*) or <br> cretinism or "learning difficulties" or ((mentally or intellect*) and (retard <br> or retarded))) | 11 |
| S9 | SU "people with mental disabilities" | 264 |
| S8 | SU "down\# syndrome" | 73 |

TI ( (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*")) ) OR AB ( (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1

|  | (disab* or disorder* or impair* or handicap* or incapacit* or handicap*) <br> or (learning N1 (disab* or disorder* or handicap* or handicap*) or <br> (mental* N1 (disab* or handicap* or handicap*)) or ((development* or <br> neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or <br> ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or <br> "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or <br> intelligence)) or ("mental retardation" not "mental retardation protein*")) <br> $)$ |  |
| :--- | :--- | :--- |


| 2. Ageline | (EBSCOhost) |
| :--- | :--- |
| Date searched | $28 / 01 / 2016$ |
| No. of records | $615(677$ records from search, but some records not | available to download)

Search modes - Boolean/Phrase

| S7 | S6 Limiters - Publication Year: 1999-2016 | 677 |
| :--- | :--- | :--- |
| S6 | S1 OR S2 OR S3 OR S4 OR S5 | 1,365 |
|  | SO ((intellect* and (disab* or disorder* or impair* or handicap* or <br> incapacit* or handicap*) ) or (learning and (disab* or disorder* or <br> handicap* or handicap*)) or (mental* and (disab* or handicap* or <br> handicap*)) or ((development* or neurodevelopment*) and disab*) <br> or cretinism or "learning difficulties" or ((mentally or intellect*) and <br> (retard or retarded))) | 56 |
| S4 | (DE "Mental Disorders") AND (DE "Disabilities" OR DE <br> "Disabled") | 116 |
| S3 | DE "Downs Syndrome" | 120 |
| S2 | DE "Developmentally Disabled" | 516 |
|  | Tl ( (angelman or "happy puppet" or "cerebral palsy" or "spastic <br> diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" <br> or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism <br> or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes <br> or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" | 1,201 |

or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*")) ) OR AB ( (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1
(disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*")) )

## 3. ASSIA(Proquest)

Date searched 15/01/2016
No. of records 571
Search limits: 1999-2016
(SU.EXACT("Developmentally disabled older people") OR
SU.EXACT("Learning disabled older people") OR SU.EXACT("Disabled older people") OR (SU.EXACT("Learning disabled adult children") OR SU.EXACT("Learning disabled elderly people") OR SU.EXACT("Learning disabled middle aged people") OR SU.EXACT("Learning disabled older people"))) OR (((TI,AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) NEAR/1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*)) OR TI,AB("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* NEAR/1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") OR TI,AB(aged NEAR/1(adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or
individual* or individual* or patient* or patient* or inpatient* or inpatient*)) OR $\mathrm{TI}, \mathrm{AB}$ (aged NEAR/2 (care or service* or centre* or center* or centered or home*)) OR TI,AB(("ageing" or "aging") NEAR/3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) OR TI,AB ("age related" NEAR/1(illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) OR $\mathrm{TI}, \mathrm{AB}($ "active aging" or "active ageing") $\mathrm{OR} \mathrm{TI}, \mathrm{AB}(($ ageing or aging) and adult*) OR TI,AB(future NEAR/2 (plan or plans or planning or need* or care or caring or support*)) OR TI,AB(anticipatory NEAR/3 care) OR TI,AB("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult*))) OR (SU.EXACT("Nursing homes") OR SU.EXACT("Disabled elderly women") OR SU.EXACT("Low income older women") OR SU.EXACT("Geriatric psychiatrists") OR SU.EXACT("Geriatric wards") OR SU.EXACT("Older women") OR SU.EXACT("Geriatric psychiatry") OR SU.EXACT("Geriatric social work") OR SU.EXACT("Mentally ill elderly women") OR SU.EXACT("Humanistic gerontology") OR SU.EXACT("Retirement homes") OR SU.EXACT("Private nursing homes") OR SU.EXACT("Early retirement") OR SU.EXACT("Sick elderly women") OR SU.EXACT("Mentally ill older people") OR SU.EXACT("Unemployed older people") OR SU.EXACT("Mandatory retirement") OR SU.EXACT("Gerontology") OR SU.EXACT.EXPLODE("Disabled elderly men" OR "Elderly men" OR "Married elderly men" OR "Mentally ill elderly men" OR "Terminally ill elderly men" OR "Widowed elderly men") OR SU.EXACT("Retirement communities") OR SU.EXACT("Disabled older people") OR SU.EXACT("Ageing") OR SU.EXACT("Homeless older people") OR SU.EXACT("Geriatric hospitals") OR SU.EXACT.EXPLODE("Learning disabled middle aged people" OR "Middle aged people" OR "Unemployed middle aged people") OR SU.EXACT("Medical gerontology") OR

SU.EXACT.EXPLODE("Brain damaged elderly people" OR "Centenarians" OR "Disabled elderly people" OR "Divorced elderly people" OR "Elderly people" OR "Emotionally disturbed elderly people" OR "Gifted elderly people" OR "Hearing impaired elderly people" OR "Homeless elderly people" OR "Housebound elderly people" OR "Language disordered elderly people" OR "Learning disabled elderly people" OR "Low income elderly people" OR "Mentally ill elderly people" OR "Remarried elderly people" OR "Retired people" OR "Sick elderly people" OR "Single elderly people" OR "Terminally ill elderly people" OR "Visually impaired elderly people") OR
SU.EXACT("Geriatric assessment teams") OR SU.EXACT.EXPLODE("Middle aged men") OR SU.EXACT("Retirement") OR SU.EXACT.EXPLODE("BlindDeaf elderly women" OR "Disabled elderly women" OR "Elderly women" OR "Married elderly women" OR "Mentally ill elderly women" OR "Sick elderly women" OR "Single elderly women" OR "Terminally ill elderly women" OR "Visually impaired elderly women") OR SU.EXACT("Geriatric assessment") OR SU.EXACT("Geriatric day hospitals") OR SU.EXACT.EXPLODE("Disabled middle aged women" OR "Middle aged women" OR "Single middle aged women") OR SU.EXACT("Geriatricians") OR SU.EXACT.EXPLODE("Developmentally disabled older people" OR "Disabled older people" OR "Homeless older people" OR "Learning disabled older people" OR "Mentally ill older people" OR "Older people" OR "Unemployed older people") OR SU.EXACT("Emotionally disturbed older women") OR SU.EXACT.EXPLODE("Older men") OR SU.EXACT("Geriatric medicine") OR SU.EXACT("Geriatric clinics")) OR SU.EXACT("Future planning")) AND ((TI,AB (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or
"Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*") or ((intellect* NEAR/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning NEAR/1 (disab* or disorder* or handicap* or handicap*)) or (mental* NEAR/1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) NEAR/1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) NEAR/5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") NEAR/1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) OR (SU.EXACT.EXPLODE("Down's syndrome") OR SU.EXACT("Learning disabled women") OR SU.EXACT("Developmentally disabled people") OR SU.EXACT("Learning disabled mothers") OR SU.EXACT("Mental retardation") OR SU.EXACT("Learning disabled young adults") OR SU.EXACT("Nonverbal learning disabilities") OR

SU.EXACT.EXPLODE("Aicardi syndrome" OR "Aspartylglucosaminuria" OR "Cri du Chat syndrome" OR "De Lange syndrome" OR "Down's syndrome" OR "Fragile $X$ syndrome" OR "Learning disabilities" OR "Nonverbal learning disabilities" OR "Prader-Willi syndrome") OR SU.EXACT("Learning disabled people") OR SU.EXACT("Community learning disability nurses") OR SU.EXACT("Learning disabled men") OR SU.EXACT("Learning disability nursing") OR SU.EXACT("Developmentally delayed people") OR SU.EXACT("Learning disabled young men") OR SU.EXACT.EXPLODE("Prader-Willi syndrome") OR SU.EXACT("Learning disability hospitals") OR SU.EXACT("Nonverbal learning disabled people") OR SU.EXACT("Learning disabled parents") OR SU.EXACT("Learning disability nurses"))))
4. British Nursing Index (HDAS)

Date searched 24/02/2016
No. of records 307


|  |  | "community" OR "communities" OR "consumer*" OR "consumer*" OR "client*" OR "clients*" OR "population*" OR "population*" OR "resident*" OR "resident*" OR "individual*" OR "individual*" OR "citizen*" OR "citizen*" OR "men" OR "men*" OR "women" OR "women*" OR "patient*" OR "patient*" OR "inpatient*" OR "inpatient*" OR service* OR centre* OR center* OR centered OR home*)).ti,ab |  |
| :---: | :---: | :---: | :---: |
| 10 | BNI | (angelman OR "happy puppet" OR "cerebral palsy" OR "spastic diplegia" OR "coffin lowry" OR "lowry coffin" OR "Cornelia de Lange" OR "cat cry" OR "cri du chat" OR "crying cat" OR idiocy OR mongolism OR mongoloidism OR "lesch nyhan" OR "nyhan disease" OR menkes OR "bell martin syndrome" OR "fragile x syndrome" OR "gillian turner" OR "martin bell" OR "turner Gillian" OR "prader willi" OR rubinstein OR "bourneville disease" OR "5p syndrome" OR lejeune* OR epiloia OR "pringle disease" OR "tuberose sclerosis" OR "wagr disease" OR "William* disease" OR rett OR rett* OR "Williams beuren" OR "sanfilippo" OR "mucopolysaccharidiosis type III" OR "untreated phenylketonuria" OR "downs" OR "down syndrome" OR "Tay-Sachs disease" OR "Laurence Moon Syndrome" OR "Congenital Hypothyroidism" OR "Bardet Biedl" OR "Foetal Alcohol Spectrum Disorder*" OR "Fetal Alcohol Spectrum Disorder*" OR (intellect* adj1 (disab* OR disorder* OR impair* OR handicap* OR incapacit* OR handicap*)) OR (learning adj1 (disab* OR disorder* OR handicap* OR handicap*)) OR (mental* adj1 (disab* OR handicap* OR handicap*)) OR ((development* OR neurodevelopment*) adj1 disab*) OR cretinism OR "learning difficulties" OR ((mentally OR intellect*) adj5 (retard OR retarded)) OR (("Sub-average" OR "subaverage" OR "sub norm*" OR "subnorm*") adj1 (intellect* OR intelligence)) OR ("mental retardation" NOT "mental retardation protein*")).ti,ab | 6125 |


| 11 | BNI | (("age in place" OR "ageing in place" OR "aging in place" OR "aged Adult*" OR "mature adult*" OR "gerontology" OR "Later life" OR "Middle age" OR "middle aged" OR "late life" OR "Elderly" OR geriatric* OR "seniors" OR "pensioner" OR "pensioners" OR "pensioner's" OR "old age" OR "old aged" OR "elders" OR "menopause" OR "menopausal" OR "retirement" OR "retired" OR "prostate" OR "nursing home*" OR "Senior age" OR "senior aged") OR (pension* adj1 age*) OR ("Mid life" OR Midlife OR "Middle life" OR "institutionalized elder*" OR "Institutionalised elder*") OR ("aged" adj1 (adult* OR adult* OR "user" OR "users" OR person* OR communit* OR consumer* OR client* OR population* OR resident* OR resident* OR individual* OR individual* OR patient* OR patient* OR inpatient* OR inpatient*))).ti,ab | 12860 |
| :---: | :---: | :---: | :---: |
| 12 | BNI | (("aged" adj2 ("care" OR service* OR centre* OR center* OR "centered" OR home*)) OR (("ageing" OR "aging") adj3 (Adult* OR adult* OR "Service" OR "services" OR "user" OR "users" OR "person" OR "persons" OR "person's" OR "people" OR "peoples" OR people* OR "community" OR "communities" OR "consumer" OR "consumers" OR consumer* OR "client" OR "clients" OR client* OR "population" OR "populations" OR "resident" OR "residents" OR resident* OR "individual" OR individual* OR "citizen" OR "citizens" OR "citizen*" OR men* OR men* OR "women" OR women* OR "patients" OR patient* OR "inpatients" OR inpatient* OR service* OR centre* OR center* OR centered OR home*))).ti, ab | 486 |
| 13 | BNI | ```("age related" adj1 (illness* OR "health" OR condition* OR challenge* OR problem* OR difficult* OR "deterioration")).ti,ab``` | 10 |
| 14 | BNI | ("active aging" OR "active ageing").ti,ab | 24 |


| 15 | $\mathrm{BNI}$ | ((("ageing" OR "aging") AND (adult* OR adult*)) OR ("future" adj2 ("plan" OR "plans" OR "planning" OR "need" OR "needs" OR "care" OR "caring" OR support*)) OR ("anticipatory" adj3 "care")).ti,ab | 601 |
| :---: | :---: | :---: | :---: |
| 17 | BNI | ("grow old*" OR "get old*" OR "growing old*" OR "getting old*" OR "become old*" OR "becoming old*").ti,ab | 98 |
| 18 | BNI | MIDDLE AGE/ OR AGEING/ OR ELDERLY/ OR LIFE EVENTS/ OR MENOPAUSE/ OR RETIREMENT/ OR ELDERLY: HEALTH/ | 5664 |
| 19 | BNI | AGE FACTORS/ OR AGED/ 26 | 2666 |
| 20 | BNI | ELDERLY/ OR ELDERLY: HEALTH/ 371 | 3719 |
| 21 | BNI | 18 OR 19 OR 20 | 7627 |
| 22 | BNI | 7 OR 11 OR 12 OR 13 OR 14 OR 15 OR 17 OR 21 | 18875 |
| 24 | BNI | LEARNING DISABILITIES: COMMUNITY NURSING/ OR LEARNING DISABILITIES NURSING/ OR LEARNING DISABILITIES NURSING : EDUCATION/ | 1065 |
| 25 | BNI | CEREBRAL PALSY/ OR CONGENITAL ABNORMALITIES/ OR DOWN SYNDROME/ | 1366 |
| 28 | BNI | exp LEARNING DISABILITIES : OLDER ADULTS/ | 153 |
| 41 | BNI | LEARNING DISABILITIES/ OR LEARNING DISABILITIES ABUSE/ OR LEARNING DISABILITIES : RIGHTS/ OR LEARNING DISABILITIES : ATTITUDES/ OR LEARNING dISABILITIES : COMMUNITY NURSING/ OR LEARNING disAbilities : SERVICES/ | 4545 |
| 42 | BNI | 10 OR 24 OR 25 OR 41 | 7353 |
| 43 | BNI | 22 AND 42 | 273 |
| 44 | BNI | 28 OR 43 | 345 |
| 45 | BNI | 44 [Limit to: Publication Year 1999-2016] | 307 |

5. CINAHL (EBSCOhost)

Date searched 29/01/2016
No. of records 2,743 records, 2,718 in English
Search modes - Boolean/Phrase

| \# | Query | Results |
| :---: | :---: | :---: |
| S42 | S41 Limiters - English Language | 2,718 |
| S41 | S40 Limiters - Publication Year: 1999-2016 | 2,743 |
| S40 | S28 AND S39 | 3,144 |
| S39 | S1 OR S2 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 | 54,570 |
| S38 | SO ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))) | 17,090 |
| S37 | (MH "Developmental Disabilities") | 6,544 |
| S36 | (MH "Fetal Alcohol Syndrome") | 1,195 |
| S35 | (MH "Tuberous Sclerosis") | 523 |
| S34 | (MH "Angelman Syndrome") | 135 |
| S33 | (MH "Rett Syndrome") OR (MH "De Lange Syndrome") OR (MH "Gaucher Disease") OR (MH "Kernicterus") OR (MH "Phenylketonuria+") OR (MH "Cockayne Syndrome") OR (MH "Coffin-Siris Syndrome") OR (MH "De Barsy Syndrome") OR (MH "Intellectual Disability+") OR (MH "Schinzel-Giedion Syndrome") | 22,628 |
| S32 | (MH "Learning Disorders") | 5,835 |
| S31 | (MH "Cerebral Palsy") | 8,163 |
| S30 | (MH "Mentally Disabled Persons") | 3,810 |
| S29 | (MH "Intellectual Disability") OR (MH "Coffin-Siris Syndrome") OR (MH "Cri-Du-Chat Syndrome") OR (MH "De Barsy Syndrome") OR (MH "De Lange Syndrome") OR (MH "Down Syndrome") OR (MH "Kleefstra Syndrome") OR (MH "Williams Syndrome") OR (MH "WAGR Syndrome") OR (MH "Schinzel-Giedion Syndrome") OR (MH "Rubinstein-Taybi Syndrome") OR (MH "Prader-Willi Syndrome") OR (MH "Mental Retardation, X-Linked") OR (MH "Adrenoleukodystrophy") OR (MH "Coffin-Lowry Syndrome") OR | 21,535 |


|  | (MH "Fragile X Syndrome") OR (MH "Kinky Hair Syndrome") OR (MH "Mucopolysaccharidosis II") OR (MH "Rett Syndrome") |  |
| :---: | :---: | :---: |
| S28 | S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 | 604,362 |
| S27 | SU "In Old Age" | 77,224 |
| S26 | (MH "Nursing Homes") OR (MH "Skilled Nursing Facilities") | 21,263 |
| S25 | (MH "Menopause+") | 14,404 |
| S24 | (MH "Retirement") | 6,255 |
| S23 | (MH "Housing for the Elderly") | 2,627 |
| S22 | (MH "Geriatric Psychiatry") OR (MH "Geriatric Nutrition") OR (MH "Geriatrics") OR (MH "Geriatric Assessment") OR (MH "Gerontologic Nurse Practitioners") OR (MH "Gerontologic Care") OR (MH "Gerontologic Nursing") OR (MH "Geriatric Functional Assessment") OR (MH "Rehabilitation, Geriatric") | 46,856 |
| S21 | (MH "Frail Elderly") OR (MH "Attitude to Aging") OR (MH "Assisted Living") OR (MH "Elder Abuse") OR (MH "Health Services for the Aged") OR (MH "Aged, Hospitalized") OR (MH "Housing for the Elderly") OR (MH "Gerontologic Nursing") OR (MH "Gerontologic Care") OR (MH "Dental Care for Aged") OR (MH "Geropsychiatric Nursing") | 47,110 |
| S20 | ((MH "Aged") OR (MH "Aged, 80 and Over") OR (MH "Aging+")) NOT (MH "child" OR MH "infant" OR MH "adolescence" OR MH "child, preschool" OR MH "prenatal diagnosis" OR MH "Pediatrics") | 488,032 |
| S19 | Tl(future N2 (plan or plans or planning or need* or care or caring or support*)) OR TI(anticipatory N3 care) OR TI("grow* old" or "get* old" or "becom* old") or $\mathrm{Tl}(($ "grow* older" or "get* older" or "becom* older") and adult*) | 2,015 |
| S18 | AB (future N 2 (plan or plans or planning or need* or care or caring or support*)) OR AB(anticipatory N3 care) OR AB("grow* old" or | 8,350 |


|  | "get* old" or "becom* old") or AB(("grow* older" or "get* older" or "becom* older") and adult*) |  |
| :---: | :---: | :---: |
| S17 | $\mathrm{TI}($ (ageing or aging) and adult*) OR TI("active aging" or "active ageing") | 1,011 |
| S16 | AB ((ageing or aging) and adult*) | 4,862 |
| S15 | AB("active aging" or "active ageing") | 121 |
| S14 | TI("age related" N1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 34 |
| S13 | AB ("age related" N 1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 234 |
| S12 | TI(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) | 2,269 |
| S11 | AB(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) | 5,406 |
| S10 | TI(aged N2 (care or service* or centre* or center* or centered or home*)) | 2,282 |


| S9 | AB(aged N2 (care or service* or centre* or center* or centered or home*)) | 1,726 |
| :---: | :---: | :---: |
| S8 | TI(aged N1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) | 2,549 |
| S7 | AB (aged N 1 (adult* or user or users or person* or communit* or consumer* $^{*}$ or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) | 18,902 |
| S6 | $\mathrm{Tl}($ "age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") | 91,056 |
| S5 | $\mathrm{AB}($ "age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") | 73,425 |
| S4 | (TI(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or | 40,912 |


|  | "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) |  |
| :---: | :---: | :---: |
| S3 | (AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) | 50,931 |
| S2 | $\mathrm{AB}($ (adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) N5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or | 9,703 |


|  | "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) |  |
| :---: | :---: | :---: |
| S1 | TI ((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) AND (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) | 11,173 |

## 6. Cochrane Database of Systematic Reviews and CENTRAL(Cochrane

 Library)| Date searched | $18 / 01 / 2016$ |
| :--- | :--- |
| No. of records | 5 (Systematic reviews) |
| No. of records | 238 (CENTRAL trials) |

\#1 ("Homes for the aged" or "health services for the aged" or "elder abuse" or "senior centers" or "Geriatrics" or "Housing for the Elderly" or "Geriatric Assessment" or "Geriatric Nursing" or "Geriatric Psychiatry" or "Geriatric Dentistry" or "Retirement" or "nursing homes"):kw
\#2 ("Aged, 80 and over" or "aged"):kw
\#3 ("frail elderly" or aging):kw
\#4 (Aging):kw
\#5 adolescent:kw
\#6 ("young adult" or "prenatal diagnosis" or "pregnancy" or "child"):kw
\#7 MeSH descriptor: [Prenatal Diagnosis] explode all trees
\#8 MeSH descriptor: [Pregnancy] explode all trees
\#9 MeSH descriptor: [Child] explode all trees
\#10 MeSH descriptor: [Infant] explode all trees
\#11 \#5 or \#6 or \#7 or \#8 or \#9 or \#10
\#12 \#2 or \#3 or \#4
\#13 \#12 not \#11
\#14 (("old" or "older" or "oldest" or "frail" or "elder" or senior) near/1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or
"client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*)):ti,ab,kw \#15 ("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* next age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*"):ti,ab,kw consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)):ti,ab,kw \#17 (aged near/2 (care or service* or centre* or center* or centered or home*)):ti,ab,kw
\#18 (("ageing" or "aging") near/3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)):ti,ab,kw \#19 ("age related" next (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)):ti,ab,kw
\#20 ("active aging" or "active ageing"):ti,ab,kw
\#21 ((ageing or aging) and adult*):ti,ab,kw
\#22 (future near/2 (plan or plans or planning or need* or care or caring or support*)):ti,ab or (anticipatory near/3 care):ti,ab,kw
\#23 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult*)):ti,ab,kw

[^0]\#25 \#1 or \#13 or \#24
\#26 ("Education of Intellectually Disabled" or "mentally disabled persons"):kw
\#27 ((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service*" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) near/5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville
disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or ((intellect* near/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning near/1 (disab* or disorder* or handicap* or handicap*)) or (mental* near/1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) next disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) near/5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") next (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein*"))):ti,ab,kw
\#28 ("adrenoleukodystrophy" or "Angelman Syndrome OR cerebral palsy" or "Coffin-Lowry Syndrome" or "cri-du-chat syndrome" or "de lange syndrome" or "down syndrome" or "lesch-nyhan syndrome" or "fragile x syndrome" or "mucopolysaccharidoses" or "Pyruvate Carboxylase Deficiency Disease" or "pyruvate dehydrogenase complex deficiency disease" or "rubinstein-taybi syndrome" or "tuberous sclerosis" or "wagr syndrome" or "Developmental Disabilities" or "Intellectual Disability" or "Learning disorders" or "LaurenceMoon Syndrome" or "Congenital Hypothyroidism" or "Bardet-Biedl Syndrome" or "Fetal Alcohol Spectrum Disorders" or "Tay-Sachs disease" or "Prader-Willi Syndrome" or "Phenylketonurias"):kw
\#29 MeSH descriptor: [Phenylketonurias] explode all trees
\#30 MeSH descriptor: [Prader-Willi Syndrome] explode all trees
\#31 \#26 or \#27 or \#28 or \#29 or \#30
\#32 \#25 and \#31
\#32 Publication Year from 1999 to 2016

## 7. CRD databases:

Date searched 18/01/2016, Date limit 1999-2015
Database of Abstracts of Reviews of Effects (No. of records
Health Technology Assessment database (No. of records 5)

1 ((("old" or "older" or "oldest" or "frail" or "elder" or senior) near1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*)))

2 (("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* near1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*"))
3 ((aged near1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)))
4 ((aged near2 (care or service* or centre* or center* or centered or home*))) 5 ((("ageing" or "aging") near3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)))
6 (("age related" near1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)))
7 (("active aging" or "active ageing"))
8 (((ageing or aging) and adult*))
9 ((future near2 (plan or plans or planning or need* or care or caring or support*)))

10 ((anticipatory near3 care))
11 (("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult*)))
12 \#1 OR \#2 OR \#3 OR \#4 OR \#5 OR \#6 OR \#7 OR \#8 OR \#9 OR \#10 OR \#11

13 (((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service*" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) near5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or ((intellect* near1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning near1 (disab* or disorder* or handicap* or handicap*)) or (mental* near1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) near1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) near5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") near1 (intellect** or intelligence))) or ("mental retardation" not "mental retardation protein*"))))
14 (("Education of Intellectually Disabled" or "mentally disabled persons")) 15 \#13 OR \#14
16 \#12 AND \#15
8. Econlit (EBSCOhost)

Date searched 25/01/2016

| $\#$ | Query |
| :--- | :--- |
| S23 | S3 AND S22 Limiters - Published Date: 19990101-20161231 |
| S22 | S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR <br> S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 |
| S21 | TI(future N2 (plan or plans or planning or need* or care or caring or support*)) <br> OR Tl(anticipatory N3 care) OR TI("grow* old" or "get* old" or "becom* old") or <br> TI(("grow* older" or "get* older" or "becom* older") and adult*) |
| S20 | AB(future N2 (plan or plans or planning or need* or care or caring or support*)) <br> OR AB(anticipatory N3 care) OR AB("grow* old" or "get* old" or "becom* old") or <br> AB(("grow* older" or "get* older" or "becom* older") and adult*) |
| S19 | TI((ageing or aging) and adult*) OR TI("active aging" or "active ageing") |
| S18 | AB((ageing or aging) and adult*) |
| S17 | AB("active aging" or "active ageing") |
| S16 | Tl("age related" N1(illness* or health or condition* or challenge* or problem* or <br> difficult* or deterioration)) |
| S15 | AB("age related" N1(illness* or health or condition* or challenge* or problem* or <br> difficult* or deterioration)) |
| SI(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or |  |
| S13 | "services" or "user" or "users" or "person" or "persons" or "person's" or "people" <br> or "peoples" or "people's" or "community" or "communities" or "consumer" or <br> "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or or "citizen" or "citizens" or "citizen's" or "men" or "men's" or <br> "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or <br> "con <br> S14 <br> "populations" or "resident" or "residents" or "resident's" or "individual" or <br> "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or <br> "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" <br> or service or centre* or center* or centered or home*)) |
|  | AB(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or <br> "services" or "user" or "users" or "person" or "persons" or "person's" or "people" |


|  | "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) |
| :---: | :---: |
| S12 | TI(aged N2 (care or service* or centre* or center* or centered or home*)) |
| S11 | AB(aged N2 (care or service* or centre* or center* or centered or home*)) |
| S10 | TI(aged N1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) |
| S9 | AB (aged N 1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) |
| S8 | TI("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") |
| S7 | AB("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") |
| S6 | (TI(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) |
| S5 | (AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" |

$\left.\begin{array}{|l|l|}\hline & \begin{array}{l}\text { or "community" or "communities" or "consumer*" or "consumer*" or "client*" or } \\ \text { "clients*" or "population*" or "population*" or "resident*" or "resident*" or } \\ \text { "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men" or } \\ \text { "women" or "women*" or "patient" or "patient" or "inpatient*" or "inpatient" or } \\ \text { service* or centre* or center* or centered or home*))) }\end{array} \\ \hline \text { S4 } & \text { SU elderly OR AGING OR AGEING } \\ \hline \text { S3 } & \begin{array}{l}\text { S1 OR S2 } \\ \text { or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or } \\ \text { "communities" or "consumer" or consumer* or client* or individual* or citizen* or } \\ \text { patient* or inpatient*) N5 (angelman or "happy puppet" or "cerebral palsy" or } \\ \text { "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat } \\ \text { cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or }\end{array} \\ \hline \text { "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile } \\ \text { x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" } \\ \text { or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or } \\ \text { "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" } \\ \text { S2 } & \begin{array}{l}\text { or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis } \\ \text { type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay- } \\ \text { Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" } \\ \text { or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol } \\ \text { Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* } \\ \text { or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or } \\ \text { handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or } \\ ((d e v e l o p m e n t * ~ o r ~ n e u r o d e v e l o p m e n t *) ~ N 1 ~ d i s a b *) ~ o r ~ c r e t i n i s m ~ o r ~ " l e a r n i n g ~\end{array} \\ \text { (difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" } \\ \text { "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat }\end{array}\right\}$

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cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "TaySachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*")))
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## 9. EMBASE (OVID SP)

Date searched 03/02/2016
No. of records 1018 (864 English language)
1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or "consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (217747)
2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or
"nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (637920)
3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (15945)

4 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (3170)

5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab. (26818)

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (1045)

7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (19522)
8 (anticipatory adj3 care).ti,ab. (188)
9 ("active aging" or "active ageing").ti,ab. (263)
10 ((ageing or aging) and adult?).ti,ab. (29218)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get*
older" or "becom* older") and adult?)).ti,ab. (1272)
121 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (841378)
13 aged/ (2353978)
14 aging/ (207428)
15 attitude to aging/ (129)
16 geriatric rehabilitation/ or geriatric surgery/ or geriatrician/ or geriatrics/ or gerontopsychiatry/ (44372)
17 geriatric assessment/ or geriatric care/ or geriatric hospital/ or geriatric nursing/ or geriatric nutrition/ or geriatric patient/ or geriatrics/ (85262)

37 ((adult*2 or people*2 or resident*2 or person*2 or women*2 or men*2 or population*2 or ageing or aging or "Service?" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer*2 or client*2 or individual*2 or citizen*2 or patient?s? or inpatient?s?) adj5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1
(disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?"))).ti,ab. (33502)

38 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (13240)

39 disabled person/ (27286)
40 learning disorder/ (23869)
41 developmental disorder/ (28629)
42 mental deficiency/ (55611)
43 intellectual impairment/ or coffin lowry syndrome/ or down syndrome/ or exp mental retardation malformation syndrome/ or sanfilippo syndrome/ or wagr syndrome/ or x linked mental retardation/ (72822)

44 fragile x syndrome/ or mental retardation malformation syndrome/ or x chromosome recessive disorder/ (9901)

45 cerebral palsy/ (27514)
46 mental retardation malformation syndrome/ or congenital disorder/ or acrocallosal syndrome/ or aicardi syndrome/ or cockayne syndrome/ or costello syndrome/ or de lange syndrome/ or fetal alcohol syndrome/ or fetal hydantoin syndrome/ or floating harbor syndrome/ or fragile x syndrome/ or happy puppet syndrome/ or infantile refsum disease/ or lesch nyhan syndrome/ or lowe syndrome/ or mauriac syndrome/ or menkes syndrome/ or prader willi syndrome/ or sjoegren larsson syndrome/ or smith lemli opitz syndrome/ or smith magenis syndrome/ or sotos syndrome/ or williams beuren syndrome/ or wolf hirschhorn syndrome/ or zellweger syndrome/ (93832)
47 cat cry syndrome/ or down syndrome/ or turner syndrome/ (37231)
48 Lesch Nyhan syndrome/ (1334)
49 Rubinstein syndrome/ (722)
tuberous sclerosis/ (8461)
51 Rett syndrome/ (3900)
52 phenylketonuria/ (8064)
53 Tay Sachs disease/ (1556)
54 Laurence Moon syndrome/ or Bardet Biedl syndrome/ (1613)
55 congenital hypothyroidism/ (5365)
5637 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 (312456)

5736 and 56 (15811)
5857 not (exp animals/ not (exp humans/ and exp animals/)) (15147)
59 limit 58 to $y r=" 1999$-Current" (10305)
60 limit 59 to exclude medline journals (1018)
61 limit 60 to English language (864)
10. Family and Society Studies Worldwide (EBSCOhost)

Date searched 28/01/2016
No. of records 937
Search modes - Boolean/Phrase
\(\left.\begin{array}{|l|l|l|}\hline \# \& Query \& Result <br>

s\end{array} \left\lvert\, $$
\begin{array}{ll}\hline \text { S25 } & \text { S24 Limiters - Date Published: 19990101-20161231 }\end{array}
$$\right.\right]\)| S24 |
| :--- |
| S21 AND S23 |
| S23 |
| S1 OR S2 OR S22 |
| ( Tl (angelman or "happy puppet" or "cerebral palsy" or "spastic <br> diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or <br> "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or <br> mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell <br> martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin <br> bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville <br> disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" <br> or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett <br> or rett* or "Williams beuren" or "sanfilippo" or <br> "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or |


| "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) OR ( AB (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "TaySachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) |
| :---: |


| S21 | S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 | 89,352 |
| :---: | :---: | :---: |
| S20 | (ZU "older people") or (ZU "elderly poor") or (ZU "frail elderly") or (ZU "retirement") or (ZU "nursing home care") or (ZU "nursing home employees") or (ZU "nursing home patients") or (ZU "menopause") or (ZU "permanency planning") or (ZU "future life") or (ZU "aging") or (ZU "middle age") or (ZU "senior centers") or (ZU "senior housing") or (ZU "geriatric care units") or (ZU "geriatric dentistry") or (ZU "geriatric health care teams") or (ZU "geriatric nursing") or (ZU "geriatric nursing -- research") or (ZU "geriatric psychiatry") or (ZU "geriatric psychology") or (ZU "geriatricians") or (ZU "geriatrics") or (ZU "longevity") or (ZU "medical care for the aged") or (ZU "retirement communities") OR (SU "older people") or (SU "elderly poor") or (SU "frail elderly") or (SU "retirement") or (SU "nursing home care") or (SU "nursing home employees") or (SU "nursing home patients") or (SU "menopause") or (SU "permanency planning") or (SU "future life") or (SU "aging") or (SU "middle age") or (SU "senior centers") or (SU "senior housing") or (SU "geriatric care units") or (SU "geriatric dentistry") or (SU "geriatric health care teams") or (SU "geriatric nursing") or (SU "geriatric psychiatry") or (SU "geriatric psychology") or (SU "geriatricians") or (SU "geriatrics") or (SU "longevity") or (SU "medical care for the aged") or (SU "retirement communities") | 16,030 |
| S19 | Tl(future N2 (plan or plans or planning or need* or care or caring or support*)) OR TI(anticipatory N3 care) OR TI("grow* old" or "get* old" or "becom* old") or $\mathrm{TI}(($ "grow* older" or "get* older" or "becom* older") and adult*) | 663 |
| S18 | AB (future N 2 (plan or plans or planning or need* or care or caring or support*)) OR AB(anticipatory N3 care) OR AB("grow* old" or "get* old" or "becom* old") or $\mathrm{AB}(($ "grow* older" or "get* older" or "becom* older") and adult*) | 5,381 |
| S17 | $\mathrm{TI}($ (ageing or aging) and adult*) OR TI("active aging" or "active ageing") | 391 |


| S16 | AB | 2,741 |
| :---: | :---: | :---: |
| S15 | AB("active aging" or "active ageing") | 53 |
| S14 | $\mathrm{TI}($ "age related" N 1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 9 |
| S13 | AB ("age related" N 1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 86 |
| S12 | TI(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) | 1,183 |
| S11 | AB(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) | 3,525 |
| S10 | TI(aged N2 (care or service* or centre* or center* or centered or home*)) | 545 |
| S9 | AB(aged N2 (care or service* or centre* or center* or centered or home*)) | 1,163 |
| S8 | TI(aged N1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) | 663 |


| S7 | AB (aged N1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) | 8,292 |
| :---: | :---: | :---: |
| S6 | $\mathrm{TI}($ "age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") | 26,275 |
| S5 | AB("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") | 44,113 |
| S4 | (TI(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) | 10,852 |
| S3 | (AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" | 25,557 |


|  | or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or <br> service* or centre* or center* or centered or home*)) ) |  |
| :--- | :--- | :--- |
| S2 | ZU ("FRAGILE X syndrome" OR "PEOPLE with mental disabilities*" <br> OR "DOWN\# syndrome" OR "DEVELOPMENTAL disabilities" OR <br> "MENTAL retardation") OR SU ("FRAGILE X syndrome" OR <br> "PEOPLE with mental disabilities" OR "DOWN\# syndrome" OR <br> "DEVELOPMENTAL disabilities" OR "MENTAL retardation") | 8,778 |
| S1 | SO ((intellect* and (disab* or disorder* or impair* or handicap* or <br> incapacit* or handicap*)) or (learning and (disab* or disorder* or <br> handicap* or handicap*)) or (mental* and (disab* or handicap* or <br> handicap*)) or ((development* or neurodevelopment*) and disab*) or <br> cretinism or "learning difficulties" or ((mentally or intellect*) and <br> (retard or retarded))) | 10,510 |

11. Health Management Information Consortium (OVID SP)

Date searched 26/01/2016
No. of records 634
1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or
"consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (9551)
2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (15534)

3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (143)
4 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (193)
5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab.

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (14)
7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (1482)
8 (anticipatory adj3 care).ti,ab. (46)
9 ("active aging" or "active ageing").ti,ab. (51)
10 ((ageing or aging) and adult?).ti,ab. (311)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult?)).ti,ab. (91)
12 old peoples homes/ or exp older people/ or centenarians/ or frail elderly people/ or frail older people/ or over 60s/ or over $65 \mathrm{~s} /$ or over $75 \mathrm{~s} /$ or over $80 \mathrm{~s} /$ or retired people/ or exp ageing/ or exp geriatrics/ or health services for elderly people/ or health services for older people/ or longevity/ or exp old age/ or exp old peoples homes/ or "residential care of the elderly"/ or "residential care of the older"/ or exp retirement/ or exp retirement communities/ (18642)
13 menopause/ (205)
14 congenital disorders/ or developmental disorders/ or genetic disorders/

15 learning difficulties/ or learning disabilities/ or downs syndrome/ or feeble mindedness/ or profound learning disabilities/ or severe learning disabilities/
or learning disability hospitals/ or learning disability nursing/ or learning disability services/ or learning disability units/ or phenylketonuria/ or learning disability nurses/ (6687)

16 learning disability nurses/ or learning disability nursing/ or learning disability services/ or learning disability units/ or learning disabilities/ or learning disability hospitals/ or learning disorders/ (6602)

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17 exp nursing homes/ (1641)
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181 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 17 (29664)

19 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (842)

20 disabilities/ (3702)
$21 \quad 12$ or 13 or 14 (19493)
2220 and 21 (480)
23 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or
intelligence))) or ("mental retardation" not "mental retardation protein?")).ti,ab. (6845)
$24 \quad 14$ or 15 or 16 or 19 or 23 (9077)
$25 \quad 18$ and 24 (820)
2622 or 25 (1265)
27 limit 26 to $y r=" 1999$-Current" (634)
12. Medline (OVID SP) (In-Process \& Other Non-Indexed Citations and Ovid MEDLINE (R) < 1946 to Present>)
Date searched 06/01/2016
No. of records 2193 (2046 after non English-language removed)
1 "Homes for the aged"/ or "health services for the aged"/ or "elder abuse"/ or "senior centers"/ or Geriatrics/ or Housing for the Elderly/ or Geriatric Assessment/ or Geriatric Nursing/ or Geriatric Psychiatry/ or Geriatric Dentistry/ or Retirement/ or nursing homes/ (112229)

2 "Aged, 80 and over"/ (700345)
3 Aged/ (2543611)
4 "frail elderly"/ (7815)
5 Aging/ (201942)
6 exp Prenatal Diagnosis/ or exp pregnancy/ or exp child/ or exp infant/ or adolescent/ or young adult/ (3818420)

7 (2 or 3 or 4 or 5) not 6 (2068636)
8 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?"
or "people*" or "community" or "communities" or "consumer?" or
"consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (172182)
9 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or
"menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (488634)
10 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (13018)

11 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (2775)
12 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab. (20408)

13 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (894)

14 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (15406)
15 (anticipatory adj3 care).ti,ab. (163)
16 ("active aging" or "active ageing").ti,ab. (231)
17 ((ageing or aging) and adult?).ti,ab. (24644)
18 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult?)).ti,ab. (1043)

198 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 (653859)
$20 \quad 1$ or 7 or 19 (2426581)
21 Education of Intellectually Disabled/ or mentally disabled persons/ (7905)

22 ((adult*2 or people*2 or resident*2 or person*2 or women*2 or men*2 or population*2 or ageing or aging or "Service?" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer*2 or client*2 or
individual*2 or citizen*2 or patient?s? or inpatient?s?) adj5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?"))).ti,ab. (26963)

23 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).nw. (9804) 24 adrenoleukodystrophy/ not Adrenoleukodystrophy/bl, cf, ci, cl, cn, di, em, et, ge, hi, im, mo, pa, pp, ra, ri, rt, su, ur (208)

25 Angelman Syndrome/ not Angelman Syndrome/bl, cl, di, em, en, et, ge, pa, pp, ra, ri, su (95)
26 cerebral palsy/ not Cerebral Palsy/bl, cf, ci, cl, cn, di, em, en, et, ge, hi, im, mi, mo, ps, pa, pd, ph, pp, ra, ri, sn, su, us, ur, ve, vi (8185)
27 Coffin-Lowry Syndrome/ not Coffin-Lowry Syndrome/cf, di, em, en, ge, pa, pp, ra (13)

28 cri-du-chat syndrome/ not cri-du-chat syndrome/cf, di, em, en, ge, pa, pp, ra (194)
de lange syndrome/ not de lange syndrome/cf, di, em, en, ge, pa, pp, ra (203)

30 down syndrome/ not Down Syndrome/bl, cf, ci, cl, cn, di, dh, dt, em, en, et, ge, hi, im, ip, mi, mo, pa, ph, pp, ra, ri, rt, su, us, ul, ur, ve, vi (7948)

31 lesch-nyhan syndrome/ not lesch-nyan syndrome/bl, cl, di, em, en, ge, hi, im, mi, mo, ps, pa, pp, ra, ri, tm, us, ul, ur, ve, vi (1179)

32 fragile x syndrome/ not Fragile X Syndrome/bl, cl, di, em, en, ge, hi, im, mi, mo, ps, pa, pp, ra, ri, tm, us, ul, ur, ve, vi (586)

33 mucopolysaccharidoses/ not Mucopolysaccharidoses/bl, cf, ci, cl, cn, di, em, en, et, ge, hi, im, me, mi, mo, nu, pa, pp, ra, ri, su, us, ur, ve (339)
34 exp Phenylketonurias/ not exp Phenylketonurias/bl, cf, ci, ch, cl, di, em, en, et, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, tm, us, ur, ve, vi (2374)

35 exp Prader-Willi Syndrome/ not exp Prader-Willi Syndrome/bl, cf, ci, cl, di, em, en, et, ge, hi, im, mi, mo, pa, pp, ra, ri, su, us, ur, ve (498)
36 Pyruvate Carboxylase Deficiency Disease/ not Pyruvate Carboxylase Deficiency Disease/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (112)
37 pyruvate dehydrogenase complex deficiency disease/ not pyruvate dehydrogenase complex deficiency disease/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (177)

38 rubinstein-taybi syndrome/ not rubinstein-taybi syndrome/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (97)
39 tuberous sclerosis/ not Tuberous Sclerosis/bl, cf, ci, cl, di, em, en, et, ge, hi, im, mo, pa, pp, ra, ri, rt, su, us, ur, ve (1595)
40 wagr syndrome/ not wagr syndrome/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (11)

41 Developmental Disabilities/ not Developmental Disabilities/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (8298)
42 Intellectual Disability/ not Intellectual Disability/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (31339)
43 Learning disorders/ not learning disorders/bl, cf, ci, cl, di, en, ge, hi, im, mi , mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (7717)
44 Laurence-Moon Syndrome/ not Laurence-Moon Syndrome/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (291) di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (2758)
46 Bardet-Biedl Syndrome/ not Bardet-Biedl Syndrome/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (48)
47 Fetal Alcohol Spectrum Disorders/ not Fetal Alcohol Spectrum
Disorders/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (1637)

48 Tay-Sachs disease/ not Tay-Sachs disease/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (261)
4921 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 (96217)

5020 and 49 (4161)
51 animals/ not (humans/ and animals/) (4081299)
5250 not 51 (4049)
53 limit 52 to (comment or editorial or historical article or legal cases or letter or news or newspaper article or video-audio media or webcasts) (129)
5452 not 53 (3920)
55 limit 54 to $\mathrm{yr}=$ "1999 -Current" (2193)
56 limit 55 to (afrikaans or albanian or arabic or armenian or azerbaijani or belorussian or bengali or bosnian or bulgarian or burmese or catalan or chinese or croatian or czech or danish or dutch or esperanto or estonian or finnish or flemish or french or gaelic, scots or georgian or german or greek or hausa or hebrew or hindi or hungarian or icelandic or indonesian or interlingua or italian or japanese or kirghiz or korean or latin or latvian or lithuanian or macedonian or malay or marathi or masai or multilingual or norwegian or persian or polish or portuguese or pushto or rumanian or russian or serbian or slovak or slovene or spanish or swahili or swedish or tagalog or tamil or telugu or thai or turkish or ukrainian or urdu or vietnamese or welsh) (151)

5755 not 56 (2042)
13. Medline - Pubmed not Medline and Medline In-Process (Web of Knowledge)

Date searched 18/01/2016
No. of records 283 (search lines \#6 and \#5 saved)

| \# | Query | Results |
| :---: | :---: | :---: |
| \#6 | (\#4) AND STATUS: (In-Process) Indexes=MEDLINE <br> Timespan=1999-2016 | 121 |
| \# 5 | (\#4) AND STATUS: (PubMed-not-MEDLINE) Indexes=MEDLINE Timespan=1999-2016 | 171 |
| \# 4 | \#3 Indexes=MEDLINE Timespan=1999-2016 | 8,489 |
| \# 3 | \#2 AND \#1 Indexes=MEDLINE Timespan=All years | 15,279 |
| \# 2 | TS=(("old" or "older" or "oldest" or "frail" or "elder" or "senior") NEAR/1 (adult\$ or adult\$s or "Service*" or user\$ or user\$s or person\$ or person\$s or people\$ or people\$s or "community" or "communities" or consumer\$ or consumer\$s or client\$ or client\$s or population\$ or population\$s or resident\$ or resident\$s or individual\$ or individual\$s or citizen\$ or citizen\$s or men\$ or men\$s or women or women\$s or patient\$ or patient\$s or inpatient\$ or inpatient\$s or service\$ or centre\$ or center\$ or "centered" or home\$)) OR TS=("age in place" or "ageing in place" or "aging in place" or "aged Adult\$" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged") or TS=(pension* NEAR/1 age\$) or TS=("Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") OR TS=("aged" NEAR/1 (adult\$ or adult\$s or "user" or "users" or person* or communit* or consumer* or client* or population* or resident\$ or resident\$s or individual\$ or individual\$s or patient\$ or patient\$s or inpatient\$ or inpatient\$s)) OR TS=("aged" near/2 ("care" or service\$ or centre\$ or center\$ or "centered" or home\$)) OR TS=(("ageing" or "aging") near/3 (Adult\$ or adult\$s or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or | 4,219,175 |


|  | ```people$s or "community" or "communities" or "consumer" or "consumers" or consumer$s or "client" or "clients" or client$s or "population" or "populations" or "resident" or "residents" or resident$s or "individual" or individual$s or "citizen" or "citizens" or "citizen$s" or men$ or men$s or "women" or women$s or "patients" or patient$s or "inpatients" or inpatient$s or service$ or centre$ or center$ or centered or home$)) OR TS=("age related" NEAR/1 (illness* or "health" or condition* or challenge* or problem$ or difficult* or "deterioration")) OR TS=("active aging" or "active ageing") OR TS=(("ageing" or "aging") and (adult$s or adult$)) OR TS=("future" near/2 ("plan" or "plans" or "planning" or "need" or "needs" or "care" or "caring" or support*)) OR TS=("anticipatory" near/3 "care") OR TS=("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and (adult$ or adult$s))) Indexes=MEDLINE Timespan=All years``` |  |
| :---: | :---: | :---: |
| \# 1 |  | 118,162 |


|  | "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or <br> "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal <br> Alcohol Spectrum Disorder*") or TS=(intellect* near/1 (disab* or <br> disorder* or impair* or handicap* or incapacit* or handicap*)) or <br> TS=("learning" near/1 (disab* or disorder* or handicap* or <br> handicap*)) or TS=(mental* near/1 (disab* or handicap* or <br> handicap*)) or TS=((development* or neurodevelopment*) |  |
| :--- | :--- | :--- |
|  | NEAR/1 disab*) or TS=("cretinism" or "learning difficulties") or <br> TS=(("mentally" or intellect*) near/5 ("retard" or "retarded")) or <br> TS=(("Sub-average" or "subaverage" or "sub norm*" or |  |
| "subnorm*") NEAR/1 (intellect* or "intelligence")) or TS=("mental |  |  |
| retardation" not "mental retardation protein*") |  |  |
| Indexes=MEDLINE Timespan=All years |  |  |

## 14. PsycINFO (EBSCOHost)

Date searched 26/01/2016
No. of records $\quad 3,129$ (3023 after non-English language removed)
Search modes - Boolean/Phrase

| $\#$ | Query | Results |
| :--- | :--- | :--- |
| S35 | S33 NOT S34 | 3,023 |
| S34 | LA (Afrikaans OR Arabic OR Bulgarian OR Catalan OR Chinese <br> OR Czech OR Danish OR Dutch OR Finnish OR French OR <br> Georgian OR German OR Greek OR Hebrew OR Hindi OR <br> Hungarian OR Italian OR Japanese OR Korean OR Lithuanian OR <br> Malaysian OR Norwegian OR Polish OR Portuguese OR <br> Romanian OR Russian OR Serbo-Croatian OR Slovak OR <br> Slovene OR Spanish OR Swedish OR Turkish OR Ukrainian) | 274,643 |
| S33 | S31 AND S32 | 3,129 |
| S32 | PY 1999-2016 | $2,272,36$ |
| S31 | S29 NOT S30 | 4 |
| S30 | MR Brain Imaging | 6,700 |
| S29 | S27 NOT S28 | 39,717 |


| S28 | TI (FXTAS OR FMR1 OR gene\# OR chromosome\#) | 16,528 |
| :---: | :---: | :---: |
| S27 | S25 NOT S26 | 6,862 |
| S26 | PO (Animal NOT (human AND animal)) | 307,977 |
| S25 | S6 AND S24 | 6,905 |
| S24 | S1 OR S2 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 | 331,549 |
| S23 | Tl(future N2 (plan or plans or planning or need* or care or caring or support*)) OR TI(anticipatory N3 care) OR TI("grow* old" or "get* old" or "becom* old") or $\mathrm{Tl}(($ "grow* older" or "get* older" or "becom* older") and adult*) | 736 |
| S22 | AB (future N 2 (plan or plans or planning or need* or care or caring or support*)) OR AB(anticipatory N3 care) OR AB("grow* old" or "get* old" or "becom* old") or AB(("grow* older" or "get* older" or "becom* older") and adult*) | 13,502 |
| S21 | $\mathrm{TI}($ (ageing or aging) and adult*) OR TI("active aging" or "active ageing") | 1,105 |
| S20 | AB ((ageing or aging) and adult*) | 12,523 |
| S19 | AB("active aging" or "active ageing") | 178 |
| S18 | TI("age related" N1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 34 |
| S17 | AB ("age related" N 1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 508 |
| S16 | TI(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) | 1,767 |


| S15 | AB(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) | 8,036 |
| :---: | :---: | :---: |
| S14 | Tl(aged N2 (care or service* or centre* or center* or centered or home*)) | 665 |
| S13 | AB(aged N2 (care or service* or centre* or center* or centered or home*)) | 2,902 |
| S12 | $\mathrm{Tl}($ aged N 1 (adult* or user or users or person* or communit* or consumer* $^{\text {or client* or population* or resident* or individual* }}$ or individual* $^{*}$ or patient* or patient* or inpatient* or inpatient*)) | 1,407 |
| S11 | AB(aged N1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) | 53,638 |
| S10 | Tl("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") | 49,158 |
| S9 | AB("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old | 105,088 |


|  | age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") |  |
| :---: | :---: | :---: |
| S8 | (TI(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) | 26,379 |
| S7 | (AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) | 74,857 |
| S6 | S3 OR S4 OR S5 | 91,503 |
| S5 | AB((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) N5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or | 39,841 |


|  | "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) |  |
| :---: | :---: | :---: |
| S4 | TI ((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) AND (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital | 23,174 |


|  | Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) |  |
| :---: | :---: | :---: |
| S3 | DE "Intellectual Development Disorder (Attitudes Toward)" OR DE "Learning Disabilities" OR DE "organic brain syndromes" OR DE "Developmental Disabilities" OR DE "Cornelia De Lange Syndrome" OR DE "Crying Cat Syndrome" OR DE "Fetal Alcohol Syndrome" OR DE "Fragile X Syndrome" OR DE "Prader Willi Syndrome" OR DE "Congenital Disorders" OR DE "Intellectual Development Disorder" OR DE "Learning Disorders" OR DE "Down's Syndrome" OR DE "Trisomy" OR DE "Williams Syndrome" OR DE "Anencephaly" OR DE "Cerebral Palsy" OR DE "Tay Sachs Disease" OR DE "Rett Syndrome" OR DE "Turners Syndrome" | 79,158 |
| S2 | AG ("middle age" OR "Aged (65 yrs \& older)" OR "very old") NOT AG("Childhood" OR "Preschool Age" OR "School Age" OR "Adolescence" OR "Young Adulthood") | 191,048 |
| S1 | DE "Gerontological Counseling" OR DE "Geriatric Patients" OR DE "Geriatric Assessment" OR DE "Geriatric Psychiatry" OR DE "Geriatric Psychotherapy" OR DE "Aged (Attitudes Toward)" OR DE "Gerontology" OR DE "Future" OR DE "Retirement" OR DE "Nursing Homes" OR DE "Retirement Communities" OR DE "Aging" OR DE "Aging (Attitudes Toward)" OR DE "Aging in Place" OR DE "Geropsychology" OR DE "Geriatrics" OR DE "Elder Care" OR DE "Elder Abuse" | 81,270 |

15. Social Policy and Practice (SPP) (OVID SP)

Date searched 29/01/2016
No. of records 1512
1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or "consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti, ab. (31553)
2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (31480)

3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (214)
4 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (510)
5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab.

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (36)
7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (1729)

8 (anticipatory adj3 care).ti,ab. (15)
9 ("active aging" or "active ageing").ti,ab. (212)
10 ((ageing or aging) and adult?).ti,ab. (1582)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult?)).ti,ab. (351)
12 (ageing or aging).sh,hw. (5036)
13 "permanency planning".sh,hw. (748)
14 elderly.sh,hw. (16180)
15 aged.sh,hw. (628)
16 senior.sh,hw. (52)
17 "geriatric*".sh,hw. (407)
18 "nursing home?".sh,hw. (5005)
19 retirement.sh,hw. (2378)
20 "menopaus*".sh,hw. (160)
21 "older people".de,hw. (73920)
22 "very old people".de,hw. (264)
23 ageing.de,hw. (5029)
24 "elder abuse".de,hw. (2266)
25 (retirement or "retirement communities").de,hw. (2378)
26 "life expectancy".de,hw. (481)
27 "elderly".de,hw. (16180)
28 Retired persons.de,hw. (137)
29 Middle aged.de,hw. (464)
30 Middle age.de,hw. (6)
31 "CPA*".an. (55959)
321 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 (87302)

33 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du
chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?")).ti,ab. (13466)

34 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (4146) 35 ("learning disabilities" or "Downs syndrome" or "Prader-Willi syndrome" or "severe learning disabilities" or "Williams syndrome" or "foetal alcohol syndrome" or "learning disabilities services" or "learning disability nursing" or "parents with learning disabilities" or "learning disabilities nursing" or "learning disabilities services" or "community learning disabilities teams").de,hw.

36 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia
or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?")).ti,ab,de,hw. (18843)

3734 or 35 or 36 (19196)
3832 and 37 (2478)
39 limit 38 to $\mathrm{yr}=$ "1999 -Current" (1567)
40 limit 39 to (consultation document or inspection report or learning resource or legislation or standards or statistical publication or statutory guidance) (55)

4139 not 40 (1512)
16. Social Sciences Citation Index (SSCI) and Conference Proceedings Citation Index - Social Science and Humanities (CPCI-SSH) (Web of Knowledge)

Date searched 18/01/2016
No. of records 1,948 (1908 English Language only, of which 1,892 from SSCI)
\# 6 1,892 \#5 Indexes=SSCI Timespan=All years
\# 5 1,908 (\#4) AND LANGUAGE: (English) Indexes=SSCI, CPCI-SSH
Timespan=1999-2016
\# 4 1,948 \#3 Indexes=SSCI, CPCI-SSH Timespan=1999-2016
\# 3 2,520 \#2 AND \#1 Indexes=SSCI, CPCI-SSH Timespan=All years
\# 2 52,626 TS=(("adult" or adult\$ or people* or resident* or person* or women* or men\$ or men\$s or population* or "ageing" or "aging" or "Service*" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual\$ or individual\$s or citizen* or patient\$ or patient\$s or inpatient*) near/5 ("angelman" or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or "idiocy" or "mongolism" or "mongoloidism" or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or "rubinstein" or "bourneville disease" or " 5 p syndrome" or lejeune* or "epiloia" or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or "rett" or rett\$ or rett\$s or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*")) or TS=(intellect* near/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or TS=("learning" near/1 (disab* or disorder* or handicap* or handicap*)) or TS=(mental* near/1 (disab* or handicap* or handicap*)) or TS=((development* or neurodevelopment*) NEAR/1 disab*) or TS=("cretinism" or "learning difficulties") or TS=(("mentally" or intellect*) near/5 ("retard" or "retarded")) or TS=(("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") NEAR/1 (intellect* or "intelligence")) or TS=("mental retardation" not "mental retardation protein*") Indexes=SSCI, CPCI-SSH Timespan=All years
\# 1 248,925 TS=(("old" or "older" or "oldest" or "frail" or "elder" or "senior") NEAR/1 (adult\$ or adult\$s or "Service*" or user\$ or user\$s or person\$ or person\$s or people\$ or people\$s or "community" or "communities" or consumer\$ or consumer\$s or client\$ or client\$s or population\$ or population\$s or resident\$ or resident\$s or individual\$ or individual\$s or citizen\$ or citizen\$s or men\$ or men\$s or women or women\$s or patient\$ or patient\$s or inpatient\$ or inpatient\$s or service\$ or centre\$ or center\$ or "centered" or home\$)) OR TS=("age in place" or "ageing in place" or "aging in place" or "aged Adult\$" or "mature adult*" or "gerontology" or "Later life" or
"Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged") or TS=(pension* NEAR/1 age\$) or TS=("Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") OR TS=("aged" NEAR/1 (adult\$ or adult\$s or "user" or "users" or person* or communit* or consumer* or client* or population* or resident\$ or resident\$s or individual\$ or individual\$s or patient\$ or patient\$s or inpatient\$ or inpatient\$s)) OR TS=("aged" near/2 ("care" or service\$ or centre\$ or center\$ or "centered" or home\$)) OR TS=(("ageing" or "aging") near/3 (Adult\$ or adult\$s or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or people\$s or "community" or "communities" or "consumer" or "consumers" or consumer\$s or "client" or "clients" or client\$s or "population" or "populations" or "resident" or "residents" or resident\$s or "individual" or individual\$s or "citizen" or "citizens" or "citizen\$s" or men\$ or men\$s or "women" or women\$s or "patients" or patient\$s or "inpatients" or inpatient\$s or service\$ or centre\$ or center\$ or centered or home\$)) OR TS=("age related" NEAR/1 (illness* or "health" or condition* or challenge* or problem\$ or difficult* or "deterioration")) OR TS=("active aging" or "active ageing") OR TS=(("ageing" or "aging") and (adult\$s or adult\$)) OR TS=("future" near/2 ("plan" or "plans" or "planning" or "need" or "needs" or "care" or "caring" or support*)) OR TS=("anticipatory" near/3 "care") OR TS=("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and (adult\$ or adult\$s))) Indexes=SSCI, CPCI-SSH Timespan=All years

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17. Social Services Abstracts (Proquest)
Date searched 03/02/2016
No. of records 893
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Date limit 1999-2016
((SU.EXACT("Life Plans") OR SU.EXACT("Geriatrics") OR
SU.EXACT("Aging") OR SU.EXACT("Middle Aged Adults") OR
SU.EXACT("Permanency Planning") OR SU.EXACT("Retirement") OR

SU.EXACT("Elderly") OR SU.EXACT("Gerontology") OR SU.EXACT("Nursing Homes") OR SU.EXACT("Elder Abuse") OR SU.EXACT("Pensions")) OR
(TI,AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) NEAR/1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*)) OR $\mathrm{TI}, \mathrm{AB}$ ("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* NEAR/1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") OR TI,AB(aged NEAR/1(adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) OR TI,AB(aged NEAR/2 (care or service* or centre* or center* or centered or home*)) OR TI,AB(("ageing" or "aging") NEAR/3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) OR TI,AB ("age related" NEAR/1(illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) OR $\mathrm{TI}, \mathrm{AB}($ "active aging" or "active ageing") OR $\mathrm{TI}, \mathrm{AB}(($ ageing or aging) and adult*) OR TI,AB(future NEAR/2 (plan or plans or planning or need* or care or caring or support*)) OR TI,AB(anticipatory NEAR/3 care) OR TI,AB("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom*
older") and adult*)))) AND ((SU.EXACT("Handicapped") OR
SU.EXACT("Language Disorders") OR SU.EXACT("Congenitally Handicapped") OR SU.EXACT("Cerebral Palsy") OR SU.EXACT("Downs Syndrome") OR SU.EXACT("Mentally Retarded") OR SU.EXACT("Learning Disabilities") OR SU.EXACT("Physically Handicapped")) OR ((TI,AB (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "TaySachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*") or ((intellect* NEAR/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning NEAR/1 (disab* or disorder* or handicap* or handicap*)) or (mental* NEAR/1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) NEAR/1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) NEAR/5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") NEAR/1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) ))
18. Social Work Abstracts (OVID SP)

Date searched 29/01/2016
No. of records 94
1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or "consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or
"patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (2345)
2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (4796)
3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (120)

4 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (53)
5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab.

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (3)

7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (267)
8 (anticipatory adj3 care).ti,ab. (0)
9 ("active aging" or "active ageing").ti,ab. (12)
10 ((ageing or aging) and adult?).ti, ab. (409)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get*
older" or "becom* older") and adult?)).ti,ab. (44)
12 (ageing or aging).sh,hw. (806)
"permanency planning".sh,hw. (102)
"Aging and the aged".cc. (4240)
elderly.sh,hw. (404)
aged.sh,hw. (3134)
senior.sh,hw. (27)
"geriatric*".sh,hw. (500)
"nursing home?".sh,hw. (500)
retirement.sh,hw. (226)
"menopaus*".sh,hw. (37)
1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (7518)
23 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?")).ti,ab,sh,hw. (1320)
24 "Intellectual Disabilities".cw. (1322)
25 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or
((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (79)
$26 \quad 23$ or 24 or 25 (1922)
$27 \quad 22$ and 26 (178)
28 limit 27 to $\mathrm{yr}=$ "1999 -Current" (94)
19. SocIndex (EBSCOhost)

Date searched 28/01/2016
No. of records 525
Search mode- Boolean
S28 S27 Limiters - Date of Publication: 19990101-20161231 (525)
S27 S4 AND S26 (916)
S26 S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25

S25 DE "ELDERLY poor" OR DE "ABUSED elderly" OR DE "RURAL elderly" OR DE "URBAN elderly" OR DE "OLDER homeless persons" OR DE "OLDER patients" OR DE "AT-risk older people"

S24 DE "NURSING care facilities" OR DE "SENIOR housing" OR DE "CONGREGATE housing"

S23 DE "MENOPAUSE" OR DE "POSTMENOPAUSE"
S22 Tl(future N2 (plan or plans or planning or need* or care or caring or support*)) OR TI(anticipatory N3 care) OR TI("grow* old" or "get* old" or "becom* old") or $\mathrm{TI}(($ "grow* older" or "get* older" or "becom* older") and adult*)

S21 AB(future N2 (plan or plans or planning or need* or care or caring or support*)) OR AB(anticipatory N3 care) OR AB("grow* old" or "get* old" or "becom* old") or $\mathrm{AB}(($ "grow* older" or "get* older" or "becom* older") and adult*)
S20 $\mathrm{TI}(($ ageing or aging $)$ and adult*) OR $\mathrm{TI}($ "active aging" or "active ageing")
S19 AB((ageing or aging) and adult*)
S18 AB("active aging" or "active ageing")
S17 TI("age related" N 1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration))

S16 AB("age related" N1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration))
S15 TI(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*))
S14 AB(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*))

S13 TI(aged N2 (care or service* or centre* or center* or centered or home*))

S12 AB(aged N2 (care or service* or centre* or center* or centered or home*))

S11 TI(aged N1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*))
S10 AB(aged N1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*))
S9 $\mathrm{TI}($ "age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid
life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*")

S8 AB ("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*")

S7 (TI(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*)))
S6 (AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*)))
S5 (DE "OLDER people -- Abuse of" OR DE "MIDDLE-aged persons" OR
DE "MIDDLE-aged women" OR DE "OLDER people -- Crimes against" OR DE "OLDER people \& the environment" OR DE "OLDER blacks" OR DE "OLDER Hispanic Americans" OR DE "OLDER Asian Americans" OR DE "MIDDLE-aged workers" OR DE "MIDDLE-aged women -- Sexual behavior" OR DE "MIDDLE-aged persons -- Sexual behavior" OR DE "MIDDLE-aged men -- Sexual behavior" OR DE "ABUSED elderly" OR DE "ELDERLY poor" OR DE "MINORITY older people" OR DE "OLDER Christians" OR DE "OLDER Native Americans" OR DE "OLDER blacks" OR DE "OLDER blind people" OR DE "OLDER couples" OR DE "OLDER homeless persons" OR

DE "OLDER men" OR DE "OLDER people -- Social conditions" OR DE "OLDER unemployed" OR DE "OLDER women" OR DE "PETS \& older people" OR DE "POLICE services for older people" OR DE "SEX education for older people" OR DE "SOCIAL work with older people" OR DE "TECHNOLOGY \& older people" OR DE "TELEVISION \& older people" OR DE "GERIATRICS" OR DE "GERONTOCRACY" OR DE "OLDER people -Civil rights" OR DE "OLDER people -- Employment" OR DE "RETIREES" OR DE "OLDER people -- Attitudes" OR DE "OLDER sexual minorities" OR DE "MIDDLE-aged LGBT people" OR DE "RETIREMENT" OR DE "AGING" OR DE "ACTIVE aging" OR DE "SUCCESSFUL aging" OR DE "ATTITUDES toward aging" OR DE "OLDER LGBT people" OR DE "GERONTOLOGY" OR DE "FUTURE, The" OR DE "PERMANENCY planning" OR DE "MIDDLE age" OR DE "MIDDLE-aged persons" OR DE "OLDER people" OR DE "LONGEVITY" OR DE "OLD age")
S4 S1 OR S2 OR S3
S3 DE "LEARNING disabilities" OR DE "DEVELOPMENTALLY disabled" OR DE "DEVELOPMENTAL disabilities" OR DE "LEARNING disabled persons" OR DE "PEOPLE with mental disabilities" OR DE "MENTAL retardation" OR DE "DOWN syndrome -- Social aspects"

S2 SO ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded)))
S1 TI ( (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or
"Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*")) ) OR AB ( (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*")) ).

## Systematic review searches for the review questions on end of life care

1. Allied and Complementary Medicine (AMED) (OVID SP)

Date searched 20/02/2017
No. of records 81

1. learning disorders/ or mental retardation/ or learning disability/ or developmental disabilities/ or down syndrome/ or mentally handicapped/ or mental handicap/
2. ((adult*2 or people*2 or resident*2 or person*2 or women*2 or men*2 or population*2 or ageing or aging or "Service?" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer*2 or client*2 or individual*2 or citizen*2 or patient?s? or inpatient?s?) adj5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?"))).ti,ab.
3. ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx,jn.
4. cerebral palsy/
5. cri-du-chat syndrome/
6. down syndrome/
7. fragile $x$ syndrome/
8. exp Prader-Willi Syndrome/
9. Developmental Disabilities/
10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11. animals/ not (humans/ and animals/)
12. hospices/ or hospice care/
13. exp palliative care/
14. death/
15. exp attitude to death/
16. terminal illness/
17. exp terminal care/
18. palliative treatment/
19. exp advance directives/
20. exp life support care/
21. (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase").ti,ab.
22. (Terminal* adj3 (nursing or care or caring or service? or support* or decision*)).ti,ab.
23. (Dying adj3 (care or caring or nursing or service? or decision* or support*)).ti,ab.
24. (End* adj2 life).ti,ab.
25. (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))).ti,ab.
26. (death adj3 (care* or caring or nursing or service? or decision* or support* or concept*)).ti,ab.
27. ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care").ti,ab.
28. ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives").ti,ab.
29. ((advance adj1 decision*) or (advanced adj1 decision*)).ti,ab.
30. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
or 25 or 26 or 27 or 28 or 29
31. 10 and 30
32. 31 not 11

## 2. Abstracts in Social Gerontology and Ageline (EBSCOHost)

 These databases were not separately searched for this review question as the original strategy and update search searched for all the records relating to learning disabilities from these two databases, including those that concern end of life care for this population.
## 3. ASSIA(Proquest)

Date searched 23/02/2017
No. of records 82
Search limits: 2005-2017
((TI,AB (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum

Disorder*" or "Fetal Alcohol Spectrum Disorder*") or ((intellect* NEAR/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning NEAR/1 (disab* or disorder* or handicap* or handicap*)) or (mental* NEAR/1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) NEAR/1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) NEAR/5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") NEAR/1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) OR (SU("Down's syndrome") OR SU("Learning disabled women") OR SU("Developmentally disabled people") OR SU("Learning disabled mothers") OR SU("Mental retardation") OR SU("Learning disabled young adults") OR SU("Nonverbal learning disabilities") OR SU("Aicardi syndrome") OR SU("AspartyIglucosaminuria") OR SU("Cri du Chat syndrome") OR SU("De Lange syndrome") OR SU("Down's syndrome") OR SU("Fragile X syndrome") OR SU("Learning disabilities") OR SU("Nonverbal learning disabilities") OR SU("Prader-Willi syndrome") OR SU("Learning disabled people") OR SU("Community learning disability nurses") OR SU("Learning disabled men") OR SU("Learning disability nursing") OR SU("Developmentally delayed people") OR SU("Learning disabled young men") OR SU("Prader-Willi syndrome") OR SU("Learning disability hospitals") OR SU("Nonverbal learning disabled people") OR SU("Learning disabled parents") OR SU("Learning disability nurses"))) AND (SU("Terminal care" OR "Terminal illness" OR "Terminally ill elderly men" OR "Terminally ill elderly people" OR "Terminally ill elderly women" OR "Terminally ill men" OR "Terminally ill people" OR "Terminally ill widowed sisters" OR "Terminally ill women" OR "Hospices" OR "Death awareness" OR "Death" OR "Dying" OR "Palliative care" OR "Palliative medicine" OR "Living wills" OR "Advance directives" OR "End of life decisions") OR TI,AB((Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") OR (Terminal* NEAR/3 (nursing or care or caring or service or services or support* or decision*)) OR (Dying NEAR/3 (care or caring or nursing or service or services or decision* or support*)) OR (End* NEAR/2 life) OR (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))) OR (death

NEAR/3 (care* or caring or nursing or service or services or decision* or support* or concept*)) OR ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") OR ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives") OR (advance NEAR/1 decision*) OR (advanced NEAR/1 decision*)))

## 4. British Nursing Index (HDAS)

Date searched 24/02/2017
No. of records 151
(("TERMINAL CARE"/ OR "TERMINAL CARE : NURSING"/ OR "DEATH : ATTITUDES"/ OR "TERMINAL CARE : HOSPICES"/ OR "TERMINAL CARE : SERVICES"/ OR "TERMINAL CARE : DOMICILIARY"/ OR RESUSCITATION/ OR "RIGHT TO DIE"/ OR DEATH/ OR "DEATH : ATTITUDES"/ OR (palliat* OR hospice* OR "end of life").so OR ((advance ADJ1 decision*) OR (advanced ADJ1 decision)).ti,ab OR ("advance directive" OR "advanced directive" OR "living will" OR "advance care directive" OR "advanced care directive" OR "advance decision" OR "advanced decision" OR "advance directives" OR "advanced directives" OR "living wills" OR "advance care directives" OR "advanced care directives").ti,ab OR ("near death" OR "advance care plan" OR "advance care plans" OR "advance care planning" OR "advanced care plan" OR "advanced care plans" OR "advanced care planning" OR "life supportive care").ti,ab OR (death ADJ3 (care* OR caring OR nursing OR service* OR decision* OR support* OR concept*)).ti,ab OR (death AND (imminen* OR nearing OR last day* OR last week* OR last hour* OR final day* OR final week* OR final hour* OR critical pathway* OR care pathway*)).ti,ab OR (dying).ti,ab OR (End* ADJ2 life).ti,ab OR (Dying ADJ3 (care OR caring OR nursing OR service* OR decision* OR support*)).ti,ab OR (Terminal* ADJ3 (nursing OR care OR caring OR service* OR support* OR decision*)).ti,ab OR (Hospice OR hospices OR Palliat* OR "Terminally ill" OR "Terminal illness" OR "Terminal phase").ti,ab) AND
((angelman OR "happy puppet" OR "cerebral palsy" OR "spastic diplegia" OR "coffin lowry" OR "lowry coffin" OR "Cornelia de Lange" OR "cat cry" OR "cri du chat" OR "crying cat" OR idiocy OR mongolism OR mongoloidism OR "lesch nyhan" OR "nyhan disease" OR menkes OR "bell martin syndrome" OR "fragile $x$ syndrome" OR "gillian turner" OR "martin bell" OR "turner Gillian" OR "prader willi" OR rubinstein OR "bourneville disease" OR " 5 p syndrome" OR lejeune* OR epiloia OR "pringle disease" OR "tuberose sclerosis" OR "wagr disease" OR "William* disease" OR rett OR rett* OR "Williams beuren" OR "sanfilippo" OR "mucopolysaccharidiosis type III" OR "untreated phenylketonuria" OR "downs" OR "down syndrome" OR "Tay-Sachs disease" OR "Laurence Moon Syndrome" OR "Congenital Hypothyroidism" OR "Bardet Biedl" OR "Foetal Alcohol Spectrum Disorder*" OR "Fetal Alcohol Spectrum Disorder*" OR (intellect* ADJ1 (disab* OR disorder* OR impair* OR handicap* OR incapacit* OR handicap*)) OR (learning ADJ1 (disab* OR disorder* OR handicap* OR handicap*)) OR (mental* ADJ1 (disab* OR handicap* OR handicap*)) OR ((development* OR neurodevelopment*) ADJ1 disab*) OR cretinism OR "learning difficulties" OR ((mentally OR intellect*) ADJ5 (retard OR retarded)) OR (("Sub-average" OR "subaverage" OR "sub norm*" OR "subnorm*") ADJ1 (intellect* OR intelligence)) OR ("mental retardation" NOT "mental retardation protein*")).ti,ab OR ("LEARNING DISABILITIES : COMMUNITY NURSING"/ OR LEARNING DISABILITIES NURSING/ OR "LEARNING DISABILITIES NURSING : EDUCATION"/) OR CEREBRAL PALSY/ OR CONGENITAL ABNORMALITIES/ OR DOWN SYNDROME/ OR LEARNING DISABILITIES/ OR "LEARNING DISABILITIES : ABUSE"/ OR "LEARNING DISABILITIES : RIGHTS"/ OR "LEARNING DISABILITIES : ATTITUDES"/ OR "LEARNING DISABILITIES : COMMUNITY NURSING"/ OR "LEARNING DISABILITIES : SERVICES"/ OR "LEARNING DISABILITIES : OLDER ADULTS"/)) [DT 2005-2017]

## 5. CINAHL Plus(EBSCOhost)

Date searched 23/02/2017
No. of records 511
Search modes - Boolean/Phrase

| $\#$ | Query | Results |
| :--- | :--- | :--- |


| S57 | S56 Limiters - Publication Year: 2005-2017, English Language | 511 |
| :---: | :---: | :---: |
| S56 | S39 AND S55 | 602 |
| S55 | S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 | 84,587 |
| S54 | SO (palliat* or hospice*) Limiters - English Language | 20,101 |
| S53 | TI ( (advance N1 decision*) OR (advanced N1 decision*) ) OR AB ( (advance N1 decision*) OR (advanced N1 decision ) Limiters English Language | 172 |
| S52 | TI ( "advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives" ) OR AB ( "advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives" ) Limiters - English Language | 2,395 |
| S51 | TI ( ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) OR AB ( ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) Limiters - English Language | 1,546 |
| S50 | TI ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) OR AB ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) <br> Limiters - English Language | 3,241 |
| S49 | TI ( (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)) ) OR AB ( (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or fina | 1,059 |


|  | week* or final hour* or critical pathway* or care pathway*)) ) <br> Limiters - English Language |  |
| :---: | :---: | :---: |
| S48 | TI dying OR AB dying Limiters - English Language | 10,593 |
| S47 | TI (End* N2 life) OR AB (End* N2 life) Limiters - English Language | 13,315 |
| S46 | TI ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) OR AB ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) Limiters - English Language | 2,430 |
| S45 | TI ( (Terminal* N3 (nursing or care or caring or service* or support* or decision*)) ) OR AB ( (Terminal* N3 (nursing or care or caring or service* or support* or decision*)) ) Limiters - English Language | 1,518 |
| S44 | TI ( (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") ) OR AB ( (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") ) Limiters - English Language | 31,753 |
| S43 | MH "Terminal care") OR (MH "Hospice care") OR (MH "Palliative Care") OR (MH "HOSPICE AND PALLIATIVE NURSING") OR (MH "Hospice patients") OR (MH "Terminally ill patients") OR (MH "Death") OR (MH "Attitude to death") OR (MH "Advance Care Planning") OR (MH "Living will") OR (MH "Advance directives") Limiters - English Language | 62,490 |
| S42 | S41 Limiters - English Language | 2,982 |
| S41 | S40 Limiters - Publication Year: 1999-2017 | 3,009 |
| S40 | S28 AND S39 | 3,410 |
| S39 | S1 OR S2 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 | 57,994 |
| S38 | SO ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))) | 18,416 |


| S37 | (MH "Developmental Disabilities") | 6,891 |
| :---: | :---: | :---: |
| S36 | (MH "Fetal Alcohol Syndrome") | 1,291 |
| S35 | (MH "Tuberous Sclerosis") | 556 |
| S34 | (MH "Angelman Syndrome") | 144 |
| S33 | (MH "Rett Syndrome") OR (MH "De Lange Syndrome") OR (MH "Gaucher Disease") OR (MH "Kernicterus") OR (MH "Phenylketonuria+") OR (MH "Cockayne Syndrome") OR (MH "Coffin-Siris Syndrome") OR (MH "De Barsy Syndrome") OR (MH "Intellectual Disability+") OR (MH "Schinzel-Giedion Syndrome") | 23,829 |
| S32 | (MH "Learning Disorders") | 5,997 |
| S31 | (MH "Cerebral Palsy") | 8,573 |
| S30 | (MH "Mentally Disabled Persons") | 3,937 |
| S29 | (MH "Intellectual Disability") OR (MH "Coffin-Siris Syndrome") OR (MH "Cri-Du-Chat Syndrome") OR (MH "De Barsy Syndrome") OR (MH "De Lange Syndrome") OR (MH "Down Syndrome") OR (MH "Kleefstra Syndrome") OR (MH "Williams Syndrome") OR (MH "WAGR Syndrome") OR (MH "Schinzel-Giedion Syndrome") OR (MH "Rubinstein-Taybi Syndrome") OR (MH "Prader-Willi Syndrome") OR (MH "Mental Retardation, X-Linked") OR (MH "Adrenoleukodystrophy") OR (MH "Coffin-Lowry Syndrome") OR (MH "Fragile X Syndrome") OR (MH "Kinky Hair Syndrome") OR (MH "Mucopolysaccharidosis II") OR (MH "Rett Syndrome") | 22,692 |
| S28 | S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 | 654,790 |
| S27 | SU "In Old Age" | 79,725 |
| S26 | (MH "Nursing Homes") OR (MH "Skilled Nursing Facilities") | 22,140 |
| S25 | (MH "Menopause+") | 15,146 |
| S24 | (MH "Retirement") | 6,589 |
| S23 | (MH "Housing for the Elderly") | 2,745 |
| S22 | (MH "Geriatric Psychiatry") OR (MH "Geriatric Nutrition") OR (MH "Geriatrics") OR (MH "Geriatric Assessment") OR (MH | 48,350 |


|  | "Gerontologic Nurse Practitioners") OR (MH "Gerontologic Care") OR (MH "Gerontologic Nursing") OR (MH "Geriatric Functional Assessment") OR (MH "Rehabilitation, Geriatric") |  |
| :---: | :---: | :---: |
| S21 | (MH "Frail Elderly") OR (MH "Attitude to Aging") OR (MH "Assisted Living") OR (MH "Elder Abuse") OR (MH "Health Services for the Aged") OR (MH "Aged, Hospitalized") OR (MH "Housing for the Elderly") OR (MH "Gerontologic Nursing") OR (MH "Gerontologic Care") OR (MH "Dental Care for Aged") OR (MH "Geropsychiatric Nursing") | 48,873 |
| S20 | ((MH "Aged") OR (MH "Aged, 80 and Over") OR (MH "Aging+")) NOT (MH "child" OR MH "infant" OR MH "adolescence" OR MH "child, preschool" OR MH "prenatal diagnosis" OR MH "Pediatrics") | 519,253 |
| S19 | Tl(future N2 (plan or plans or planning or need* or care or caring or support*)) OR TI(anticipatory N3 care) OR TI("grow* old" or "get* old" or "becom* old") or $\mathrm{Tl}(($ "grow* older" or "get* older" or "becom* older") and adult*) | 2,139 |
| S18 | AB(future N2 (plan or plans or planning or need* or care or caring or support*)) OR AB(anticipatory N3 care) OR AB("grow* old" or "get* old" or "becom* old") or AB(("grow* older" or "get* older" or "becom* older") and adult*) | 9,704 |
| S17 | $\mathrm{TI}($ (ageing or aging) and adult*) OR TI("active aging" or "active ageing") | 1,136 |
| S16 | AB ((ageing or aging) and adult*) | 5,723 |
| S15 | AB ("active aging" or "active ageing") | 137 |
| S14 | TI("age related" N1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 38 |
| S13 | AB("age related" N 1 (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)) | 280 |
| S12 | TI(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or | 2,469 |


|  | "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) |  |
| :---: | :---: | :---: |
| S11 | AB(("ageing" or "aging") N3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)) | 6,271 |
| S10 | TI(aged N2 (care or service* or centre* or center* or centered or home*)) | 2,510 |
| S9 | AB(aged N2 (care or service* or centre* or center* or centered or home*)) | 1,972 |
| S8 | TI(aged N1 (adult** or user or users or person* or communit* or consumer* or client** or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) | 2,941 |
| S7 | AB (aged N 1 (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)) | 23,919 |
| S6 | TI("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or | 98,582 |


|  | Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") |  |
| :---: | :---: | :---: |
| S5 | AB("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* N1 age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") | 86,218 |
| S4 | (TI(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) | 45,190 |
| S3 | (AB(("old" or "older" or "oldest" or "frail" or "elder" or senior) N1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*))) | 58,829 |
| S2 | AB((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or | 10,460 |


|  | inpatient*) N5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) |  |
| :---: | :---: | :---: |
| S1 | TI ((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) AND (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* | 12,004 |


|  | or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr <br> disease" or "William* disease" or rett or rett* or "Williams beuren" <br> or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated <br> phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs <br> disease" or "Laurence Moon Syndrome" or "Congenital <br> Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum <br> Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 <br> (disab* or disorder* or impair* or handicap* or incapacit* or <br> handicap*)) or (learning N1 (disab* or disorder* or handicap* or <br> handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or <br> $(($ development* or neurodevelopment*) N1 disab*) or cretinism or |  |
| :--- | :--- | :--- |
|  | learning difficulties" or ((mentally or intellect*) N5 (retard or <br> retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or <br> "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" <br> not "mental retardation protein*"))) |  |

6. Cochrane Database of Systematic Reviews and CENTRAL(Cochrane Library)

Date searched 23/02/2017
No. of records 6 (Systematic reviews)
No. of records 8 (CENTRAL trials)
\#1 ("Homes for the aged" or "health services for the aged" or "elder abuse" or "senior centers" or "Geriatrics" or "Housing for the Elderly" or "Geriatric Assessment" or "Geriatric Nursing" or "Geriatric Psychiatry" or "Geriatric Dentistry" or "Retirement" or "nursing homes"):kw
\#2 ("Aged, 80 and over" or "aged"):kw
\#3 ("frail elderly" or aging):kw
\#4 (Aging):kw
\#5 adolescent:kw
\#6 ("young adult" or "prenatal diagnosis" or "pregnancy" or "child"):kw
\#7 MeSH descriptor: [Prenatal Diagnosis] explode all trees
\#8 MeSH descriptor: [Pregnancy] explode all trees
\#9 MeSH descriptor: [Child] explode all trees
\#5 or \#6 or \#7 or \#8 or \#9 or \#10
\#2 or \#3 or \#4
\#13
\#12 not \#11
\#14 (("old" or "older" or "oldest" or "frail" or "elder" or senior) near/1 ("Adult" or "adult*" or "Service*" or "user*" or "user*" or "person*" or "person*" or "people*" or "community" or "communities" or "consumer*" or "consumer*" or "client*" or "clients*" or "population*" or "population*" or "resident*" or "resident*" or "individual*" or "individual*" or "citizen*" or "citizen*" or "men" or "men*" or "women" or "women*" or "patient*" or "patient*" or "inpatient*" or "inpatient*" or service* or centre* or center* or centered or home*)):ti,ab,kw \#15 ("age in place" or "ageing in place" or "aging in place" or "aged Adult*" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged" or (pension* next age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*"):ti,ab,kw
\#16 (aged next (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual* or individual* or patient* or patient* or inpatient* or inpatient*)):ti,ab,kw
\#17 (aged near/2 (care or service* or centre* or center* or centered or home*)):ti,ab,kw
\#18 (("ageing" or "aging") near/3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service* or centre* or center* or centered or home*)):ti,ab,kw \#19 ("age related" next (illness* or health or condition* or challenge* or problem* or difficult* or deterioration)):ti,ab,kw
\#23 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult*)):ti,ab,kw
\#24 \#14 or \#15 or \#16 or \#17 or \#18 or \#19 or \#20 or \#21 or \#22 or \#23
\#25 \#1 or \#13 or \#24
\#26 ("Education of Intellectually Disabled" or "mentally disabled persons"):kw
\#27 ((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service*" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) near/5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or ((intellect* near/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning near/1 (disab* or disorder* or handicap* or handicap*)) or (mental* near/1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) next disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) near/5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") next (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein*"))):ti,ab,kw or "Coffin-Lowry Syndrome" or "cri-du-chat syndrome" or "de lange syndrome" or "down syndrome" or "lesch-nyhan syndrome" or "fragile x syndrome" or "mucopolysaccharidoses" or "Pyruvate Carboxylase Deficiency Disease" or "pyruvate dehydrogenase complex deficiency disease" or "rubinstein-taybi syndrome" or "tuberous sclerosis" or "wagr syndrome" or "Developmental Disabilities" or "Intellectual Disability" or "Learning disorders" or "LaurenceMoon Syndrome" or "Congenital Hypothyroidism" or "Bardet-Biedl Syndrome" or "Fetal Alcohol Spectrum Disorders" or "Tay-Sachs disease" or "Prader-Willi Syndrome" or "Phenylketonurias"):kw
\#29 MeSH descriptor: [Phenylketonurias] explode all trees
\#30 MeSH descriptor: [Prader-Willi Syndrome] explode all trees
\#44 (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase" or (Terminal* near/3 (nursing or care or caring or service* or support* or decision*)) or (Dying near/3 (care or caring or nursing or service* or decision* or support*)) or (End* near/2 life) or dying or (death near/3 (care* or caring or nursing or service* or decision* or support* or concept*)) or ("near death" or "advance care plan*" or "life supportive care" or "advance directives" or "advance directive*" or "living will*" or "advance care plan*" or "advanced care plan*" or "advance care directive*" or "advanced care directive*" or "advance decision*" or "advanced decision*")):ti,ab,kw
\#45 (death and ("last day" or "last week" or "last hour" or "final day" or "final week" or "final hour" or "critical pathway" or "care pathway")) or (death and ("last days" or "last weeks" or "last hours" or "final days" or "final weeks" or "final hours" or "critical pathways" or "care pathways")):ti,ab,kw \#46 \#34 or \#35 or \#36 or \#37 or \#38 or \#39 or \#40 or \#41 or \#42 or \#43 or \#44 or \#45
\#47 \#46 and \#31
\#48 \#47 Publication Year from 2005 to 2017

## 7. CRD databases:

Date searched 23/02/2017, Date limit 2005-2015
No. of records $\quad 1$ (Database of Abstracts of Reviews of Effects)
No. of records 0 (Health Technology Assessment database)
No. of records 2 (NHS Economic Evaluation Database)

| Line | Query | Results |
| :--- | :--- | :--- |
| 13 | $((($ (adult* or people* or resident* or person* or women* or men*  <br>  or population* or ageing or aging or "Service*" or "care" or <br>  "user" or "users" or "community" or "communities" or <br> "consumer" or consumer* or client* or individual* or citizen* or  <br> patient* or inpatient*) near5 (angelman or "happy puppet" or  <br>  "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry <br> coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or  <br>  "crying cat" or idiocy or mongolism or mongoloidism or "lesch <br> nyhan" or "nyhan disease" or menkes or "bell martin syndrome"  <br> or "fragile x syndrome" or "gillian turner" or "martin bell" or  <br>  "turner Gillian" or "prader willi" or rubinstein or "bourneville <br> disease" or "5p syndrome" or lejeune* or epiloia or "pringle  <br> disease" or "tuberose sclerosis" or "wagr disease" or "William*  <br> disease" or rett or rett* or "Williams beuren" or "sanfilippo" or  <br> "mucopolysaccharidiosis type III" or "untreated  <br> phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs  <br> disease" or "Laurence Moon Syndrome" or "Congenital  <br> Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum  |  |


|  | ```Disorder*" or "Fetal Alcohol Spectrum Disorder*" or ((intellect* near1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning near1 (disab* or disorder* or handicap* or handicap*)) or (mental* near1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) near1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) near5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") near1 (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein*")))))``` |  |
| :---: | :---: | :---: |
| 14 | ((("Education of Intellectually Disabled" or "mentally disabled persons"))) | 18 |
| 15 | \#13 OR \#14 | 248 |
| 16 | (*) and (Project record:ZDT OR Full publication record:ZDT) | 16802 |
| 17 | (*) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS) OR (Cochrane review:ZDT) OR (Cochrane related review record:ZDT)) IN DARE | 45310 |
| 18 | (* ) and ((Economic evaluation:ZDT and Bibliographic:ZPS) OR (Economic evaluation:ZDT and Abstract:ZPS)) IN NHSEED | 17612 |
| 19 | (Hospices OR "Hospice Care" OR "Palliative Care" OR "Death" OR "Attitude to Death" OR "Terminally III" or "Terminal Care" or "Advance Care Planning" or "Advance Directives" or "Life Support Care") | 5841 |
| 20 | ((Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase")) | 966 |
| 21 | ((Terminal* near3 (nursing or care or caring or service* or support* or decision*))) | 168 |
| 22 | ((Dying near3 (care or caring or nursing or service* or decision* or support*)) ) | 4 |
| 23 | ((End* near2 life) ) | 124 |
| 24 | (dying) | 221 |


| 25 | ((death near3 (care* or caring or nursing or service* or decision* or support* or concept*))) | 82 |
| :---: | :---: | :---: |
| 26 | ((death and ("last day" or "last week" or "last hour" or "final day" or "final week" or "final hour" or "critical pathway" or "care pathway")) or (death and ("last days" or "last weeks" or "last hours" or "final days" or "final weeks" or "final hours" or "critical pathways" or "care pathways"))) | 42 |
| 27 | (("advanced care plan" or "advanced care plans" or "advanced care planning" or "advance care directives" or "advanced care directives" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance decisions" or "advanced decisions")) | 2 |
| 28 | (("advance care" or "life supportive" or "advance directives" or "advance directive" or "living will" or "living wills") ) | 45 |
| 29 | \#19 OR \#20 OR \#21 OR \#22 OR \#23 OR \#24 OR \#25 OR \#26 OR \#27 OR \#28 | 6217 |
| 30 | \#15 AND \#29 | 12 |
| 31 | \#16 AND \#30 | 2 |
| 32 | \#18 AND \#30 | 7 |
| 33 | \#17 AND \#30 | 3 |
| 35 | * FROM 2005 TO 2017 | 61892 |
| 36 | \#30 AND \#35 | 3 |

8. Econlit (EBSCOhost)

Date searched 17/02/2017
No. of records 1

| $\#$ | Query | Result |
| :--- | :--- | :--- |
| s |  |  |$|$| S16 | S3 AND S15 |
| :--- | :--- |
| S15 | S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 <br> OR S13 OR S14 |


| S13 | TI ( (advance N1 decision*) OR (advanced N1 decision*) ) OR AB ( (advance N 1 decision*) OR (advanced N 1 decision ) ) | 32 |
| :---: | :---: | :---: |
| S12 | TI ( "advance directive" or "advanced directive" or "living will" or <br> "advance care directive" or "advanced care directive" or "advance <br> decision" or "advanced decision" or "advance directives" or <br> "advanced directives" or "living wills" or "advance care directives" or <br> "advanced care directives" ) OR AB ( "advance directive" or <br> "advanced directive" or "living will" or "advance care directive" or <br> "advanced care directive" or "advance decision" or "advanced <br> decision" or "advance directives" or "advanced directives" or "living <br> wills" or "advance care directives" or "advanced care directives" ) | 42 |
| S11 | TI ( ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) OR AB ( ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) | 18 |
| S10 | TI ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) OR AB ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) | 102 |
| S9 | TI ( death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)) ) OR AB ( (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)) ) | 12 |
| S8 | TI dying OR AB dying | 326 |
| S7 | T1 (End* N 2 life) OR AB (End* N 2 life) | 395 |
| S6 | TI ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) OR AB ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) | 10 |
| S5 | TI ( (Terminal* N 3 (nursing or care or caring or service* or support* or decision*)) ) OR AB ( (Terminal* N3 (nursing or care or caring or service* or support* or decision*)) ) | 65 |


| S4 | $\begin{aligned} & \text { TI ( (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal } \\ & \text { illness" or "Terminal phase") ) OR AB ( (Hospice or hospices or } \\ & \text { Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") ) } \end{aligned}$ | 167 |
| :---: | :---: | :---: |
| S3 | S1 OR S2 | 991 |
| S2 | AB((angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect*N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) | 848 |
| S1 | TI((angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or | 225 |


| "pringle disease" or "tuberose sclerosis" or "wagr disease" or |
| :--- | :--- | :--- |
| "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" |
| or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" |
| or "downs" or "down syndrome" or "Tay-Sachs disease" or |
| "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or |
| "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal |
| Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or |
| impair* or handicap* or incapacit* or handicap*)) or (learning N1 |
| (disab* or disorder* or handicap* or handicap*)) or (mental* N1 |
| (disab* or handicap* or handicap*)) or ((development* or |
| neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" |
| or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub- |
| average" or "subaverage" or "sub norm*" or "subnorm*") N1 |
| (intellect* or intelligence)) or ("mental retardation" not "mental |
| retardation protein*"))) |$\quad$|  |
| :--- |

9. EMBASE (OVID SP)

Date searched 23/02/2017
No. of records 361
Database: Embase Classic+Embase <1947 to 2017 February 22>
1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or "consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (261270)
2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or
"nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (746058)
3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (20619)

4 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (3795)
5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab. (31699)

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (1207)
7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (23114)
8 (anticipatory adj3 care).ti,ab. (219)
9 ("active aging" or "active ageing").ti,ab. (342)
10 ((ageing or aging) and adult?).ti, ab. (34632)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get*
older" or "becom* older") and adult?)).ti,ab. (1571)
121 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (990644)
13 aged/ (2641968)
14 aging/ (273218)
15 attitude to aging/ (154)
16 geriatric rehabilitation/ or geriatric surgery/ or geriatrician/ or geriatrics/ or gerontopsychiatry/ (47825)
17 geriatric assessment/ or geriatric care/ or geriatric hospital/ or geriatric nursing/ or geriatric nutrition/ or geriatric patient/ or geriatrics/ (91447)

37 ((adult*2 or people*2 or resident*2 or person*2 or women*2 or men*2 or population*2 or ageing or aging or "Service?" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer*2 or client*2 or individual*2 or citizen*2 or patient?s? or inpatient?s?) adj5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1
(disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?"))).ti,ab. (38949)

38 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (15076)

39 disabled person/ (41370)
40 learning disorder/ (29051)
41 developmental disorder/ (35676)
42 mental deficiency/ (70329)
43 intellectual impairment/ or coffin lowry syndrome/ or down syndrome/ or exp mental retardation malformation syndrome/ or sanfilippo syndrome/ or wagr syndrome/ or x linked mental retardation/ (89352)

44 fragile $x$ syndrome/ or mental retardation malformation syndrome/ or $x$ chromosome recessive disorder/ (11075)
45 cerebral palsy/ (34039)
46 mental retardation malformation syndrome/ or congenital disorder/ or acrocallosal syndrome/ or aicardi syndrome/ or cockayne syndrome/ or costello syndrome/ or de lange syndrome/ or fetal alcohol syndrome/ or fetal hydantoin syndrome/ or floating harbor syndrome/ or fragile x syndrome/ or happy puppet syndrome/ or infantile refsum disease/ or lesch nyhan syndrome/ or lowe syndrome/ or mauriac syndrome/ or menkes syndrome/ or prader willi syndrome/ or sjoegren larsson syndrome/ or smith lemli opitz syndrome/ or smith magenis syndrome/ or sotos syndrome/ or williams beuren syndrome/ or wolf hirschhorn syndrome/ or zellweger syndrome/ (117745)

47 cat cry syndrome/ or down syndrome/ or turner syndrome/ (46055)
48 Lesch Nyhan syndrome/ (1732)

50 tuberous sclerosis/ (10927)
51 Rett syndrome/ (4561)
52 phenylketonuria/ (10189)
53 Tay Sachs disease/ (2133)
54 Laurence Moon syndrome/ or Bardet Biedl syndrome/ (1965)
55 congenital hypothyroidism/ (6665)
5637 or 38 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 (356424)

5736 and 56 (14341)
5857 not (exp animals/ not (exp humans/ and exp animals/)) (13575)
59 limit 58 to $y r=" 1999$-Current" (8880)
60 limit 59 to english language (8330)
61 limit 60 to exclude medline journals (948)
62 exp palliative therapy/ (97404)
63 exp terminal care/ (58342)
64 Death/ (411261)
65 Hospice/ (12865)
66 Attitude to death/ (10033)
67 Living will/ (8410)
68 Palliative nursing/ (450)
69 Hospice nursing/ (70)
70 Hospice patient/ (781)
71 Terminally ill patient/ (8303)
72 (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase").ti,ab. (109896)

73 (Hospice or hospices or Palliat* or "end of life").jx. (18720)
74 (Terminal* adj3 (nursing or care or caring or service? or support* or decision*)).ti,ab. (4213)

75 (Dying adj3 (care or caring or nursing or service? or decision* or support*)).ti,ab. (3316)
76 (End* adj2 life).ti,ab. (25585)
77 (death adj3 (care* or caring or nursing or service? or decision* or support* or concept*)).ti,ab. (7283)

78 (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))).ti,ab. (41974)
79 ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care").ti,ab. (3526)
80 ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives").ti,ab. (5415)
81 ((advance adj1 decision*) or (advanced adj1 decision*)).ti,ab. (159)
8262 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 (622617)
8356 and 82 (6095)
8483 not (exp animals/ not (exp humans/ and exp animals/)) (5740)
85 limit 84 to $\mathrm{yr}=$ "2005 -Current" (3612)
86 limit 85 to english language (3448)
87 limit 86 to exclude medline journals (361)
10. Family and Society Studies Worldwide (EBSCOhost)

Date searched 17/02/2017
No. of records 151
Search modes - Boolean/Phrase

| $\#$ | Query | Results |
| :--- | :--- | :--- |
| S19 | S18 Limiters - Date Published: 20050101-20171231 | 151 |
| S18 | S4 AND S17 | 270 |
| S17 | S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR <br> S13 OR S14 OR S15 OR S16 | 31,346 |
| S16 | SO palliat* or hospice* | 10,254 |
| S15 | Tl ( (advance N1 decision*) OR (advanced N1 decision*) ) OR AB <br> ( (advance N1 decision*) OR (advanced N1 decision ) | 70 |
| S14 | Tl ( "advance directive" or "advanced directive" or "living will" or <br> "advance care directive" or "advanced care directive" or "advance | 916 |


|  | decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives" ) OR AB ( "advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives" ) |  |
| :---: | :---: | :---: |
| S13 | TI ( ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) OR AB ( ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) | 651 |
| S12 | TI ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) OR AB ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) | 2,209 |
| S11 | TI ( (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)) ) OR AB ( (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)) ) | 585 |
| S10 | TI dying OR AB dying | 6,609 |
| S9 | TI (End* N2 life) OR AB (End* N2 life) | 5,850 |
| S8 | TI ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) OR AB ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) | 1,565 |
| S7 | TI ( (Terminal* N3 (nursing or care or caring or service* or support* or decision*)) ) OR AB ( (Terminal* N3 (nursing or care or caring or service* or support* or decision*)) ) | 1,243 |
| S6 | TI ( (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") ) OR AB ( (Hospice or hospices or | 13,694 |


|  | Palliat* or "Terminally ill" or "Terminal illness" or "Terminal <br> phase") ) |  |
| :--- | :--- | :--- |
|  | $((((((((((((((((Z U$ "death")) or ((ZU "terminal care"))) or ((ZU  <br>  "terminally ill"))) or ((ZU "hospice care"))) or ((ZU "advance <br> directives (medical care)"))) or ((ZU "living wills"))) or ((ZU  <br> "palliative treatment"))) or ((ZW "death") or (ZW "death \& dying")))  <br> or ((ZW "terminal care"))) or ((ZW "terminally ill"))) or ((ZW  <br> "hospice") or (ZW "hospice care"))) or ((ZW "hospices"))) or ((ZU  |  |
|  | "hospices (terminal care facilities)"))) or ((ZW "advance directive") <br> or (ZW "advance directives"))) or ((ZW "advance care directive") |  |
| or (ZW "advance care directives") or (ZW "advance care plan") or |  |  |
| (ZW "advance care planning"))) or ((ZW "living will") or (ZW "living |  |  |
| wills"))) or ((ZW "palliative") or (ZW "palliative \& continuing care") |  |  |
| or (ZW "palliative and end-of-life care") or (ZW "palliative care"))) |  |  |
| or ((ZW "end-of-life") or (ZW "end-of-life care") or (ZW "end-of-life |  |  |
| decision making") or (ZW "end-of-life decision-making"))) or ((ZW |  |  |,


|  | (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) OR ( AB (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) |  |
| :---: | :---: | :---: |
| S2 | ZU ("FRAGILE X syndrome" OR "PEOPLE with mental disabilities*" OR "DOWN\# syndrome" OR "DEVELOPMENTAL disabilities" OR "MENTAL retardation") OR SU ("FRAGILE X | 7,890 |


|  | syndrome" OR "PEOPLE with mental disabilities" OR "DOWN\# <br> syndrome" OR "DEVELOPMENTAL disabilities" OR "MENTAL <br> retardation") |  |
| :--- | :--- | :--- |
| S1 | SO ((intellect* and (disab* or disorder* or impair* or handicap* or <br> incapacit* or handicap*)) or (learning and (disab* or disorder* or <br> handicap* or handicap*)) or (mental* and (disab* or handicap* or <br> handicap*) or ((development* or neurodevelopment*) and disab*) <br> or cretinism or "learning difficulties" or ((mentally or intellect*) and <br> (retard or retarded))) | 10,962 |

11. Health Management Information Consortium (OVID SP)

Date searched 20/02/2016
No. of records 64
1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or "consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (9767)
2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (15668)
3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (145) home?)).ti,ab. (203)
5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab.

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (15)

7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (1509)
8 (anticipatory adj3 care).ti,ab. (47)
9 ("active aging" or "active ageing").ti, ab. (52)
10 ((ageing or aging) and adult?).ti, ab. (322)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult?)).ti,ab. (95)

12 old peoples homes/ or exp older people/ or centenarians/ or frail elderly people/ or frail older people/ or over 60s/ or over 65s/ or over 75 s/ or over $80 \mathrm{~s} /$ or retired people/ or exp ageing/ or exp geriatrics/ or health services for elderly people/ or health services for older people/ or longevity/ or exp old age/ or exp old peoples homes/ or "residential care of the elderly"/ or "residential care of the older"/ or exp retirement/ or exp retirement communities/ (19027)
13 menopause/ (207)
14 congenital disorders/ or developmental disorders/ or genetic disorders/

15 learning difficulties/ or learning disabilities/ or downs syndrome/ or feeble mindedness/ or profound learning disabilities/ or severe learning disabilities/ or learning disability hospitals/ or learning disability nursing/ or
learning disability services/ or learning disability units/ or phenylketonuria/ or learning disability nurses/ (6772)
16 learning disability nurses/ or learning disability nursing/ or learning disability services/ or learning disability units/ or learning disabilities/ or learning disability hospitals/ or learning disorders/ (6683)
17 exp nursing homes/ (1659)
181 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 17 (30196)

19 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (866)

20 disabilities/ (3738)
$21 \quad 12$ or 13 or 14 (19882)
$22 \quad 20$ and 21 (486)
23 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or
intelligence))) or ("mental retardation" not "mental retardation protein?")).ti,ab. (6902)
$24 \quad 14$ or 15 or 16 or 19 or 23 (9173)
$25 \quad 18$ and 24 (832)
2622 or 25 (1283)
27 limit 26 to $y r=" 1863$-1998" (611)
2826 not 27 (672)
29 (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase").ti,ab. (2812)
30 (Hospice or hospices or Palliat* or "end of life").jx. (496)
31 (Terminal* adj3 (nursing or care or caring or service? or support* or decision*)).ti,ab. (395)

32 (Dying adj3 (care or caring or nursing or service? or decision* or support*)).ti,ab. (414)

33 (End* adj2 life).ti,ab. (1501)
34 (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))).ti,ab. (1595)

35 (death adj3 (care* or caring or nursing or service? or decision* or support* or concept*)).ti,ab. (226)

36 ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care").ti,ab. (121)
37 ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives").ti,ab. (172)

38 ((advance adj1 decision*) or (advanced adj1 decision*)).ti,ab. (33)
39 Palliative care/ or End of life care/ or terminal care/ or Death/ or Hospices/ or Terminal illness/ or advance care planning/ or living wills/ or hospice care/ or advance directives/ (4602)

29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 (6144)
4124 and 40 (104)
$42 \quad 22$ and 40 (8)

44 limit 43 to $\mathrm{yr}=$ "1863-2004" (45)
4543 not 44 (64)
12. Medline (OVID SP)

Ovid MEDLINE(R) Epub Ahead of Print, In-Process \& Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) < 1946 to Present> Date searched 20/02/2017

No. of records 267 (245 after non English-language removed)
1 "Homes for the aged"/ or "health services for the aged"/ or "elder abuse"/ or "senior centers"/ or Geriatrics/ or Housing for the Elderly/ or Geriatric Assessment/ or Geriatric Nursing/ or Geriatric Psychiatry/ or Geriatric Dentistry/ or Retirement/ or nursing homes/ (116350)

2 "Aged, 80 and over"/ (742908)
3 Aged/ (2640058)
4 "frail elderly"/ (8581)
5 Aging/ (206500)
6 exp Prenatal Diagnosis/ or exp pregnancy/ or exp child/ or exp infant/ or adolescent/ or young adult/ (3995007)

7 (2 or 3 or 4 or 5) not 6 (2146077)
8 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or
"consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (190473)

9 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or
"Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (525969)

10 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (14066)

11 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (3230)

12 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab. (23088)

13 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (998)

14 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (17362)

15 (anticipatory adj3 care).ti,ab. (173)
16 ("active aging" or "active ageing").ti,ab. (309)
17 ((ageing or aging) and adult?).ti,ab. (27183)
18 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult?)).ti,ab. (1130)

198 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 (708381)
201 or 7 or 19 (2543881)
21 Education of Intellectually Disabled/ or mentally disabled persons/ (8564)

22 ((adult*2 or people*2 or resident*2 or person*2 or women*2 or men*2 or population*2 or ageing or aging or "Service?" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer*2 or client*2 or individual*2 or citizen*2 or patient?s? or inpatient?s?) adj5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or
"lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?"))).ti,ab. (28763) 23 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).nw. (10794) 24 adrenoleukodystrophy/ not Adrenoleukodystrophy/bl, cf, ci, cl, cn, di, em, et, ge, hi, im, mo, pa, pp, ra, ri, rt, su, ur (221)
25 Angelman Syndrome/ not Angelman Syndrome/bl, cl, di, em, en, et, ge, pa, pp, ra, ri, su (109)

26 cerebral palsy/ not Cerebral Palsy/bl, cf, ci, cl, cn, di, em, en, et, ge, hi, im, mi, mo, ps, pa, pd, ph, pp, ra, ri, sn, su, us, ur, ve, vi (8802)
27 Coffin-Lowry Syndrome/ not Coffin-Lowry Syndrome/cf, di, em, en, ge, pa, pp, ra (16)
28 cri-du-chat syndrome/ not cri-du-chat syndrome/cf, di, em, en, ge, pa, pp, ra (198)

29 de lange syndrome/ not de lange syndrome/cf, di, em, en, ge, pa, pp, ra
down syndrome/ not Down Syndrome/bl, cf, ci, cl, cn, di, dh, dt, em, en, et, ge, hi, im, ip, mi, mo, pa, ph, pp, ra, ri, rt, su, us, ul, ur, ve, vi (8666)
lesch-nyhan syndrome/ not lesch-nyan syndrome/bl, cl, di, em, en, ge, hi, im, mi, mo, ps, pa, pp, ra, ri, tm, us, ul, ur, ve, vi (1168)
32 fragile $x$ syndrome/ not Fragile X Syndrome/bl, cl, di, em, en, ge, hi, im, mi, mo, ps, pa, pp, ra, ri, tm, us, ul, ur, ve, vi (591)

33 mucopolysaccharidoses/ not Mucopolysaccharidoses/bl, cf, ci, cl, cn, di, em, en, et, ge, hi, im, me, mi, mo, nu, pa, pp, ra, ri, su, us, ur, ve (409)
34 exp Phenylketonurias/ not exp Phenylketonurias/bl, cf, ci, ch, cl, di, em, en, et, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, tm, us, ur, ve, vi (2490)
35 exp Prader-Willi Syndrome/ not exp Prader-Willi Syndrome/bl, cf, ci, cl, di, em, en, et, ge, hi, im, mi, mo, pa, pp, ra, ri, su, us, ur, ve (539)
36 Pyruvate Carboxylase Deficiency Disease/ not Pyruvate Carboxylase Deficiency Disease/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (106)
37 pyruvate dehydrogenase complex deficiency disease/ not pyruvate dehydrogenase complex deficiency disease/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (178)
38 rubinstein-taybi syndrome/ not rubinstein-taybi syndrome/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (116)

39 tuberous sclerosis/ not Tuberous Sclerosis/bl, cf, ci, cl, di, em, en, et, ge, hi, im, mo, pa, pp, ra, ri, rt, su, us, ur, ve (2163)
40 wagr syndrome/ not wagr syndrome/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (9)
41 Developmental Disabilities/ not Developmental Disabilities/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (8759)

42 Intellectual Disability/ not Intellectual Disability/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (32331)
43 Learning disorders/ not learning disorders/bl, cf, ci, cl, di, en, ge, hi, im, mi , mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (7825)
44 Laurence-Moon Syndrome/ not Laurence-Moon Syndrome/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (302)
45 Congenital Hypothyroidism/ not Congenital Hypothyroidism/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (2917) ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (126)

## 47 Fetal Alcohol Spectrum Disorders/ not Fetal Alcohol Spectrum

Disorders/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (1670)

48 Tay-Sachs disease/ not Tay-Sachs disease/bl, cf, ci, cl, di, en, ge, hi, im, mi, mo, ps, pa, ph, pp, ra, ri, su, us, ur, vi (439)

4921 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 (101706)
$50 \quad 20$ and 49 (4374)
51 animals/ not (humans/ and animals/) (4290715)
5250 not 51 (4261)
53 limit 52 to (comment or editorial or historical article or legal cases or letter or news or newspaper article or video-audio media or webcasts) (130) 5452 not 53 (4131)
55 limit 54 to $\mathrm{yr}=$ "1999 -Current" (2389)
56 limit 55 to (afrikaans or albanian or arabic or armenian or azerbaijani or belorussian or bengali or bosnian or bulgarian or burmese or catalan or chinese or croatian or czech or danish or dutch or esperanto or estonian or finnish or flemish or french or gaelic, scots or georgian or german or greek or hausa or hebrew or hindi or hungarian or icelandic or indonesian or interlingua or italian or japanese or kirghiz or korean or latin or latvian or lithuanian or macedonian or malay or marathi or masai or multilingual or norwegian or persian or polish or portuguese or pushto or rumanian or russian or serbian or slovak or slovene or spanish or swahili or swedish or tagalog or tamil or telugu or thai or turkish or ukrainian or urdu or vietnamese or welsh) (158)

5755 not 56 (2231)
58 (2016* or "2017").ez. or "2016".dc. or 2017*.dc. or 2016*.ed. or $2017^{*}$.ed. or $2016^{*}$.da. or $2017^{*}$.da. or $2016 *$.up. or $2017^{*}$.up. (27168989)
5957 and 58 (2231)
60 hospices/ or hospice care/ (9927)
61 exp palliative care/ (47267)
62 death/ (15909)
exp attitude to death/ (14898)
terminally ill/ (6009)
exp terminal care/ (45855)
exp advance care planning/ (7834)
67 exp advance directives/ (6471)
68 exp life support care/ (8283)
69 (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase").ti,ab. (73963)
70 (Terminal* adj3 (nursing or care or caring or service? or support* or decision*).t.ti,ab. (3508)
71 (Dying adj3 (care or caring or nursing or service? or decision* or support*)).ti,ab. (2860)
72 (End* adj2 life).ti,ab. (18733)
73 (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)).ti,ab. (31051)
74 (death adj3 (care* or caring or nursing or service? or decision* or support* or concept*)).ti,ab. (5366)
75 ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care").ti,ab. (2368)
76 ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives").ti,ab. (4239)
77 ((advance adj1 decision*) or (advanced adj1 decision*)).ti,ab. (133)
7860 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 (182968)
7949 and 78 (905)
$80 \quad 79$ not 51 (903)
81 limit 80 to (comment or editorial or historical article or legal cases or letter or news or newspaper article or video-audio media or webcasts) (119)
8280 not 81 (784)
83 limit 82 to $y r=" 2005$-Current" (267)
limit 83 to (afrikaans or albanian or arabic or armenian or azerbaijani or belorussian or bengali or bosnian or bulgarian or burmese or catalan or chinese or croatian or czech or danish or dutch or esperanto or estonian or finnish or flemish or french or gaelic, scots or georgian or german or greek or hausa or hebrew or hindi or hungarian or icelandic or indonesian or interlingua or italian or japanese or kirghiz or korean or latin or latvian or lithuanian or macedonian or malay or marathi or masai or multilingual or norwegian or persian or polish or portuguese or pushto or rumanian or russian or serbian or slovak or slovene or spanish or swahili or swedish or tagalog or tamil or telugu or thai or turkish or ukrainian or urdu or vietnamese or welsh) (22)
8583 not 84 (245)
13. Medline - Pubmed not Medline and Medline In-Process (Web of Knowledge)

Date searched 23/02/2017
No. of records 67

| $\#$ | Query | Results |
| :--- | :--- | :--- |
| \# 8 | (\#7) AND STATUS: (In-Process OR PubMed-not-MEDLINE) <br> Indexes=MEDLINE Timespan=2005-2017 | 67 |
| \# 7 6 | (\#6 AND \#1) AND STATUS: (In-Process OR PubMed-not- <br> MEDLINE) <br> Indexes=MEDLINE Timespan=1999-2017 | 74 |
|  | (TS=((Hospice or hospices or Palliat* or "Terminally ill" or <br> (Terminal illness" or "Terminal phase") OR (Terminal* NEAR/3 <br> (nursing or care or caring or service\$ or support* or decision*)) <br> OR (Dying NEAR/3 (care or caring or nursing or service\$ or <br> decision* or support*)) OR (End* NEAR/2 life) OR (dying or <br> (death and (imminen* or nearing or last day* or last week* or <br> last hour* or final day* or final week* or final hour* or critical <br> pathway* or care pathway*))) OR (death NEAR/3 (care* or <br> caring or nursing or service\$ or decision* or support* or <br> concept*)) OR ("near death" or "advance care plan" or <br> "advance care plans" or "advance care planning" or "advanced | (a1,838 |


|  | ```care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") OR ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives") OR (advance NEAR/1 decision*) OR (advanced NEAR/1 decision*))) AND STATUS: (In-Process OR PubMed-not-MEDLINE) Indexes=MEDLINE Timespan=1999-2017``` |  |
| :---: | :---: | :---: |
| \# 1 | TS=(("adult" or adult\$ or people* or resident* or person* or women* or men\$ or men\$s or population* or "ageing" or "aging" or "Service*" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual\$ or individual\$s or citizen* or patient\$ or patient\$s or inpatient*) near/5 ("angelman" or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or "idiocy" or "mongolism" or "mongoloidism" or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or "rubinstein" or "bourneville disease" or " 5 p syndrome" or lejeune* or "epiloia" or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or "rett" or rett\$ or rett\$s or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*")) or TS=(intellect* near/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or TS=("learning" near/1 (disab* or disorder* or handicap* or | 120,732 |


| handicap*)) or TS=(mental* near/1 (disab* or handicap* or |  |
| :--- | :--- | :--- |
| handicap*)) or TS=((development* or neurodevelopment*) |  |
| NEAR/1 disab*) or TS=("cretinism" or "learning difficulties") or |  |
| TS=(("mentally" or intellect*) near/5 ("retard" or "retarded")) or |  |
| TS=(("Sub-average" or "subaverage" or "sub norm*" or |  |
| "subnorm*") NEAR/1 (intellect* or "intelligence")) or |  |
| TS=("mental retardation" not "mental retardation protein"") |  |
| Indexes=MEDLINE Timespan=All years |  |

14. PsycINFO (EBSCO Host)

Date searched 24/02/2017
No. of records 413 (407 after non-English language removed)
Search modes - Boolean/Phrase

| $\#$ | Query | Results |
| :--- | :--- | :--- |
| S56 | S54 NOT S55 | 407 |
| S55 | LA (Afrikaans OR Arabic OR Bulgarian OR Catalan OR <br> Chinese OR Czech OR Danish OR Dutch OR Finnish OR <br> French OR Georgian OR German OR Greek OR Hebrew <br> OR Hindi OR Hungarian OR Italian OR Japanese OR <br> Korean OR Lithuanian OR Malaysian OR Norwegian OR <br> Polish OR Portuguese OR Romanian OR Russian OR <br> Serbo-Croatian OR Slovak OR Slovene OR Spanish OR <br> Swedish OR Turkish OR Ukrainian) | 279,291 |
| S54 | S52 AND S53 |  |
| S53 | PY 2005-2017 | 413 |
| S52 | S50 NOT S51 | $1,986,889$ |
| S51 | S28 OR S30 | 669 |
| S50 | S49 NOT S26 | 64,988 |
| S49 | S6 AND S48 | 674 |
| S48 | S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 <br> OR S43 OR S44 OR S45 OR S46 OR S47 | 54,663 |
| S47 | TI ( (Hospice or hospices or Palliat* or "Terminally ill" or <br> "Terminal illness" or "Terminal phase") ) OR AB ( (Hospice | 14,196 |


|  | or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") ) |  |
| :---: | :---: | :---: |
| S46 | TI ( (Terminal* N3 (nursing or care or caring or service* or support* or decision*)) ) OR AB ( (Terminal* N3 (nursing or care or caring or service* or support* or decision*)) ) | 1,067 |
| S45 | TI ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) OR AB ( (Dying N3 (care or caring or nursing or service* or decision* or support*)) ) | 1,452 |
| S44 | TI (End* N2 life) OR AB (End* N2 life) | 9,040 |
| S43 | TI dying OR AB dying | 9,445 |
| S42 | TI ( (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)) ) OR AB ( (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*)) ) | 1,020 |
| S41 | TI ( ("nearing death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) OR AB ( ("nearing death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") ) | 743 |
| S40 | TI ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) OR AB ( (death N3 (care* or caring or nursing or service* or decision* or support* or concept*)) ) | 3,546 |
| S39 | TI ( "advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care | 1,489 |


|  | directives" ) OR AB ( "advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives" ) |  |
| :---: | :---: | :---: |
| S38 | TI ( (advance N1 decision*) OR (advanced N1 decision*) ) OR AB ( (advance N1 decision*) OR (advanced N1 decision ) | 179 |
| S37 | SO (palliat* or hospice* OR "END OF LIFE") | 7,273 |
| S36 | DE("Palliative Care" OR "Death and Dying" OR "Terminally III Patients" or "Hospice" OR "Advance Directives" OR "Death anxiety" OR "Death attitudes" OR "Death education" OR "Terminal cancer") | 43,135 |
| S30 | MR Brain Imaging | 46,803 |
| S28 | TI (FXTAS OR FMR1 OR gene\# OR chromosome\#) | 18,841 |
| S26 | PO (Animal NOT (human AND animal)) | 328,858 |
| S6 | S3 OR S4 OR S5 | 102,383 |
| S5 | AB ((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) N5 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams | 41,309 |


|  | beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or handicap* or handicap*)) or (mental* N1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) N1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) |  |
| :---: | :---: | :---: |
| S4 | TI ((adult* or people* or resident* or person* or women* or men* or population* or ageing or aging or "Service\#" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual* or citizen* or patient* or inpatient*) AND (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon | 23,914 |


|  | Syndrome" or "Congenital Hypothyroidism" or "Bardet <br> Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal <br> Alcohol Spectrum Disorder*" or (intellect* N1 (disab* or <br> disorder* or impair* or handicap* or incapacit* or <br> handicap*)) or (learning N1 (disab* or disorder* or <br> handicap* or handicap*)) or (mental* N1 (disab* or <br> handicap* or handicap*)) or ((development* or <br> neurodevelopment*) N1 disab*) or cretinism or "learning <br> difficulties" or ((mentally or intellect*) N5 (retard or <br> retarded)) or (("Sub-average" or "subaverage" or "sub <br> norm*" or "subnorm*") N1 (intellect* or intelligence)) or <br> ("mental retardation" not "mental retardation protein*"))) |  |
| :--- | :--- | :--- |
| S3 | DE "Intellectual Development Disorder (Attitudes Toward)" <br> OR DE "Learning Disabilities" OR DE "organic brain <br> syndromes" OR DE "Developmental Disabilities" OR DE <br> "Cornelia De Lange Syndrome" OR DE "Crying Cat <br> Syndrome" OR DE "Fetal Alcohol Syndrome" OR DE <br> "Fragile X Syndrome" OR DE "Prader Willi Syndrome" OR <br> DE "Congenital Disorders" OR DE "Intellectual <br> Development Disorder" OR DE "Learning Disorders" OR <br> DE "Down's Syndrome" OR DE "Trisomy" OR DE <br> "Williams Syndrome" OR DE "Anencephaly" OR DE <br> "Cerebral Palsy" OR DE "Tay Sachs Disease" OR DE |  |
| "Rett Syndrome" OR DE "Turners Syndrome" |  |  |


|  | DE "Retirement Communities" OR DE "Aging" OR DE |  |
| :--- | :--- | :--- |
| "Aging (Attitudes Toward)" OR DE "Aging in Place" OR DE |  |  |
| "Geropsychology" OR DE "Geriatrics" OR DE "Elder Care" |  |  |
| OR DE "Elder Abuse" $\quad$ Search modes - |  |  |
| Boolean/Phrase Interface - EBSCOhost Research |  |  |
| Databases |  |  |

15. Social Policy and Practice (SPP) (OVID SP)

Date searched 23/02/2017
No. of records 218
1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or "consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti, ab. (32783)

2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or "Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (32145)

3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (223)
4 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (604)
5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or
"consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab. (3382)

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (38)
7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (1818)
8 (anticipatory adj3 care).ti,ab. (15)
9 ("active aging" or "active ageing").ti,ab. (242)
10 ((ageing or aging) and adult?).ti, ab. (1739)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get*
older" or "becom* older") and adult?)).ti,ab. (370)
12 (ageing or aging).sh,hw. (5343)
13 "permanency planning".sh,hw. (774)
14 elderly.sh,hw. (16534)
15 aged.sh,hw. (648)
16 senior.sh,hw. (52)
17 "geriatric*".sh,hw. (422)
18 "nursing home?".sh,hw. (5139)
19 retirement.sh,hw. (2450)
20 "menopaus*".sh,hw. (162)
21 "older people".de,hw. (76070)
22 "very old people".de,hw. (275)
23 ageing.de,hw. (5336)
24 "elder abuse".de,hw. (2355)
25 (retirement or "retirement communities").de,hw. (2450)
26 "life expectancy".de,hw. (494)
27 "elderly".de,hw. (16534)
28 Retired persons.de,hw. (143)
29 Middle aged.de,hw. (483)
30 Middle age.de,hw. (6)

1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 (89622)
33 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?")).ti,ab. (13873)

34 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (4366) 35 ("learning disabilities" or "Downs syndrome" or "Prader-Willi syndrome" or "severe learning disabilities" or "Williams syndrome" or "foetal alcohol syndrome" or "learning disabilities services" or "learning disability nursing" or "parents with learning disabilities" or "learning disabilities nursing" or "learning disabilities services" or "community learning disabilities teams").de,hw.
(angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or "5p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation
protein?")).ti,ab,de,hw. (19343)
3734 or 35 or 36 (19708)
$38 \quad 32$ and 37 (2540)
39 limit 38 to $\mathrm{yr}=$ "1999 -Current" (1256)
40 limit 39 to (consultation document or inspection report or learning resource or legislation or standards or statistical publication or statutory guidance) (58)
4139 not 40 (1198)
4238 not 39 (1284)
43 limit 42 to $y r=" 1890-1998 "(643)$
4438 not 43 (1897)
45 ("Terminal care" or "Palliative care" or "Death" or "End of life care" or "Terminal illness" or "Hospices" or "Dying").sh,hw,de. (7110)
46 (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase").ti,ab. (2039)

47 (Terminal* adj3 (nursing or care or caring or service? or support* or decision*)).ti,ab. (214)

48 (Dying adj3 (care or caring or nursing or service? or decision* or support*)).ti,ab. (296)

49 (End* adj2 life).ti,ab. (1578)
50 (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))).ti,ab. (1400)

51 (death adj3 (care* or caring or nursing or service? or decision* or support* or concept*)).ti,ab. (258)
52 ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care").ti,ab. (171)

53 ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives").ti,ab. (278)
54 ((advance adj1 decision*) or (advanced adj1 decision*)).ti,ab. (58)
55 (Hospice or hospices or Palliat* or "end of life").jx. (269)
5645 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 (8345)
5737 and 56 (332)
58 limit 57 to (consultation document or inspection report or learning resource or legislation or standards or statistical publication or statutory guidance) (13)
5957 not 58 (319)
60 limit 59 to $y r=" 1890-2004 "(101)$
6159 not 60 (218)
16. Social Sciences Citation Index (SSCI) (Web of Knowledge)

Date searched 23/02/2017
No. of records 294 (287 English Language only)

| $\#$ | Query | Results |
| :--- | :--- | :--- |
| $\# 10$ | (\#9) AND LANGUAGE: (English) | 287 |


|  | Indexes=SSCI Timespan=2005-2017 |  |
| :---: | :---: | :---: |
| \# 9 | $\begin{aligned} & \text { \#8 } \\ & \text { Indexes=SSCI Timespan=2005-2017 } \end{aligned}$ | 294 |
| \# 8 | $\begin{aligned} & \text { \#7 AND \#2 } \\ & \text { Indexes=SSCI Timespan=1999-2017 } \end{aligned}$ | 352 |
| \# 7 | TS=((Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") OR (Terminal* NEAR/3 (nursing or care or caring or service\$ or support* or decision*)) OR (Dying NEAR/3 (care or caring or nursing or service\$ or decision* or support*)) OR (End* NEAR/2 life) OR (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))) OR (death NEAR/3 (care* or caring or nursing or service\$ or decision* or support* or concept*)) OR ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") OR ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives") OR (advance NEAR/1 decision*) OR (advanced NEAR/1 decision*)) Indexes=SSCI Timespan=1999-2017 | 39,783 |
| \# 6 | \#5 | 2,057 |
| \# 5 | (\#4) AND LANGUAGE: (English) Indexes=SSCI, CPCI-SSH Timespan=1999-2017 | 2,079 |
| \# 4 | \#3 <br> Indexes=SSCI, CPCI-SSH Timespan=1999-2017 | 2,120 |
| \# 3 | \#2 AND \#1 <br> Indexes=SSCI, CPCI-SSH Timespan=All years | 2,687 |


| \# 2 | TS=(("adult" or adult\$ or people* or resident* or person* or women* or men\$ or men\$s or population* or "ageing" or "aging" or "Service*" or "care" or "user" or "users" or "community" or "communities" or "consumer" or consumer* or client* or individual\$ or individual\$s or citizen* or patient\$ or patient\$s or inpatient*) near/5 ("angelman" or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or "idiocy" or "mongolism" or "mongoloidism" or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or "rubinstein" or "bourneville disease" or "5p syndrome" or lejeune* or "epiloia" or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or "rett" or rett\$ or rett\$s or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*")) or TS=(intellect* near/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or TS=("learning" near/1 (disab* or disorder* or handicap* or handicap*)) or TS=(mental* near/1 (disab* or handicap* or handicap*)) or TS=((development* or neurodevelopment*) NEAR/1 disab*) or TS=("cretinism" or "learning difficulties") or TS=(("mentally" or intellect*) near/5 ("retard" or "retarded")) or TS=(("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") NEAR/1 (intellect* or "intelligence")) or TS=("mental retardation" not "mental retardation protein*") Indexes=SSCI, CPCI-SSH Timespan=All years | 54,980 |
| :---: | :---: | :---: |
| \# 1 | TS=(("old" or "older" or "oldest" or "frail" or "elder" or "senior") NEAR/1 (adult\$ or adult\$s or "Service*" or user\$ or user\$s or person\$ or person\$s or people\$ or people\$s or "community" or "communities" or consumer\$ or consumer\$s or client\$ or client\$s | 272,622 |

or population\$ or population\$s or resident\$ or resident\$s or individual\$ or individual\$s or citizen\$ or citizen\$s or men\$ or men\$s or women or women\$s or patient\$ or patient\$s or inpatient\$ or inpatient\$s or service\$ or centre\$ or center\$ or "centered" or home\$)) OR TS=("age in place" or "ageing in place" or "aging in place" or "aged Adult\$" or "mature adult*" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home*" or "Senior age" or "senior aged") or TS=(pension* NEAR/1 age\$) or TS=("Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*") OR TS=("aged" NEAR/1 (adult\$ or adult\$s or "user" or "users" or person* or communit* or consumer* or client* or population* or resident\$ or resident\$s or individual\$ or individual\$s or patient\$ or patient\$s or inpatient\$ or inpatient\$s)) OR TS=("aged" near/2 ("care" or service\$ or centre\$ or center\$ or "centered" or home\$)) OR TS=(("ageing" or "aging") near/3 (Adult\$ or adult\$s or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or people\$s or "community" or "communities" or "consumer" or "consumers" or consumer\$s or "client" or "clients" or client\$s or "population" or "populations" or "resident" or "residents" or resident\$s or "individual" or individual\$s or "citizen" or "citizens" or "citizen\$s" or men\$ or men\$s or "women" or women\$s or "patients" or patient\$s or "inpatients" or inpatient\$s or service\$ or centre\$ or center\$ or centered or home\$)) OR TS=("age related" NEAR/1 (illness* or "health" or condition* or challenge* or problem\$ or difficult* or "deterioration")) OR TS=("active aging" or "active ageing") OR TS=(("ageing" or "aging") and (adult\$s or adult\$)) OR TS=("future" near/2 ("plan" or "plans" or "planning" or "need" or "needs" or "care" or "caring" or support*)) OR TS=("anticipatory" near/3 "care") OR TS=("grow* old" or "get* old" or "becom* old" or

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(("grow* older" or "get* older" or "becom* older") and (adult$ or
adult$s)))
Indexes=SSCI, CPCI-SSH Timespan=All years
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17. Social Services Abstracts (Proquest)

Date searched 23/02/2017
No. of records 46
Date limit 2005-2017
((SU.EXACT("Hospices") OR SU.EXACT("Right to Die") OR
SU.EXACT("Dying") OR SU.EXACT("Death") OR SU.EXACT("Death
Attitudes") OR SU.EXACT("Terminal Illness") OR SU.EXACT("Palliative
Care")) OR TI,AB((Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") OR (Terminal* NEAR/3 (nursing or care or caring or service or services or support* or decision*)) OR (Dying NEAR/3 (care or caring or nursing or service or services or decision* or support*)) OR (End* NEAR/2 life) OR (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))) OR (death NEAR/3 (care* or caring or nursing or service or services or decision* or support* or concept*)) OR ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care") OR ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives") OR (advance NEAR/1 decision*) OR (advanced NEAR/1 decision*))) AND ((SU.EXACT("Handicapped") OR SU.EXACT("Language Disorders") OR SU.EXACT("Congenitally Handicapped") OR SU.EXACT("Cerebral Palsy") OR SU.EXACT("Downs Syndrome") OR SU.EXACT("Mentally Retarded") OR SU.EXACT("Learning Disabilities") OR SU.EXACT("Physically Handicapped")) OR ((TI,AB (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or
"nyhan disease" or menkes or "bell martin syndrome" or "fragile x syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "Foetal Alcohol Spectrum Disorder*" or "Fetal Alcohol Spectrum Disorder*") or ((intellect* NEAR/1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning NEAR/1 (disab* or disorder* or handicap* or handicap*)) or (mental* NEAR/1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) NEAR/1 disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) NEAR/5 (retard or retarded)) or (("Sub-average" or "subaverage" or "sub norm*" or "subnorm*") NEAR/1 (intellect* or intelligence)) or ("mental retardation" not "mental retardation protein*"))) ))

| 18. Social Work Abstracts | (OVID SP) |
| :--- | :--- | :--- |
| Date searched | $23 / 02 / 2017$ |
| No. of records | 1 |

1 (("old" or "older" or "oldest" or "frail" or "elder" or senior) adj1 ("Adult" or "adult?s?" or "Service?" or "user?" or "user?s?" or "person?" or "person?s?" or "people*" or "community" or "communities" or "consumer?" or "consumer?s?" or "client?" or "clients?" or "population?" or "population?s?" or "resident?" or "resident?s?" or "individual?" or "individual?s?" or "citizen?" or "citizen?s?" or "men" or "men?s?" or "women" or "women?s?" or "patient?" or "patient?s?" or "inpatient?" or "inpatient?s?" or service? or centre? or center? or centered or home?)).ti,ab. (2423)

2 ("age in place" or "ageing in place" or "aging in place" or "aged Adult?" or "mature adult?" or "gerontology" or "Later life" or "Middle age" or "middle aged" or "late life" or "Elderly" or geriatric* or "seniors" or "pensioner" or "pensioners" or "pensioner's" or "old age" or "old aged" or "elders" or "menopause" or "menopausal" or "retirement" or "retired" or "prostate" or "nursing home?" or "Senior age" or "senior aged" or (pension* adj age) or
"Mid life" or Midlife or "Middle life" or "institutionalized elder*" or "Institutionalised elder*").ti,ab. (4851)

3 (aged adj (adult* or user or users or person* or communit* or consumer* or client* or population* or resident* or individual? or individual?s? or patient? or patient?s? or inpatient? or inpatient?s?)).ti,ab. (120)

4 (aged adj2 (care or service? or centre? or center? or centered or home?)).ti,ab. (58)
5 (("ageing" or "aging") adj3 ("Adult" or "adults" or "adult's" or "Service" or "services" or "user" or "users" or "person" or "persons" or "person's" or "people" or "peoples" or "people's" or "community" or "communities" or "consumer" or "consumers" or "consumer's" or "client" or "clients" or "client's" or "population" or "populations" or "resident" or "residents" or "resident's" or "individual" or "individual's" or "citizen" or "citizens" or "citizen's" or "men" or "men's" or "women" or "women's" or "patients" or "patient's" or "inpatients" or "inpatient's" or service? or centre? or center? or centered or home?)).ti,ab.

6 ("age related" adj (illness* or health or condition? or challenge? or problem? or difficult* or deterioration)).ti,ab. (3)

7 (future adj2 (plan or plans or planning or need? or care or caring or support*)).ti,ab. (269)

8 (anticipatory adj3 care).ti,ab. (0)
9 ("active aging" or "active ageing").ti,ab. (13)
10 ((ageing or aging) and adult?).ti,ab. (428)
11 ("grow* old" or "get* old" or "becom* old" or (("grow* older" or "get* older" or "becom* older") and adult?)).ti,ab. (45)
12 (ageing or aging).sh,hw,de. (869)
13 "permanency planning".sh,hw,de. (102)
14 "Aging and the aged".cc. (4370)
15 elderly.sh,hw,de. (417)
16 aged.sh,hw,de. (3137)
17 senior.sh,hw,de. (27)
18 "geriatric*".sh,hw,de. (500)
19 "nursing home?".sh,hw,de. (501)
20 retirement.sh,hw,de. (233)

1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (7673)
23 (angelman or "happy puppet" or "cerebral palsy" or "spastic diplegia" or "coffin lowry" or "lowry coffin" or "Cornelia de Lange" or "cat cry" or "cri du chat" or "crying cat" or idiocy or mongolism or mongoloidism or "lesch nyhan" or "nyhan disease" or menkes or "bell martin syndrome" or "fragile $x$ syndrome" or "gillian turner" or "martin bell" or "turner Gillian" or "prader willi" or rubinstein or "bourneville disease" or " 5 p syndrome" or lejeune* or epiloia or "pringle disease" or "tuberose sclerosis" or "wagr disease" or "William* disease" or rett or rett* or "Williams beuren" or "sanfilippo" or "mucopolysaccharidiosis type III" or "untreated phenylketonuria" or "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or "F?e?tal Alcohol Spectrum Disorder?" or ((intellect* adj1 (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning adj1 (disab* or disorder* or handicap* or handicap*)) or (mental* adj1 (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) adj disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) adj5 (retard or retarded)) or (("Subaverage" or "subaverage" or "sub norm*" or "subnorm*") adj (intellect* or intelligence))) or ("mental retardation" not "mental retardation protein?")).ti,ab,sh,hw. (1341)
24 "Intellectual Disabilities".cw. (1368)
25 ((intellect* and (disab* or disorder* or impair* or handicap* or incapacit* or handicap*)) or (learning and (disab* or disorder* or handicap* or handicap*)) or (mental* and (disab* or handicap* or handicap*)) or ((development* or neurodevelopment*) and disab*) or cretinism or "learning difficulties" or ((mentally or intellect*) and (retard or retarded))).jx. (79)

23 or 24 or 25 (1975)
2722 and 26 (187)
28 limit 27 to $y r=" 1999$-Current" (103)
29 (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase").ti,ab. (377)

30 (Hospice or hospices or Palliat* or "end of life").jx. (164)

31 (Terminal* adj3 (nursing or care or caring or service? or support* or decision*)).ti,ab. (42)
32 (Dying adj3 (care or caring or nursing or service? or decision* or support*)).ti,ab. (47)
33 (End* adj2 life).ti,ab. (228)
34 (death adj3 (care* or caring or nursing or service? or decision* or support* or concept*)).ti,ab. (73)
35 (dying or (death and (imminen* or nearing or last day* or last week* or last hour* or final day* or final week* or final hour* or critical pathway* or care pathway*))).ti,ab. (295)
36 ("near death" or "advance care plan" or "advance care plans" or "advance care planning" or "advanced care plan" or "advanced care plans" or "advanced care planning" or "life supportive care").ti,ab. (40)
37 ("advance directive" or "advanced directive" or "living will" or "advance care directive" or "advanced care directive" or "advance decision" or "advanced decision" or "advance directives" or "advanced directives" or "living wills" or "advance care directives" or "advanced care directives").ti,ab. (84)
38 ((advance adj1 decision*) or (advanced adj1 decision*)).ti,ab. (3)
3929 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 (821)
40 "End-of-life".sh. (71)
41 palliative care.sh. (20)
42 End-of-life care.sh. (46)
43 death.sh. (354)
44 dying.sh. (30)
45 terminal illness.sh. (75)
46 hospices.sh. (65)
4740 or 41 or 42 or 43 or 44 or 45 or 46 (599)
4839 or 47 (1064)
4926 and 48 (14)
50 limit 49 to $\mathrm{yr}=$ "2005 -Current" (1)
19. SocIndex (EBSCOhost)

Date searched 17/02/2017
No. of records 46

Search mode- Boolean

| $\#$ | Query | Results |
| :--- | :--- | :--- |
| S19 | S18 Limiters - Date of Publication: 20050101-20171231 | 46 |
| S18 | S4 AND S17 | 115 |
| S17 | S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 <br> OR S14 OR S15 OR S16 | 15,468 |
| S16 | SO palliat* or hospice* | 509 |
| S15 | TI ( (advance N1 decision*) OR (advanced N1 decision*) ) OR AB ( <br> (advance N1 decision*) OR (advanced N1 decision ) | 35 |
| "advance care directive" or "advanced care directive" or "advance |  |  |
| decision" or "advanced decision" or "advance directives" or |  |  |
| "advanced directives" or "living wills" or "advance care directives" or |  |  |
| "advanced care directives" ) OR AB ( "advance directive" or |  |  |
| "advanced directive" or "living will" or "advance care directive" or |  |  |
| "advanced care directive" or "advance decision" or "advanced |  |  |
| decision" or "advance directives" or "advanced directives" or "living |  |  |
| wills" or "advance care directives" or "advanced care directives" ) |  |  |$\quad 585$


| S9 | TI (End* N2 life) OR AB (End* N2 life) | 2,528 |
| :--- | :--- | :--- |
| S8 | TI ( (Dying N3 (care or caring or nursing or service* or decision* or <br> support*)) ) OR AB ( (Dying N3 (care or caring or nursing or service* <br> or decision* or support*)) ) | 461 |
| S6 | TI ( (Terminal* N3 (nursing or care or caring or service* or support* or <br> decision*)) ) OR AB ( (Terminal* N3 (nursing or care or caring or <br> service* or support* or decision*)) ) $^{\text {S6 }}$TI ( (Hospice or hospices or Palliat* or "Terminally ill" or "Terminal <br> illness" or "Terminal phase") ) OR AB ( (Hospice or hospices or | 352 |
| Palliat* or "Terminally ill" or "Terminal illness" or "Terminal phase") ) |  |  |$\quad 3,004$


|  | "downs" or "down syndrome" or "Tay-Sachs disease" or "Laurence |
| :--- | :--- | :--- |
| Moon Syndrome" or "Congenital Hypothyroidism" or "Bardet Biedl" or |  |
| "Foetal Alcohol Spectrum Disorder"" or "Fetal Alcohol Spectrum |  |
| Disorder" or (intellect* N1 (disab* or disorder* or impair* or handicap* |  |
| or incapacit* or handicap*)) or (learning N1 (disab* or disorder* or |  |
| handicap* or handicap*)) or (mental* N1 (disab* or handicap* or |  |
| handicap*)) or ((development* or neurodevelopment*) N1 disab*) or |  |
| cretinism or "learning difficulties" or ((mentally or intellect*) N5 (retard |  |
| or retarded)) or (("Sub-average" or "subaverage" or "sub norm" or |  |
| "subnorm*") N1 (intellect* or intelligence)) or ("mental retardation" not |  |$|$


|  | DE "LEARNING disabilities" OR DE "DEVELOPMENTALLY disabled" <br> S2 | OR DE "DEVELOPMENTAL disabilities" OR DE "LEARNING <br> disabled persons" OR DE "PEOPLE with mental disabilities" OR DE <br> "MENTAL retardation" OR DE "DOWN syndrome -- Social aspects" |
| :--- | :--- | :--- |
| S1 | SO ((intellect* and (disab* or disorder* or impair* or handicap* or <br> incapacit* or handicap*)) or (learning and (disab* or disorder* or <br> handicap* or handicap*) or (mental* and (disab* or handicap* or <br> handicap*)) or ((development* or neurodevelopment*) and disab*) or <br> cretinism or "learning difficulties" or ((mentally or intellect*) and <br> (retard or retarded))) | 2,730 |

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[^0]:    \#14 or \#15 or \#16 or \#17 or \#18 or \#19 or \#20 or \#21 or \#22 or \#23

