Supporting older people with learning disabilities:

a toolkit for health and social care commissioners

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People with learning disabilities and people with autism want to make their own choices and decisions about the things that affect their lives. To help make this happen, BILD works to influence policy-makers and campaigns for change, and our services can help organisations improve their service design and develop their staff to deliver great support.

This toolkit has been produced by BILD in partnership with NDTi. It is part of the BILD Ageing Well project that aims to promote a better understanding of the lives and needs of older people with a learning disability. For more information about the project go to www.bild.org.uk/ageingwell

The NDTi (www.ndti.org.uk) is a not for profit organisation concerned with promoting inclusion and equality for people who are at risk of exclusion and who need support to lead a full life. They have a particular interest in issues around age, disability and health.

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Introduction

People with learning disabilities are living longer. It is estimated that by 2030, there will be a 30% increase in the number of adults with learning disabilities aged 50+ using social care services. This figure masks variations by age group. For example, it is estimated that there will be a 164% increase in adults with learning disabilities over 80 using social care. There are also big variations in need. For example, approximately 1% of the population have autism, and approximately half of those have learning disabilities. The number of people with learning disabilities in the population will be higher than the number known to services (Emerson and Hatton, 2011). However life expectancy is still much lower when compared to the general population. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) found that men with learning disabilities died on average 13 years sooner than men in the general population, and women died 20 years sooner. Forty two percent of the deaths reviewed were deemed to be premature. The most common reasons for deaths being assessed as premature were service failures (Heslop et al, 2013).

(Older) people with a learning disability experience health inequalities, however many of the determinants of health inequalities sit outside health services, and are the result of the interaction of several factors including increased rates of exposure to common 'social determinants' of poorer health (eg poverty, poor housing, social exclusion), individual lifestyle factors, barriers to accessing health care and experience of overt discrimination (Emerson et al, 2012). Many are living with family carers who are themselves ageing and require support. Some people with learning disabilities may themselves become owner occupiers when their family is no longer alive. Whilst this is a key driver towards independence and is welcomed, there is a hidden danger of isolation and loneliness, that if not addressed leaves people with learning disabilities vulnerable to hate crime. People with learning disabilities are also targeted by people who 'befriend' them in order to steal, bully or otherwise abuse them.

Commissioners of public services have a duty to reduce health inequalities in line with the public sector equality duty, and need to plan appropriate services and support to meet the needs of older people with learning disabilities and their families, working across 'client group' boundaries and sharing knowledge and expertise. For example, dementia is a key government priority, yet people with Down syndrome who are likely to experience early onset dementia, are often excluded from mainstream initiatives. The Care Bill in England that is currently making its way through Parliament charges local authorities to look at a more diverse range of support for adults needing social care, which is crucial for this group.

In order to support commissioners and others to develop good quality services for older people with learning disabilities and family carers, the British Institute of Learning Disabilities (BILD) commissioned this self-assessment and toolkit from the NDTi, which brings together information from policy, practice, older people with learning disabilities (the Growing Older with Learning Disabilities GOLD group), and those that support them, to provide an easy reference point for local areas, along with practical ideas to improve practice. The policy and legislation referenced relates to England only, but the issues for older people with learning disabilities referenced in the toolkit are common ones, and thus much of the toolkit is relevant across the UK.

Policy context

Policies regarding older people and people with learning disabilities have tended to work alongside each other, with little in the way of cross cutting policy. The White Paper *Valuing People* (Department of Health, 2001) and the subsequent document *Valuing People Now* (Department of Health, 2009) set the overall policy context for the commissioning of learning disability services. *Valuing People Now* was adopted by the Coalition government and is based on the four key principles of:

- Rights
- Independent living
- Control
- Inclusion

Valuing People Now included the Government's response to *Healthcare for All* by Sir Jonathan Michael (Michael, 2008). The independent inquiry was commissioned by the then Secretary of State for Health, following *Death by Indifference* (Mencap, 2007) which detailed the cases of six people with learning disabilities who died while in the care of the NHS. The inquiry found that 'people with learning disabilities receive less effective care than they are entitled to receive', and made a number of recommendations to address these inequalities including setting up a learning disabilities public health observatory and the Confidential Inquiry. The Confidential Inquiry reported in 2013 and made a number of recommendations that the government has now responded to (Department of Health,

2013). Although there is nothing specific about older people with learning disabilities in the recommendations, issues regarding poor health care have a disproportionate impact on this group. The joint Health and Social Care Self–Assessment Framework also says nothing specific about older people with learning disabilities, but has relevance for this group.

See: www.improvinghealthandlives.org.uk/projects/hscldsaf

Fulfilling and Rewarding Lives (HM Government, 2010) is the strategy for adults with autism in England. The strategy and associated documents are available at: www.autism.org.uk/working-with/autism-strategy.aspx

In terms of wider policy and strategy around older people and ageing issues, there are five key priorities which will have a particular bearing on local action to better support older people with a learning disability. These are set out below:

1. Preparing for an ageing society: understanding the new demographic picture
2. Care and support
3. Promoting better health and wellbeing
4. Housing and support for an ageing population
5. The importance of social networks and community capacity building

1. Preparing for an ageing society: understanding the new demographic picture

The House of Lords Select Committee on Public Service and Demographic Change *Ready for Ageing?* (2013) report highlights the lack of preparedness in government, public services and the financial sector for future increases in longevity and the corresponding ageing of the UK population. The committee draws a number of conclusions and makes recommendations for action both before and after the 2015 general election. Amongst the conclusions, it highlights that by 2022 there will be 3.3 million people over 65 living with a disability in England. Whilst the type of disability is not specified it draws attention to the need for national and local action to both recognise and meet the specific needs of older people with multiple support needs as a result of ageing with a learning disability. The government published a response to this report in (Department of Health, 2013a), outlining the programme of reforms that are already in place and lists additional activity since the House of Lords report was published including backing for the 'Centre for Ageing Better' Big Lottery Fund; *Living Well for Longer: a call to action to reduce avoidable premature mortality* (Department of Health, 2013b); the May 2013 Pensions Bill to introduce a single tier flat rate state pension; and a commitment to push forward on creating pooled health and social care budgets.

The government has also asked the Government Chief Scientist to lead an analysis of the challenges of an ageing society; publish an action plan to extend working lives; and develop the detail of an NHS England plan for vulnerable older people in primary care and urgent and emergency care.

2. Care and support

The White Paper *Caring for our Future: reforming care and support* (Department of Health, 2012), which was followed by the Care Bill currently making its way through Parliament, sets out the government's vision for the reformed care and support system including a continued focus on personalisation and prevention. It is widely recognised that progress on personalisation is not as advanced with and for older people as for other population groups, and action is being taken by TLAP (Think Local Act Personal www.thinklocalactpersonal.org.uk/) and others to help local services and communities address this. NDTi has developed resources for the Department of Health to enable more older people with a wide range of support needs to access and experience personalised support www.ndti.org.uk/uploads/files/OPA_Consultancy_offer.pdf

Alongside and as a crucial part of these reforms, the government is committed to fully integrating health and social care by 2018 (National Collaboration for Integrated Care and Support, 2013). In 2013, the Department of Health (England) identified 14 integration pioneer areas who are seen as leading the way for health and care reform by bringing services closer together than ever before, highlighting the importance of fewer hospital admissions and easier access to therapy. In addition to the above structural reforms, there continues to be a focus on better diagnosis and access to treatment and support for people living with dementia, including those with a learning disability. The Dementia Action Alliance (www.dementiaaction.org.uk) is a coalition of over 700 organisations, agencies and sectors committed to making progress on the National Dementia Declaration, a common set of seven outcomes informed by people with dementia and their family

carers. The Declaration provides an ambitious and achievable vision of how people with dementia and their families can be supported by society to live well with the condition.

With concern over the future of the Liverpool Care Pathway for End of Life, the government is continuing to assess the impact of the *End of Life Care Strategy* published in 2008 (Department of Health, 2008). The Third Annual Report on the Strategy (Department of Health, 2011) refers to a resource developed with the Dying Matters coalition for people with learning disabilities (National End of Life Care Programme, 2011); and highlights consultations that have taken place with the GOLD (Growing Older with a Learning Disability) group and others about the quality of support available to older people with a learning disability and their families.

A final consideration in thinking about and planning local care and support services that meet the individual and collective needs of people growing older with a learning disability, is the local readiness to meet the legal requirements of the Equality Act 2010, in particular new requirements on age equality. An online resource designed to help local health and social care services assess the extent to which they are 'age equal' or 'age discriminatory' is available at http://age-equality.southwest.nhs.uk/

3. Promoting better health and wellbeing
Both physical and psychological health and wellbeing are important for older people, whatever related conditions they are living with. People ageing with a learning disability are at risk of poorer health outcomes due to poor treatment by health services, combined with lower levels of fitness (Emerson et al, 2012). Health and Wellbeing Boards have a duty to produce Joint Strategic Needs

Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs) setting out how they will address health inequalities locally (see below). It will be important to ensure that the needs of people with learning disabilities are addressed in these documents.

There have been numerous national initiatives established to achieve a greater focus on improving health and wellbeing in later life. Many of these are designed to result in a shift away from reactive, secondary care provision to proactive planning for a healthy ageing population. Key amongst these has been the Partnerships for Older People Programme (POPP) focusing on early intervention and prevention; LinkAge Plus, focusing on joined up public services; the Ageing Well programme led by the Local Government Association; and the new Ageing Better programme funded by the Big Lottery where 32 local authorities have been shortlisted to receive funding to enable them to pilot and embed approaches that lead to a better quality of life in older age, '*combining the highest standards of evidence generation with a commitment to practical change with the aim of empowering older people to stay active, healthier and happier for longer*' (http://bit.ly/1dy0hDo). Whilst many of these programmes have identified the need to recognise and respond to the diversity of the older and ageing population, very few local initiatives have focused on improving the health and wellbeing of older people with a learning disability.

4. Housing and support for an ageing population

Suitable, affordable housing, including housing with support, is and will become even more important with increased longevity. Many people with learning disabilities live in the family home, which may continue to be their home when their family are no longer alive. The Joseph Rowntree Foundation (2007) looked at the impact of 'supporting people funding' on people with learning disabilities, and found that outcomes varied, depending on whether people lived alone with floating support, or whether they lived in shared tenancies with support. The latter model addressed isolation, but did not increase independence, whilst the former resulted in increased independence, but also a higher prevalence of loneliness. This project focused on younger people; however the issues facing older people will be very similar, and loneliness is likely to be exacerbated for older people with learning disabilities and autism. The Shared Lives model that enables some older people with learning disabilities and dementia to live independent lives through the support of a Shared Lives carer, has recently received additional funding from government (Shared Lives Plus) and has been shown to be both a cost effective and preferred option for many older people with high support needs, including those with a learning disability (Bowers et al, 2013).

5. The importance of social networks and community capacity building

The growing numbers of older people who experience isolation and loneliness have been well documented (Age UK, 2010) such that preventing isolation and loneliness are now central elements of a number of contemporary areas where there are government policies and grant funded innovation programmes. A key focus in these programmes is ensuring that local authorities, their partners and local communities work together to adopt strategies and interventions that effectively address the underlying root causes of systemic isolation (depression, poor health, disability, exclusion, stigma and discrimination) and not just the apparent symptoms (more people living alone). The Adult Social Care Outcomes Framework now includes a 'measure of social isolation' alongside dementia, integration, and re-ablement. The Campaign to End Loneliness has developed a toolkit for Health and Wellbeing Boards that provides a way of building measures into JSNAs and JHWSs to tackle isolation and loneliness. (see also Windle et al 2011).

Section one
Knowing about the local population of older people with learning disabilities

Rationale

Unless commissioners have good information about the local population of people with learning disabilities, including information on age range, they won't be able to plan services to meet the needs of older people with learning disabilities. Information about (older) people with learning disabilities known to services is important, but gathering information about people not known to services is also important, as up to 25% of people with learning disabilities living with older family carers, are not known to services until there is a crisis (Department of Health, 2001).

Health and Wellbeing Boards must produce Joint Strategic Needs Assessments, which set out the current and future health and social care needs of the local population (Department of Health, 2013c). Although the content of JSNAs is not specified, both qualitative and quantitative information should be included, and attention should be paid to addressing inequalities and improving outcomes. Local areas may want to focus on particular groups with poorer health outcomes. The statutory guidance notes that:

> *'Health and Wellbeing Boards will need to consider: …. how needs may be harder to meet for those in disadvantaged areas or vulnerable groups who experience inequalities, such as …. people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging.'*

(Older) people with learning disabilities experience poorer health outcomes than their non-disabled peers. These differences are to an extent avoidable, and as such represent health inequalities (Emerson et al, 2012). The statutory guidance further notes that:

> *'Integrating equality considerations into the JSNA … process can help public sector organisations to promote equality and discharge their responsibilities under the Public Sector Equality Duty, which is something boards should routinely do as part of their work.'*

Unless the needs of older people with learning disabilities and their families are included in JSNAs, it is unlikely they will be prioritised in commissioning plans. In autumn 2012, IHAL (www.improvinghealthandlives.org.uk) analysed information on people with learning disabilities in available JSNAs, and found that while four out of five JSNAs made some mention of people with learning disabilities, only 46% contain a specific section of the JSNA devoted to adults with learning disabilities, and 8% to older adults with learning disabilities. The information included was in many cases unlikely to be of value in planning future services (Baines et al, 2013). Local Healthwatch organisations have a seat on Health and Wellbeing Boards and gather people's views and experiences of local services, to inform decision making. They are expected to be representative of local communities and work to ensure that the views of those who struggle to get their voices heard are included (Department of Health, 2012a).

Good practice examples

For some examples of JSNAs that have helpful information about older people with learning disabilities. See:

Bradford Joint Strategic Needs Assessment

Older people with learning disabilities

Links to useful resources

Improving Health and Lives Health Profiles are compiled using nationally collected health and social care data broken down into reports for local authority areas. They are used by planners in health services and social services.

The Equality Delivery System is an optional tool to support NHS commissioners and providers to deliver better outcomes for patients and communities.

The Health Equality Framework is an outcomes framework for specialist learning disability services based on the determinants of health inequalities.

Self–assessment

How well are we doing at knowing about the local population of older people with learning disabilities?

- • JSNAs include estimated numbers of people with learning disabilities locally including information about age range.

- • In addition, JSNAs include some locally collected information about older people with learning disabilities, and set out what the information means for services and desired outcomes.

- • As well as national estimates and locally collected information, JSNAs include information about numbers of older people with learning disabilities from black and minority ethnic groups, and information from local older people with learning disabilities and their families about their needs and aspirations.

- • The information is cross-referenced with data and local information about older people with autism, and other conditions with significant overlap.

- • Desired outcomes include the reduction of health inequalities for this group.

EVIDENCE

- • All JSNAs should be published.

- • It is good practice to publish some information on how data has been analysed to inform the JSNA.

- • It is good practice to publish ways in which concerns about the JSNA can be raised with the Health and Wellbeing Board.

Section two
Planning for the local population

Rationale

In order to improve services for older people with learning disabilities and their families, information in JSNAs needs to be turned into commissioning plans and actions. Joint Health and Wellbeing Strategies (JHWSs) set out how Health and Wellbeing Boards plan to meet the needs identified in the JSNA, and should specify clear outcomes. The statutory guidance suggests that JSNAs and JHWSs are *an opportunity to tackle and make a real impact on extreme inequalities experienced by some vulnerable and seldom heard groups*. Local Authority (LA), Clinical Commissioning Group (CCG) and National Health Service Commissioning Board (NHS CB) commissioning plans should be informed by JSNAs and JHWSs.

JHWSs should address equality considerations, in line with the Equality Act 2010, and the Public Sector Equality Duty. People with learning disabilities are deemed to have 'protected characteristics' under the Act, and JHWSs should set out how local services will reduce inequalities for protected groups.

JHWSs can also promote integration between services. This is important for older people with learning disabilities and their families, who often need a range of different, but co-ordinated services.

Good practice examples

Although we found Joint Health and Wellbeing Strategies that referenced people with learning disabilities and older people, we didn't find one that referenced older people with learning disabilities (although this doesn't mean one doesn't exist). For an example of a Joint Health and Wellbeing Strategy that includes information on supporting people with learning disabilities to live well, including increasing the number of health checks, and references to the Learning Disability Partnership Board see: http://bit.ly/1eF9JkB

Links to useful resources
Department of Health
Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategies Explained

Department of Health
Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies

Self-assessment

How well are we doing at planning for the local population?

- JHWSs and local commissioning plans make reference to the needs of older people with learning disabilities and their families.

- JHWSs and local commissioning plans include strategies to meet the needs of older people with learning disabilities and their families.

- The plans make reference to how inequalities are being addressed.

- JHWSs and local commissioning plans set out clear outcomes for older people with learning disabilities and their families, that reflect their views, and demonstrate how inequalities are being addressed.

- The plans include the needs and views of older people from black and minority ethnic groups.

- Specific reference is made to how services can work together to improve outcomes, and how issues for older people with learning disabilities and their families are embedded in wider strategies for older people.

EVIDENCE	
	• JHWSs.
	• CCG commissioning plans.
	• LA commissioning plans.
	• NHS CB commissioning plans.

Section three
Information and advice for older people with learning disabilities and their families

Rationale

Unless older people with learning disabilities and their families get good advice and information, they will struggle to make informed choices about the options available to them. Information should be in accessible formats and should be given in a timely and appropriate manner. Local services need to know about older people with learning disabilities living locally in order to target this information appropriately.

Good quality information and advice materials should be developed in consultation with older people and their families, so that what is produced is meaningful and effective. Positive signposting works hand in hand with the provision of information and advice, and should be part of good services.

There is clear evidence that self-directed support in the form of direct payments, individual or personal budgets, or personal health budgets can enhance people's sense of control over their lives as well as satisfaction with services. They can also make a significant difference to family carers lives (Newbronner et al, 2011). However, in order to access personal budgets, people need to be made aware of them. Local authority staff have a crucial role in raising awareness of personal budgets, but other staff working with older people with learning disabilities should also be aware of their potential, and be able

to signpost people to appropriate information and support. Personal budgets can also be problematic if they are not properly implemented. One GOLD group member is on a personal budget but because he lives with other people the organisation tends to decide on the availability of support staff. Another GOLD group member relies on the group for support with their personal budget:

> *'If I didn't know the GOLD group, I would be struggling to sort it myself'*

Family carers play an important role in person centred assessment and support planning for personal budgets, but may also require a carer's assessment which reflects their own changing needs. Older family carers are more likely to suffer from ill health than the general population. The Carers Strategy includes a number of suggestions to support family carers and minimise the impact of caring on their health, including health checks for carers, appropriate support and information, and breaks from care (HM Government, 2010a). However, recent research indicates that separate assessments of carers needs are uncommon; carers felt that practitioners made assumptions about their ability to keep on caring; there was a lack of clarity regarding carer involvement and conducting or linking separate service user and carer reviews (Mitchell et al, 2013). It is crucial that the increasing challenges older family carers

face, and worries they may have about the future, are taken into account in the support planning process to improve quality of life and avoid crises.

Person centred assessments and support planning should also take account of any mutual caring that may have developed as family carers become increasingly frail. In these circumstances it will be important for older people with learning disabilities to get support as a carer in their own right (Foundation for People with Learning Disabilities, 2010).

Older people with learning disabilities and their families may be vulnerable and in need of advocacy services or support. Most members of the GOLD group had experienced someone taking advantage of them. Self and peer advocacy, citizen advocacy, non-instructed advocacy (for people who can find it difficult to say what they want), and professional or case based advocacy, may all be available locally, and can enable people with learning disabilities to have a stronger voice. Family carer support services are also available and services should signpost carers to them.

Advocacy services need to equip themselves to understand the specific needs of older people with learning disabilities and their family carers, including providing advocacy support for people when their family is no longer alive to support them.

Good practice examples

The Supporting Older Families: making a real difference toolkit, authored by Dalia Magrill (2005) and produced by the Foundation for People with Learning Disabilities, offers a resource for people working with older families, with examples of what works well for them, and what helps them plan for the future, in order to maintain independence.

Dalia Magrill also co-ordinated the Sharing Caring Project from Sheffield Mencap. The project has created a number of resources such as life books, and an Older Carers Support Scheme. An accompanying report (1997) sets out the experiences of people growing older with learning disabilities in Sheffield.

The Thinking Ahead project and subsequent good practice guide from the Foundation for People with Learning Disabilities uses evidence from older families themselves to provide guidance on planning ahead for a range of life events such as housing and support, emergencies, maintaining social networks and finance.

Mencap Cymru Older Voices project provides older people with learning disabilities with opportunities to influence their community through advocacy and campaigning. Initiatives such as training bus drivers to know how to best deal with scenarios that may arise on a journey have proved insightful.

Links to useful resources

Age UK
Information and Advice Evidence Review

Alzheimer's Society factsheet
Learning Disabilities and Dementia

BILD factsheet
Older People with a Learning Disability

Joseph Rowntree Foundation, Cally Ward
Perspectives on Ageing
with a Learning Disability

Macintyre
Hot Tips for Supporting People
with a Learning Disability and Dementia

SCIE
Fair Access to Care Services (FACS):
prioritising eligibility for care and support

SCIE knowledge resources
Personalisation and Learning Disabilities

The Learning Disabilities Observatory
Improving Health and Lives (IHAL)

Think Local Act Personal
Personal Health Budgets: including
people with learning disabilities

Self-assessment

How well are we commissioning for good quality signposting, information, advice and advocacy?

BRONZE

- Information for older people with learning disabilities and family carers is available in accessible formats but it is not clear how the information is disseminated.

- Accessible information on personal budgets is available.

- Information on local advocacy and family carer support organisations is available.

SILVER

- There is a strategy for disseminating accessible information to older people with learning disabilities and family carers which includes information on signposting to other services.

- Local authority staff actively promote accessible information on personal budgets to older people and family carers.

- Staff routinely give out information on advocacy and family carer support organisations. Advocacy services understand the needs of older people with learning disabilities and their families.

GOLD

- Older people with learning disabilities and family carers have been involved in developing the accessible information and the strategy.

- Services have checked how helpful the information is and have acted on any feedback.

- As well as promoting accessible information on personal budgets, staff offer family carers their own assessment, and are clear about the distinction between support for the individual and support for the family carer. Mutual caring considerations are taken into account.

- In addition, local services work with local advocacy and family carer organisations to see how they can work together better to support people.

- Advocacy services have strategies in place to support older people with learning disabilities when their families are no longer able to support them.

EVIDENCE

- Examples of accessible information.

- Copy of the strategy for disseminating information.

- Feedback from older people with learning disabilities and family carers.

- Examples of any changes that have been made to information/ practice following feedback.

- Examples of accessible information.

- Numbers of older people with learning disabilities and family carers who have been given information/have a personal budget.

- Number of family carer assessments.

- Feedback from older people with learning disabilities and family carers.

- Interviews with local authority staff.

- Information on local advocacy and family carer support organisations.

- Feedback from older people with learning disabilities/family carers.

- Feedback from staff.

- Feedback from local advocacy and family carer organisations.

Section four
Accommodation and support

Rationale

Many older people with learning disabilities live at home with family carers who may need additional support themselves as they age. The situation can be complex, as the person with learning disabilities may also be supporting the older family carer, and the role of brothers and sisters and other family members should also be considered. For more information on mutual caring see: http://bit. ly/1dP4TF9 It is therefore vital that services plan ahead with older people with learning disabilities and their families to ensure a smooth transition as circumstances change. When parents die, it may be possible for the individual to continue living at home with another member of the family, or to live alone with support, but this requires responsive services so that individuals do not 'fall through the net', or end up in crises. If people do need to move, planning should be timely and person centred, taking into consideration what people want in their lives:

'I had to wait a while for a review meeting, for a place to be available; the staff were getting a bit worried... I spoke up at the meeting, I said I wanted somewhere near so that I can do my activities, I didn't want to be stuck indoors. That's how I got where I am now' (GOLD group member)

Considerations include:

- the need for home adaptations or assistive technology solutions to stay independent
- enhanced support at home
- flexible and knowledgeable support, for example if the individual has Down syndrome, as they are at risk of developing very early onset dementia (Housing LIN factsheet, see Links to useful resources at the end of this section).

Older people with learning disabilities and their carers therefore need a wide range of person centred options, and early planning for living arrangements in later life. These options may include remaining at home with support as above; supported living; general sheltered or extra care housing; a KeyRing Network (a supported living arrangement where people live in a group of properties in close proximity, with a support worker in the same location); Shared Lives (a regulated arrangement where the Shared Lives carer is 'matched' with the person they support, either taking them into their own home, or closely supporting them by living next door or above/below the individual needing support). Providers should work closely with the people they support to ensure that person centred and personalised support is available in every instance. Older people with learning disabilities also need enough support:

'We can live independently but need support to do it' (GOLD group member)

However, many GOLD group members reported that they did not have a social worker any more, have not been reviewed, and are being told they are independent enough not to need them.

Many older people with learning disabilities still live in residential or nursing home care, with little choice and control over how they are supported. As they age, they may need to move, due to accommodation or staff support considerations. They may also find themselves in older people's residential services, at an earlier age than those they are living with.

Good practice examples

Markyes Close is a residential care home specifically for older people with learning disabilities, provided by Aspire Living, in Ross on Wye, Hereford. Markyes Close consists of two, recently developed bungalows, set within a cul-de-sac that is within walking distance of the town centre. The scheme offers specialised support for residents that have complex needs, including dementia and/or sensory loss. The approach is person centred with communication profiles and individual support plans that include palliative care and end of life planning. The staff received extensive training in areas such as safeguarding, mental capacity, dementia and end of life care planning. The scheme has recently undergone redevelopment, which has been undertaken sensitively in consultation with residents. For example, one resident who finds change difficult was able to stay in his own room which was partitioned off during the refurbishment. Other residents were moved into temporary accommodation and were able to choose all of their own colours and furnishings for their newly modernised home.

For details, visit: http://aspirehereford.org.uk/markyes_close

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Links to useful resources

BILD accessible factsheet
Moving Home

BILD accessible factsheet
Making Plans

Care and Repair England have resources dedicated to the accommodation needs of people with learning disabilities, including a report:
Living on the Edge – enabling older owner occupiers with mild learning disabilities

Department of Health and Housing Options
Planning and Commissioning Housing for People with Learning Disabilities – a toolkit for local authorities

Housing LIN Factsheet No.3
New Provisions for Older People with Learning Disabilities

In Control
Progress for Providers – a toolkit for checking progress on providing personalised support for people living at home

In Control
Seven Steps to Being in Control (of your support)

Joseph Rowntree Foundation, Cally Ward
Perspectives on Ageing with a Learning Disability

The NDTi worked with the Putting People First delivery team at the Department of Health to publish a guide:
Personal Budgets for Older People – making it happen

Self-assessment

How well are housing and support needs understood and addressed?

BRONZE

- Services are aware of the individual's current living arrangements.

- Some initial scoping work has been done with providers on services currently available for older people with learning disabilities.

- Some training is available for staff regarding meeting the needs of older people with learning disabilities, but it is ad hoc.

SILVER

In addition to Bronze:

- A discussion has taken place with the individual and their family about what housing and support options could look like should things change. Easy Read information is provided along with a clear, verbal explanation of what the options are. Individuals are encouraged to exercise choice and control in their housing and support preferences.

- Commissioners and providers have discussed the needs of older people with learning disabilities locally, and have a plan in place to address identified needs.

- Staff training is part of the plan, and training is provided on a regular basis.

GOLD

In addition to Silver:

- Services keep track of the individual's life transitions, and should a sudden change occur, they are able to provide immediate support, work with the person to look at housing and support options, and choose the option that meets the person's choices and that preserves and develops independence, reducing the risk of dependency on services in the long term.

- Older people with learning disabilities and their families have been involved in developing local plans. Plans include better co-ordination of mainstream and specialist older people's services.

- Older people with learning disabilities and family carers are involved in delivering the training.

EVIDENCE

- Number of people that have had an early discussion with family about accommodation and support options.

- Increased numbers able to remain living where they choose to live, with support, using person centred supports such as personal budgets.

- Decreased number of inappropriate care home placements.

- Examples of Easy Read information about housing and support.

- Evidence that services are working in partnership (ie health, housing and social care) to provide best outcome.

- Plans to address the needs of older people with learning disabilities and their families.

- Training plans.

- Interviews with providers.

- Interviews with staff.

- Feedback from older people with learning disabilities and family carers.

Section five
Support to remain active and maintain relationships

Rationale

Older people with learning disabilities have the same needs as other older people to be valued, lead productive and active lives and be treated with dignity and respect. However, as well as experiencing ageism, many older people with learning disabilities experience discrimination because of their learning disability. In addition, they may have reduced social networks because of life experiences. As a result, older people with learning disabilities are at greater risk of social isolation, exclusion, depression and ill health. Lack of significant others in the lives of people with learning disabilities may also make them more vulnerable to a premature death (Heslop et al, 2013). Not only do these issues impact on people's quality of life, but consequent physical and mental health problems can have a negative impact on service costs.

It is therefore important to support people with learning disabilities to maintain and develop social networks and relationships, and this should be a key consideration if changes in accommodation are needed. Some older people with learning disabilities marry in later life, often to another person with a learning disability. This can address isolation and improve wellbeing; however it is important that both partners are able to access support, as couples and individuals.

Many older people with learning disabilities will never have had a job, but this doesn't mean they are incapable of working, and job opportunities should be considered. Many older people also volunteer, which can be another way for older people with learning disabilities to meet new people and contribute to society.

It is important to ensure that older people with learning disabilities are included in any mainstream activities to reduce isolation and loneliness for older people generally. For information on the campaign to end loneliness see: www.campaigntoendloneliness.org

Good practice examples

The GOLD group came together in 1998 to support a project about getting older at the Foundation for People with Learning Disabilities. Although the project ended in 2002, the group continue to meet socially and to talk about their experience of growing older. They also support each other to remain as independent as possible.

The Dorset Friendship Club is open to all people with learning disabilities in Dorset. It started in 2008 and now has 500 members who meet regularly. Approximately 50 members are over 60, and the number of older people using the club is growing. The Friendship Club is user led and as a consequence has grown organically. Activities are chosen, and often run, by members. These take place mainly in the evenings and might include meeting friends for a drink in the pub or cafe, skittles, bowling, educational talks, discos, bingo, quiz nights, stand-up comedy, walks, fitness, bell ringing, boccia and more. Around 150 events take place in 12 towns across Dorset annually. Co-ordinators signpost members to other activities or groups in the community and the club also acts as a safety net by directing members to professional support if required. Members are also supported to meet up with their friends independently outside club times. The use of mainstream activity settings and involvement from volunteers helps provide members with opportunities to build friendships beyond learning disability circles, promoting social acceptance and understanding within the community.

For further information please see:
http://peoplefirstdorset.org.uk/join-in/friendship-club/

The City and County of Swansea local authority have developed new day services for older people, which are quieter, more relaxed with a focus on maintaining relationships and health. People can decide if and when they want to opt in. There is no age related criteria for attendance, it is about need and appropriateness of the support.

Links to useful resources
BILD accessible factsheet
Friends and Family

British Association
for Supported Employment
Valuing People Now publishes range
of resources and guidance

Campaign to End Loneliness
Loneliness and Isolation. A Toolkit
for Health and Wellbeing Boards

NDTi
Social Inclusion Training Pack

NDTi
Inclusion Web Resource Pack

The Silver Line
(information, friendship and advice
to older people)
www.thesilverline.org.uk

Self-assessment

How well are we doing on supporting
people to remain active?

- Staff are aware of the importance of maintaining social networks and activities for older people with learning disabilities.

- There is a strategy in place to make sure that older people with learning disabilities maintain and develop social networks, and this is evident in an individual's person centred plan.

- The strategy includes developing job and volunteering opportunities, maintaining links with family and friends.

- There is evidence that older people with learning disabilities play a positive role in their local communities and have wide social networks. There is also evidence of older people with learning disabilities who have jobs and who volunteer.

- Generic work to tackle loneliness and isolation is inclusive of older people with learning disabilities.

EVIDENCE

- Interviews with staff.

- Strategies/plans.

- Examples of person centred plans.

- Interviews with people with learning disabilities.

- Numbers of older people with learning disabilities who have jobs/volunteer.

Section six
Support with health

Rationale
People with learning disabilities have poorer health than their non-disabled peers, which is in part due to poor access to health services. Many people with learning disabilities also have unhealthy lifestyles, with little physical exercise and a poor diet, so will already be at a disadvantage as they get older. In addition to the physical and psychological changes and age related health risks that other older people experience, older people with learning disabilities may have syndrome specific risks such as early onset Alzheimer's disease for people with Down syndrome. Indeed, all people with learning disabilities are at greater risk of developing dementia than the general population (22% vs 6% aged 65 and above). Adults with learning disabilities are more likely to experience psychiatric disorders than adults generally although reported prevalence varies considerably.

People with learning disabilities have unmet health needs. Therefore health checks are an important reasonable adjustment that services can put in place, as research demonstrates that health checks detect unmet health needs, and lead to actions to address these needs. The need for health checks can also be raised during social care reviews. In addition to health checks, older people with learning disabilities should be supported to access national screening programmes and attend regular hearing and sight tests and dental checks. Health Action Plans can help people with learning disabilities to understand their health needs and take appropriate actions, but it is important to check on how much support people need. One GOLD group member needed extra help with their medication, but this only came to light when the group were away together. Hospital passports or similar are also important tools for helping health professionals to understand the health needs of people with learning disabilities.

Good practice examples

Bristol did a scoping exercise to find out about the health needs of people with learning disabilities who were over 60 living in the area to inform planning and service development. Replies were received from 291 individuals with learning difficulties, aged between 59 and 97 years. Four out of five lived in a residential care home or nursing home. The majority attended day service provision, but a large minority were described as having no regular activities outside their home. A large proportion of the sample was reported to have one or more health conditions, 42% were reported to have a visual impairment, 24% a hearing impairment and 14% were affected by both. One in five had epilepsy, while one in ten had dementia or diabetes. About one in seven had other types of serious chronic illness such as cancer or renal problems. About half of the sample was described as having reduced mobility.

The University of South Wales have just started a study aiming to explore the experiences of residential support workers meeting the health needs of older people with learning disabilities. The purpose of the study is to identify the developmental and support needs of residential support workers so that the health needs of older people with learning disabilities may more effectively be met. Initial findings will be published in mid-2014 and the final report will be published in mid-2015.

Care UK used a traffic light system to support an older woman with Down syndrome and a severe learning disability to have better health. M lives in supported living with another woman in the North East of England. Three years ago she was diagnosed with dementia. M has never liked personal care and frequently declines to eat or drink. She does however enjoy an active community life and is very sociable. Her staff team were very concerned about her diagnosis. At the time she was steadily losing weight and generally seemed unwell and stressed. However it was noticed that M definitely had good and bad days, and a plan to use a traffic light system was devised to capitalise on this. It was a pictorial image that staff could see and was noted in M's support notes.

- If M was having a **Green** day she would be encouraged to eat and drink as much as possible, have a shower and go out for a walk, or out shopping or sightseeing.
- If she was having an **Amber** day, all the above would be tried, but if she started to get distressed staff would immediately cease and perhaps try later.
- If M was having a **Red** day then staff would support and monitor her but with minimum attempts to encourage her to eat or have a wash (just using wet wipes on her hands) and would offer her favourite drink with Fortisip in it.

The programme began three years ago. Since then M's physical health has improved significantly, she has put on weight, goes out for a walk or drive most days and seems very content and happy. The system has also helped M's staff team to cope with her mood swings without feeling they are failing in their duty of care.

Links to useful resources

BILD accessible factsheet
Keeping Healthy

BILD accessible factsheet
Seeing your Doctor

BILD accessible factsheet
Things Getting Harder

Easyhealth.org.uk
Examples of Health Action Plans

Easyhealth.org.uk
Examples of Hospital Passports

IHAL
Health Inequalities and People
with Learning Disabilities in the UK:
2011. Implications and actions for
commissioners and providers of social
care. Evidence into practice report no.4

IHAL
Improving the Uptake of Health Checks
for Adults with Learning Disabilities.
Evidence into practice report no.6

IHAL
Making Reasonable Adjustments
to Dentistry Services for People
with Learning Disabilities

IHAL
Making Reasonable Adjustments
to Eye Care Services for People
with Learning Disabilities

Mencap
Health tools and resources
(including information on health checks)

Self-assessment

How are we doing supporting people with their health?

BRONZE

- Accessible information on healthy lifestyles and health checks is available.

SILVER

- In addition, some staff have received training on supporting healthy lifestyles and the health needs of older people with learning disabilities.

- Over 60% of older people with learning disabilities who are eligible have had an annual health check.

- Over 60% of older people with learning disabilities are supported to get their eyes and hearing tested, and have their teeth checked

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GOLD

- Older people with learning disabilities are routinely supported to understand the importance of a healthy lifestyle, and have regular health checks, eye and hearing tests and trips to the dentist.

- Providers routinely support people to eat a good diet, take regular exercise and attend appointments.

- All older people with learning disabilities who want one, have a Health Action Plan and Health Passport.

- Staff are trained to understand the health needs of older people with learning disabilities.

- Community learning disability teams work with social care providers to make sure older people with learning disabilities' health needs are met.

EVIDENCE

- Numbers of people who have had a health check.

- Examples of accessible information on health checks and healthy lifestyles.

- Staff training records.

- Examples of health action plans and hospital passports.

- Interviews with people with learning disabilities and staff.

- Examples of collaboration between community learning disability teams and social care providers.

Section seven
Support at the end of life

How people are supported

It is just as important to achieve 'a good death' for people with learning disabilities as for anyone else. However, CIPOLD identified a number of factors that made people with learning disabilities vulnerable to a poor quality death. These included problems with identifying when someone was nearing the end of their lives and thus failure to implement an end of life care pathway, failure to co-ordinate care around the individual, including problems with anticipatory prescribing and family support, and problems with accessing NHS Continuing Care funding. Older people with learning disabilities will also need support when family members and friends die.

> *'My mum died in hospital... they wouldn't let me go to the funeral'* (GOLD group member)

How staff are trained to support older people with learning disabilities

Staff supporting older people with learning disabilities in any setting ought to be providing high quality care and support that takes end of life support/care into account. This means that training should be up to date on areas such as developing 'advance care plans', the Mental Capacity Act and Deprivation of Liberty Safeguards. Where appropriate, staff should also be trained to understand the specific needs of people that are ageing with a learning disability. Staff need to engage in proactive support that does not dismiss pain or other unexplained symptoms. There needs to be a culture where talking about death with the individual and their family is not seen as 'taboo' and training should reflect this.

End of life care plans

Individuals receiving support should be encouraged to prepare 'advance care plans' with support whilst they are able to do so, in case they lose capacity to make decisions about their care and support in the future. Funeral arrangements should be part of the conversation when planning for a good death with the individual. Many older people with a learning disability will have lives that are mostly centred around the family, so families and friends should also be involved, although the interests of the individual are paramount.

The National End of Life Care Programme's resource The Route to Success in End of Life Care: achieving quality for people with learning disabilities (2011) notes that the number of over 60s with a learning disability will increase by 36% by 2021, so clear strategies for end of life care are needed.

The hospice movement has also provided information for practitioners on ensuring access to palliative care. Help the Hospices has produced a resource, Future Ambitions for Hospice Care: our mission and our opportunity that sets out evidence and best practice that professionals need to consider. The resource includes older people, as well as older family carers including bereavement support.

Good practice examples

The Palliative Care for People with Learning Disabilities network includes a number of good practice examples. See: www.pcpld.org/real-life-stories/

Haringey Learning Disabilities Partnership have developed end of life and symptom management care pathways.

Staff at **Halas homes**, a residential home for people with learning disabilities in Halesowen, West Midlands, have found that involvement of the district nurse team and Macmillan nurses is crucial to good end of life care. District nurses are responsible for controlled drugs and additional pain relief when end of life is near and they have always been professionally and emotionally supportive of service users and staff.

Working together with district nurses, staff at the home can provide in-depth knowledge of individuals, their likes and dislikes, and preferred communication methods. This is essential to ensure service users are not fearful or anxious. Staff also work in partnership with families. Relatives have stayed by bedsides for many hours night and day and this has been important for the service user and relative.

Where possible, staff adapt bedrooms to suit end of life needs and district nurses have always proved crucial in ensuring they have the correct profile beds, oxygen canisters, palliative drugs and other essentials.

Good communication is key; personal care plans, food and fluid charts and observation charts, easy access to essential emergency telephone numbers for contact at all times (night and day), detailed staff handovers, staff supervision, liaison with community nurse teams, and other health staff, all play a part in enabling the provision of good palliative care to people with learning disabilities living at Halas Homes.

Links to useful resources
BILD accessible factsheet
People Dying

Books Beyond Words
When Dad Died; When Mum Died; When Someone Died; Am I Going to Die

Department of Health
Government Response to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities

Dying Matters
End of Life Care for Adults with a Learning Disability
(Nottinghamshire resources)

Easyhealth.org
Dying leaflets

Help the Hospices
Widening Access to Palliative Care for People with Learning Disabilities

National End of Life Care Programme
Commissioning Person Centred End of Life Care Toolkit

Norah Fry Research Centre
Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)

The Palliative Care for People with Learning Disabilities network:
www.pcpld.org/

Self-assessment

How well are older people with learning disabilities and their families able to plan positively for end of life?

Is good bereavement support available?

BRONZE

- Staff have general training and a broad understanding of end of life care, based on the general population.

- Staff have had some training on the Mental Capacity Act (MCA).

- An end of life care pathway is available.

- There is information available on accessing NHS continuing healthcare funding.

- Some information is available for older people with learning disabilities and their families regarding what happens when people die.

- Some generic bereavement support is available, but it is not routinely signposted.

SILVER

- Staff receive specific training in caring for older people with learning disabilities, including end of life care and recognising when someone may be approaching end of life.

- Staff have up to date training in Mental Capacity, Deprivation of Liberty Safeguards.

- There is a policy on implementing the end of life care pathway, and there is evidence that some older people with learning disabilities have used the pathway.

- Staff are aware of people's rights to continuing healthcare funding, and work to ensure that eligible people receive it.

- Staff routinely signpost older people with learning disabilities and family carers to appropriate information including bereavement support.

GOLD

- In addition, staff have training on understanding different cultural attitudes to death, and work with palliative care services to ensure that people with learning disabilities have a good death.

- In addition to up to date training, staff have access to a range of resources to enable them to implement the MCA appropriately.

- People with learning disabilities who are nearing the end of their life are routinely put on an agreed end of life pathway.

- Older people with learning disabilities who are nearing the end of their life and their families are routinely given information in appropriate formats on continuing healthcare funding, and all people eligible for this receive it in a timely fashion.

- In both care settings and in the community, people growing older with learning disabilities and their families are supported to talk about dying, and what they need and want.

- Older people are able to make plans for their own funerals, and are supported to make a will.

EVIDENCE

- Numbers of trained staff.

- Number of end of life care plans in place.

- Extent to which individuals receiving support and their family have been supported to be able to talk about end of life.

- Numbers of people with learning disabilities offered palliative care.

- Number of funeral plans in place and a mechanism for updating those plans.

Conclusion

People with learning disabilities are living longer, which is a cause for celebration. However, there is an acute need for health, social care, community and housing services to ensure that the support they provide will be sufficiently flexible and co-ordinated to meet people's needs and ensure they can continue to be a part of, and contribute to, the communities in which they live. Alongside this, the needs of families who have spent most of their adult lives as carers must be considered. We hope this toolkit will support commissioners to work with older people with learning disabilities and family carers to ensure support is shaped appropriately to meet local needs.

Glossary

CCG — Clinical Commissioning Group

CIPOLD — Confidential Inquiry into the Premature Deaths of People with Learning Disabilities

GOLD — Growing Older with Learning Disabilities

IHAL — Improving Health and Lives (Public Health Observatory for People with Learning Disabilities)

JHWS — Joint Health and Wellbeing Strategy

JSNA — Joint Strategic Needs Assessment

LA — Local Authority

LIN — Local Implementation Network

NHS CB — National Health Service Commissioning Board

POPP — Partnerships for Older People Programme

SCIE — Social Care Institute for Excellence

TLAP — Think Local Act Personal

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