



Need2Know Hidden in Plain Sight – Dementia and Learning Disability



Mental Health
Foundation



foundation for
people with
learning disabilities

Introduction

Hidden in Plain Sight highlights how more than a million of people with learning disabilities have become invisible in national dementia policy. People with a learning disability are three times more likely to develop Dementia than the rest of the population. But a review of current Government strategy – has revealed that their needs are barely mentioned. It is vital that 1.4 million in Britain identified as having a learning disability are not invisible.

We want to work with policy makers and services to make sure their needs are clearly recognised and they are provided with appropriate and targeted support as they age and if they develop Dementia.

Health and social care services and policy for older people are quickly evolving to respond to the UK's ageing population and their inevitable age-related disabilities. It is evident, however, that individuals ageing with learning disabilities¹ do not receive the attention required to live independently to old age.

People with learning disabilities are living longer than ever and are developing health conditions related to older age. In fact, people with learning disabilities, particularly individuals with Down's syndrome, are at an increased risk for developing dementia earlier in life.

Early progression of dementia requires policies to evolve with the new health and social care demands. Policies need to be founded in a clear understanding of what good support – support that promotes independent living – looks like. Individuals with learning disabilities need to be included in this process.

A rights-based approach

A rights-based approach is central to providing an environment that makes life easier and fairer for people with learning disabilities and dementia. This approach is internationally accepted and rooted in the principles of the United Nations Convention on the Rights of Persons with Disabilities² and protected by the United Kingdom through the Human Rights Act.³ It underpins the requirement that this group need to be supported by policies that promote greater inclusion, equity, and empowerment, and that value and recognise agency.

A rights-based approach raises issues around how learning disabilities and dementia are viewed and discussed, and focuses on how to increase legal protections and entitlement to services. In present policy, dementia is not readily recognised as a disability and is rarely considered in human rights debates. This absence of dementia from disability conversations has a direct impact on securing rights through law.

1. Appleby, J. (2013). Spending on health and social care over the next 50 years: Why think long term? London: King's Fund.
2. United Nations. (2017). Convention on the Rights of Persons with Disabilities (CRPD). Geneva: Division for Social Policy and Development Disability.
3. HM Government. (1998). Human Rights Act. London: HM Government.

A rights-based approach towards disability does not mean new policies need to be introduced; rather, it highlights what needs to be developed and improved to ensure compliance with the law. People with both a learning disability and dementia have the same rights as the rest of the population: to be provided with accessible information; to be supported in exercising their right to participate in decisions and policies which affect them; to live as independently as possible in their community; and, to have full participation in care needs assessment, planning, and decision-making.⁴

The specific issues

The life-expectancy of people with severe learning disabilities remains lower than that of the general population; however, the life-expectancy of people with mild learning disabilities is now comparable to that of the general population. Thus, the overall population with learning disabilities is steadily increasing. It has been predicted that the proportion of people over 65 with learning disabilities or Down's syndrome will double by 2020. By the same year, over a third of people with learning disabilities will be over 50.

With increasing age, there is an associated increase in the prevalence of dementia. Among people with Down's syndrome, this increased prevalence begins in their 30s and continues into the 60s. Should they live to age 70, it has been calculated that nearly 70% of older adults with Down's syndrome are likely to develop dementia symptoms. One in 50, 30 to 39-year-olds with Down's syndrome develop Alzheimer's disease. For 40 to 49-year-olds this rate is one in 10; for 50 to 59-year-olds it is one in three; and for individuals over 60, the rate is more than one in two.

Figure 1: Comparison of dementia prevalence rates by age

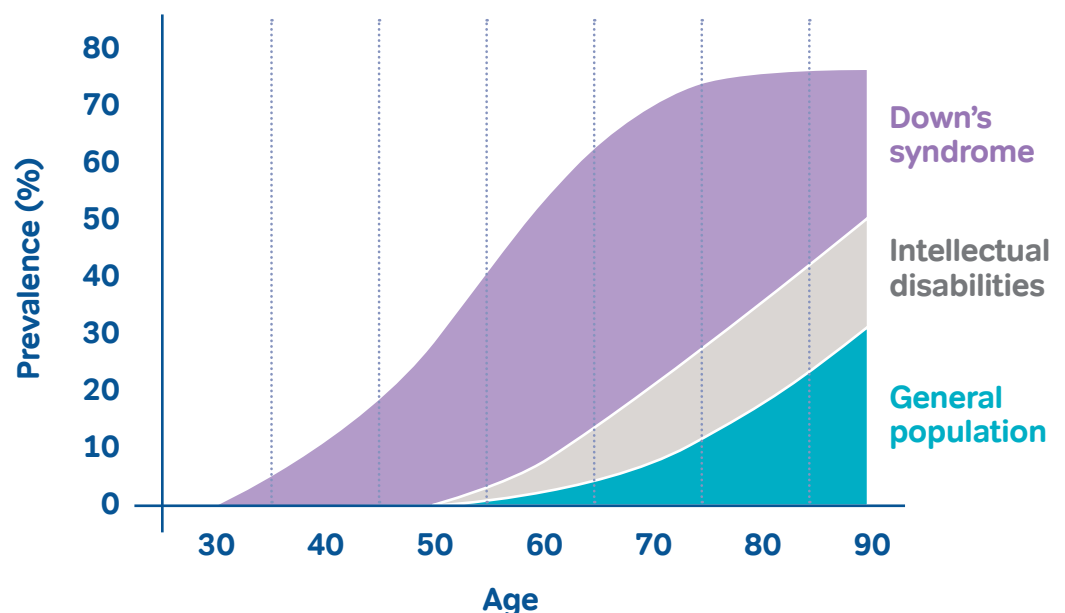


Figure 1 summarises the age-related prevalence of dementia in people with Down's syndrome, in people with other learning disabilities, and in the general population. The exact rates should be considered with caution; however, the trend represented in this figure is now increasingly accepted.

4. A Disability Rights Commission. (2006). Equal Treatment – Closing the Gap. A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems. London: Disability Rights Commission.

Data monitoring the number of people with both Down's syndrome and dementia are more readily available than data monitoring people with other learning disabilities and dementia. Between the ages of 50 and 60, the rate of someone with a learning disability developing dementia doubles with every five years.⁵

Beyond 60, some have found that prevalence continues to increase, with most individuals eventually being diagnosed with dementia.^{6,7} Other research has identified decreased prevalence in individuals 60 and above due to dementia-associated mortality.⁸

Individuals with both a learning disability and dementia face a range of challenges. Loneliness is one such pertinent issue. Feelings of isolation are further exacerbated as they and their parents (who are often their main source of support and advocacy) age.⁹

Prevalence across the UK

In 2015, Public Health England estimated that there were 1,087,100 people (930,400 adults) with learning disabilities in England alone. This figure was calculated by collating information collected by government departments on service-use among people with learning disabilities.¹⁰ To date, there is no definitive record of people with learning disabilities; rather, there are predictions based on departmental figures and epidemiological research. What is clear, is that people with learning disabilities experience significantly higher rates of dementia when compared to the general population.

Studies focused on people with both learning disabilities and dementia are limited across the UK. Without the availability of current and consistent data, the scale of support this group needs remains unknown. Furthermore, the inconsistent evidence base across England, Wales, Scotland, and Northern Ireland makes it challenging to monitor trends and conduct meaningful comparisons.

Issues with diagnosis provide some explanation for the gaps in the data. A study of adults with learning disabilities across London boroughs¹¹ concluded that inconsistent diagnostic criteria caused variations in rates of dementia measured among participants.¹²

5. Coppus, A., Evenhuis, H., Verberne, G.J., Visser, F., Van Gool, P., Eikelenboom, P., et al. (2006). Dementia and mortality in persons with Down's syndrome. *Journal of Intellectual Disability Research*, 50(Pt 10), 768-777.
6. Visser, F.E., Aldenkamp, A.P., Van Huffelen, A.C. and Kuilman, M. (1997). Prospective study of the prevalence of Alzheimer-type dementia in institutionalized individuals with Down syndrome. *American Journal on Mental Retardation*, 101(4), 412.
7. Tyrrell, J., Cosgrave, M., McCarron, M., McPherson, J., Calvert, J., Kelly, A., et al. (2001). Dementia in people with Down's syndrome. *International Journal of Geriatric Psychiatry*, 16(12), 1168-1174.
8. Coppus, A., Evenhuis, H., Verberne, G.J., Visser, F., Van Gool, P., Eikelenboom, P., et al. (2006). Dementia and mortality in persons with Down's syndrome. *Journal of Intellectual Disability Research*, 50(Pt 10), 768-777.
9. Turner, S. and Bernard, C. (2014). Supporting older people with learning disabilities: a toolkit for health and social care commissioners. Birmingham: British Institute of Learning Disabilities (BILD).
10. Public Health England. (2016). Learning Disabilities Observatory. People with Learning Disabilities in England 2015: Main report. London: Public Health England.
11. Strydom, A., Livingston, G., King, M., and Hassiotis, A. (2007). Prevalence of dementia in intellectual disability using different diagnostic criteria. *British Journal of Psychiatry*, 191, 150-157.
12. British Psychological Society. (2009). Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with intellectual disabilities who develop dementia. Leicester: British Psychological Society.

Alzheimer's disease was found to be the most common type of dementia among people with learning disabilities, with prevalence rates of 8.6% in individuals 60 and older. This figure represents a three-time greater risk when compared with the general older adult population.¹³

To date, the rate of dementia among people 60 and over is estimated at 54.6 cases for every 1,000 persons per year. The highest incidence rate falls within the 70 to 74 age group.¹⁴

Prevalence of dementia and learning disabilities across the UK	
UK wide	<p>The number of people living with dementia in the UK is estimated to reach over 1 million by 2025.</p> <p>There are more than 40,000 people living with Down's syndrome in the UK</p>
England	<p>According to 2015 figures, 84% of people in the UK with dementia live in England.</p> <p>The birth prevalence of Down's syndrome in England and Wales has remained relatively stable, while mean life expectancy has increased to 58 years.</p> <p>Since 2012, dementia diagnoses in England have increased by almost 50%.</p>
Scotland	<p>Of those living with dementia in the UK, 8% live in Scotland.</p> <p>In 2014, there were 26,786 adults with learning disabilities known to local authorities across Scotland.</p> <p>This equates to 6 people with learning disabilities per 1,000 people in the general population.</p>
Northern Ireland	<p>Of those living with dementia in the UK, 2% live in Northern Ireland. There are 19,400 people with dementia living in Northern Ireland.</p> <p>People with dementia in Northern Ireland are more likely to get a diagnosis than anywhere else in the UK.</p>
Wales	<p>Of those living with dementia in the UK, 5% live in Wales.</p> <p>There were 15,010 people with learning disabilities listed on registers in 2015.</p> <p>12,884 (86%) were living in community placements and 2,126 (14%) were in residential establishments.</p>

13. Strydom, A., Hassiotis, A., King, M., and Livingston, G. (2009). The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID. *Psychological Medicine*, 39(1), 13.

14. Strydom, A., Chan, T., King, M., Hassiotis, A. and Livingston, G. (2013). Incidence of dementia in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 34, 1881-1885.

Policy context

Including learning disabilities in current dementia policy

Tackling dementia has been identified as a national priority in England, Northern Ireland, Wales, and Scotland. Former Prime Minister David Cameron launched the Dementia Challenge in March 2012. By personally taking on the mantle of delivering improvements in dementia care and research, he indicated significant political engagement with this health issue.

The national dementia strategies and their corresponding implementation plans provide the foundation to establish policies and priorities reflecting the needs of people with dementia. The National Institute for Clinical Excellence (NICE)¹⁵ has also translated this national focus into guidance for practitioners. However, the strategies and guidelines lack a targeted focus on individuals with both a learning disability and dementia, indicating a need to refine policy.

England

In 2009, the Department of Health (DH) launched the first ever National Dementia Strategy for England.¹⁶ The strategy had three key steps: tackling stigma through improving awareness and understanding of dementia; early diagnosis and intervention; and, improving the quality of care for people with dementia. It set out 17 recommendations for the NHS, local authorities, and others to take to improve dementia care services.

Three champion groups were set up to focus on the principal areas for action: driving improvements in health and care, creating dementia-friendly communities, and improving dementia research. However, there was no explicit call for action referencing support for those with learning disabilities. While the three key areas targeted will inadvertently impact dementia care for those with learning disabilities, the strategy did not make targeted recommendations.

Northern Ireland

The Department of Health and Social Care (DHSSPS) launched its regional strategy in 2011: Improving Dementia Services in Northern Ireland.¹⁷ Although implementation has been slow, the strategy made specific recommendations

15. National Institute for Health and Clinical Excellence. (2010). Dementia Quality Standard 1. Retrieved from: <http://www.nice.org.uk/guidance/qs1/chapter/list-of-statements>.

16. Department of Health. (2009). Living Well with Dementia: a national dementia strategy. London: Department of Health.

to provide tailored support to those with learning disabilities. In addition, learning disabilities were recognised alongside age, gender, and genetics as non-modifiable, key risk factors.¹⁸

Wales

The National Dementia Vision for Wales was launched in February 2011 by the Welsh Assembly, in partnership with Alzheimer's Society. While the strategy noted that individuals with learning disabilities are at an increased risk for developing dementia, there were no related action plans.¹⁹

Scotland

The Scottish Government published its first Dementia Strategy in June 2010, outlining the work that the Scottish Government, NHS Scotland, and voluntary and private sector partners were doing to improve support, care, and treatment for families, carers, and people with dementia.²⁰ The strategy did not make any specific reference to support and care for individuals with both a learning disability and dementia.

Scotland's second National Dementia Strategy 2013–2016, published in 2013, built on the 2010 strategy by responding to new evidence that prevalence rates continue to rise.²¹ This strategy recognised the higher risk of developing dementia among individuals with learning disabilities as one of its five key challenges.

Prime Minister's challenge on dementia 2020

Recognising dementia as “*one of the greatest challenges of our lifetime*”, former Prime Minister David Cameron launched the Dementia Challenge in March 2012: a long-term strategy focused on enhancing research, improving care, and increasing public awareness around dementia across the UK. It outlines more than 50 specific commitments that aim to make England the world-leader in dementia care, research, and awareness by 2020.

The strategy sets targets in three areas:

1. **Health and care**
2. **Dementia friendly communities**
3. **Improving dementia research**

17. Department of Health, Social Services and Public Safety. (2011). Improving Dementia in Northern Ireland: A Regional Strategy. London: Department of Health.

18. Department of Health, Social Services and Public Safety. (2011). Improving Dementia in Northern Ireland: A Regional Strategy. Retrieved from: <https://www.healthni.gov.uk/sites/default/files/publications/dhssps/improving-dementia-services-2011.pdf>

19. Welsh Assembly Government. (2011). National Dementia Vision for Wales: Dementia Supportive Communities. Retrieved from: <http://gov.wales/docs/dhss/publications/110302dementiaen.pdf>.

20. The Scottish Government. (2010). Scotland's National Dementia Strategy. Retrieved from: <http://www.gov.scot/Resource/Doc/324377/0104420.pdf>.

21. The Scottish Government. (2010). Scotland's National Dementia Strategy. Retrieved from: <http://www.gov.scot/Resource/0042/00423472.pdf>.

Dementia care became Cameron's champion cause. However, as with the other four regional dementia strategies, care, support and treatment were not explored for individuals living with learning disabilities. The challenge notes that while those with learning disabilities are at a greater risk of developing dementia, it does not respectively outline a tailored strategy.²²

Challenge on dementia 2020: implementation plan

The implementation plan sets out how the commitments outlined in Cameron's challenge on dementia 2020 will be met. It establishes priority actions and the organisations responsible across four themes: risk reduction, health and care, awareness and social action, and research.

A full formal review of this Implementation Plan will take place in 2018. It will look toward actions required by 2020 and will develop more detailed delivery plans.²³ Noting the current gaps in the strategy with regards to those with learning disabilities, the review needs to not only draw attention to this group, but translate the particular needs into tailored policies to support individuals across the learning disability community.

It is important to note that while the strategy does not directly mention learning disabilities, the implementation plan could inadvertently impact diagnosis and care for this key population group through its plans to amend how each Clinical Commissioning Group's (CCG) commissioning performance is rated. The plan outlines that performance ratings of either 'Outstanding', 'Good', 'Requires improvement' or 'Inadequate' for CCGs commissioning learning disabilities and dementia will be used moving forward.

The plan focuses on risk reduction and early dementia diagnosis. Since individuals with learning disabilities face a heightened risk of early onset dementia, this facet of the challenge on dementia is likely to draw attention to the higher rates of dementia among this group and to the different demands this places on dementia services. An example of this strategy shift can be seen in a pilot scheme delivered in partnership with Alzheimer's Society and Alzheimer's Research UK. The strategy will be extended to include individuals aged 40 or older – down from 65. The plan outlines an upcoming campaign titled 'One You.' This new campaign focuses on increasing health literacy of the population regarding 'healthy brain ageing' as well as on providing advice on prevention.²⁴

By 2020, the strategy aims to provide the most appropriate dementia-friendly health and care settings across the UK. Publication of improvements and the assessment frameworks will facilitate more transparent comparisons and provide the necessary data to build upon the best care models.

Dementia care pathways should be able to identify issues that are likely to arise, and therefore develop prevention strategies. Rather than care planning in response to problems, care plans need to anticipate problems. The way to do this is to ensure the needs of individuals with both a learning disability and dementia are understood by policy makers.

22. Department of Health. (2015). Prime Minister's challenge on dementia 2020. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf p12.

23. Department of Health. (2015). Prime Minister's challenge on dementia 2020. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf p9.

24. Department of Health. (2015). Prime Minister's challenge on dementia 2020. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf p.12.



The National Institute for Health and Care Excellence (NICE) guidance

The National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE) published a joint clinical guideline on the management of dementia in 2006 (NICE, 2006). NICE went on to publish quality standards and audit tools^{25,26} covering a range of principles, including: risk, prevention, early identification and diagnosis, promoting choice, integrating and coordinating care, and promoting independence. In addition, the tools provided guidance on interventions, living arrangements, and hospital and palliative care for individuals with dementia and learning disabilities. NICE recognised the risk that people with learning disabilities are likely to develop dementia at a younger age and noted complexities that can occur when shaping appropriate care and support plans.²⁷

With dementia taking centre stage across UK policy, and guidance outlining new standards of care, the development of new means of treatment and care for those with dementia have moved up policy makers' agendas.²⁸ The Equality Act now requires local authorities to make 'reasonable adjustments' when working with people with learning disabilities. Clear progress is being made; however, outcome measures for people with learning disabilities and dementia remain in their infancy.

Excellence in dementia care requires everyone involved to have an in-depth understanding of dementia's impact on the individual. However, people with learning disabilities do not have enough understanding of their diagnosis. Furthermore, the limited evidence base means policy-makers take a broad-brush approach when generating new dementia policies, without appropriately recognising the needs of this group.

25. National Institute for Health and Clinical Excellence. (2010). Dementia Quality Standard 1. Retrieved from: <http://www.nice.org.uk/guidance/qs1/chapter/list-of-statements>.

26. National Institute for Health and Clinical Excellence. (2013). QS30 Supporting People to Live well with dementia. Retrieved from: <https://www.nice.org.uk/guidance/qs30>.

27. The British Psychological Society. (2015). Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia. Leicester: British Psychological Society.

28. Ibid.

Policy recommendations

Health service commissioners need to be clear about the care pathway – from primary care, to appropriate secondary care, to palliative care – for people with both a learning disability and dementia. Care should involve working-partnerships between learning disability services, older people’s services, primary and secondary health care, palliative care, specialist health professionals, and social care. Services should collaboratively develop an integrated dementia strategy for the care of people with learning disabilities.

Social care commissioners need to recognise that dementia is a deteriorating condition and that people’s needs increase over time. Therefore, needs need to be established and funding needs to be processed efficiently to ensure prompt Continuing Healthcare Assessments when necessary. Most people do not reach the criteria for Continuing Healthcare Assessments and if they do, it is at a late stage. It is therefore necessary to consider alternatives such as flexible social Care funding that offers 1:1 support and waking night staff. High quality services give people the best opportunity for a good quality of life regarding both their learning disability and their dementia.

Staff involved in assessment, diagnosis, interventions, and support need to be trained in dementia care. In the current landscape, most people do not have a care manager—identifying care managers for individuals with a learning disability and dementia is crucial. Care managers play an essential role in ensuring that services are monitored and responsive to the individual’s changing needs. People with both a learning disability and dementia should have access to regular reviews (one to six times per year depending on the rate of deterioration) by an identified care manager.

End of Life care needs to be planned early, using the same principles and services available to the general population. Good partnerships with palliative care services are essential to supporting both the person and the carers.

Living with a learning disability and dementia – communities for people with learning disabilities

In this context, community is made up of relationships and physical space. Dementia 2020 stressed the importance of supporting people with dementia to stay in their homes, in familiar surroundings, around people they know. This community living priority applies to everyone with dementia, including those with learning disabilities.

Communities based around relationships offer opportunities to strengthen community awareness and early identification.²⁹ This requires educating people and organisations about learning disabilities and dementia, and making them see people who appear “different” in a welcoming and understanding light. A “friendly community” must focus on improving everyday contact points for individuals living with both a learning disability and dementia.³⁰

29. Mental Health Foundation (2015). Dementia, Rights and the Social Model of Disability. London: Mental Health Foundation.

30. VODG. (2017). Staying Put: Developing Dementia-Friendly Care and Support for People with a Learning Disability. London: VODG.

Case study

Karen was born with Down's syndrome and was diagnosed with Alzheimer's Disease in 2014. The Head of Service and staff at MacIntyre, a consultant, a GP, Karen, and Karen's brother were all involved during the diagnostic process. Since, the MacIntyre staff have done their utmost to provide Karen with the best possible support. Her brother's involvement has provided further stability.

Dementia has had a significant impact on Karen and her quality of life. She has prolonged periods of crying and screaming and can no longer communicate beyond an occasional smile or a "no." However, despite her deteriorating health, MacIntyre has made several adaptations to support Karen in her home. Staff moved her to an adapted downstairs room, bought a swivel seat to help Karen get onto the bus, and purchased crockery and cutlery designed to help people who are living with dementia. Staff puree her meals and speech and language teams make regular visits*.

* Following the completion of this case study, Karen has now moved to a MacIntyre residential home in a neighbouring county. Staff carefully planned the transition. Karen's brother remains actively involved and Karen has been linked into a new network of health professionals.



Photo: MacIntyre Charity

The Asset Based Community Development model assumes that people and communities labelled as disabled or disadvantaged have assets – abilities, strengths, skills, and knowledge – to offer.³¹ Individuals and communities can use these assets to grow, thus eliminating the need for professional services to come and “fix the problem”. This “enabling” approach to community engagement is recognised as the way forward for people with mild or moderate learning disabilities and dementia.

However, this approach is more challenging for people with severe learning disabilities and/or advanced dementia. This means that some individuals’ care is prioritised, while others are not provided with a community care option. Education and training provide an option to bridge gaps in community provision and support the movement towards a locally-available, fully inclusive model.

Physical space is important in shaping a community which supports individuals living with learning disabilities and dementia. A study conducted in 2004 explored the experiences of 18 people with Down’s syndrome and dementia living in a range of environments. The study found that while relationships were important to providing consistent support, the physical environment was also hugely important.

Short-term memory issues associated with dementia make it easiest to support people in their established place of residence. Substantial changes to the built environment lead to confusion, which can often be mistaken for a deteriorating progression of dementia.³²

Using the Dementia Friendly Communities model for people with learning disabilities

As people with learning disabilities experience higher rates of dementia, they represent a community of shared identity.³³ Dementia friendly communities support and include these individuals. There is a lack of understanding about dementia and the challenges that result from associated impairments. Therefore, dementia friendly communities also address stigma by helping people recognise that dementia affects everyone’s cognition, behaviour, and physical ability differently.³⁴

Dementia friendly communities are flexible and focus on individualised support and understanding. They provide a platform from which to provide tailored care to people with both a learning disability and dementia. While in its initial stages, this model of care has been successfully implemented across Europe and is being rolled out across the UK. Dementia friendly communities have the potential to ensure that all people are treated with respect and dignity in their community.

31. Frost, S. (2011). Asset Based Community Development (ABCD). Wakefield: Altogether Better Learning Network.

32. Joseph Rowntree Foundation. (2004). Support for people with learning difficulties in residential settings who develop dementia. Retrieved from: <https://www.jrf.org.uk/report/support-people-learning-difficulties-residential-settings-who-develop-dementia>.

33. Williamson, T. (2016). Mapping dementia-friendly communities across Europe. A Study Commissioned by the European Foundations’ Initiative on Dementia (EFID). Mental Health Foundation: London.

34. Alzheimer’s Society. (2013). Building dementia-friendly communities: A priority for everyone. London: Alzheimer’s Society.

Elements of excellent service

Commissioners should ensure

- Monitoring and identification of needs in relation to learning disabilities, Down's syndrome, and dementia.
- A multi-agency dementia strategy.
- A multi-agency care pathway for assessment, diagnosis, intervention, and support of people with learning disabilities and dementia.
- A multi-disciplinary approach to assessment, diagnosis, and support.
- Prompt access (by age 30) to assessment and diagnostic services for people with Down's syndrome.
- Person-centred dementia care.
- An effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic, and social interventions.
- Dementia-friendly living and day service environments.
- Support for the individual to remain in their familiar home with additional support provided in a timely manner.
- Support available to family carers and service providers.
- A capable workforce able to deliver excellence in dementia care.
- End of Life care following the requirements of the National End of Life Strategy.

Risk factors can be avoided through good planning. To best respond to the needs of individuals with mild to moderate learning disabilities (who may not be known to specialist services), it is important to create a collaborative environment.

Late dementia diagnosis can result in unnecessary transfer to residential or nursing care homes and loss of contact with social networks and activities. Early diagnosis provides the opportunity for advanced planning. This may involve ensuring that there is a good record of an individual's likes and dislikes in relation to food, clothes, people, or places, for when they are no longer able to express preferences.

MacIntyre's example of what good service looks like offers a multifaceted evidence base to inform policy makers, commissioners, and providers alike. More evidence-based research is needed to ensure that we can learn from examples; appropriately inform services; and train staff.



Photo: MacIntyre Charity

Case study

Martin was born with Down's syndrome and was diagnosed with Alzheimer's Disease at age 57. After his diagnosis, Martin began developing several new health concerns: epilepsy, double incontinence, dysphagia, immobility, chest infections, and UTI's.

MacIntyre staff helped Martin move to a new care service where he received extensive support from a multidisciplinary health team—he worked with a physiotherapist, a dietician, a dermatology specialist, an optician, an audiologist and an occupational therapist.

Despite his poor health and decreasing independence, staff supported him and provided him with choice and control at every step. Nurturing his passions, staff helped Martin create a memory box to acknowledge what lay ahead. End of Life care was put in place early on.

Despite his deteriorating health, the good relationship with his family, the breadth of access to external healthcare professionals, and the knowledge staff had built of Martin's likes and dislikes, gave his life both quality and longevity. Due to extensive support from the dementia friendly, MacIntyre community, he lived well until his death.

Recommendations from Dementia Action Alliance

The Foundation for People with Learning Disabilities, MacIntyre, The Learning Disabilities Senate, The Royal College of Nursing, and others organisations have supported the work of the Dementia Action Alliance (DAA). The Foundation chaired the roundtable and welcomed recommendations. We envisage that these will lead to solid policy development that can be incorporated into mainstream action.

The key messages highlighted by the DAA roundtable and 2017 conference demonstrate consensus around placing the person at the centre of their care. What are their needs, and what adjustments are required to support them to live an independent and well-supported life in the community?



1. Importance of early diagnosis and person-centred care

- It is important to see the person, not the learning disability or dementia.
- Noticeable changes need to be acted upon quickly. Accurate, differential diagnosis should be made.
- Conversations might be difficult; however, health professionals need to tell the person their diagnosis and use the word 'dementia'. The diagnosis needs to be understood and explained in a way that makes sense to the person.
- Diagnosis needs to be followed-up and relevant professionals need to be involved at the appropriate time.

2. Joined-up working

- Following diagnosis, health and social care professionals need to work together.
- Individuals with a learning disability and dementia, and their carers, should be involved throughout the process. Has their diagnosis been explained in a way that makes sense to them? Do they fully understand what this means and the impacts? Work together to ensure this.
- Practitioners working in learning disability and dementia need to understand systems and have relevant training.
- Funding must be holistic and present at all stages of the care pathway.

3. Awareness and support for isolated individuals outside of the current system

- People who have a learning disability, but haven't been assessed and aren't accessing services
- People living at home with their parents
- People living in small services
- People with a learning disability who may be a carer for a parent

4. Commissioning

- Commissioners need to understand the issues faced by people with both a learning disability and dementia.
- Money needs to be invested in these areas.
- Access to person-centred commissioning needs to be improved.
- Commissioners should follow the British Psychological Society (BPS) guidelines for commissioners.

5. Living in their own homes for as long as possible

- People shouldn't have to move to a new house following a diagnosis, as their home can often be the most appropriate care setting. Support needs to be funded so people can age in their own homes.
- Local authorities should work closely with the person with a learning disability and dementia and their care providers to fund the changing needs within their homes.

This Need2Know briefing highlights the need to develop quality in practice for people ageing with learning disabilities. The challenges are extensive, from timely diagnosis to the development of quality practice and support. It is essential to deliver person centred care pathways.

Commissioners should be encouraged to identify needs and plan ahead, providing extra resources as required.³⁵ With prevention in mind, there is a need to strengthen awareness in people with learning disabilities, their families, friends, communities, and support staff. The inequalities experienced by people with learning disabilities are many and the response from those there to support them, from policy to practice, are wanting.

We need to question how we treat the weakest individuals in society and apply a rights-based approach. By following the identified recommendations, we can reduce the inequalities experienced by individuals with learning disabilities and dementia, support their wellbeing, and reduce costs to individuals and societies.

We need to build on the evidence base, ensure robust recommendations, and drive forward the agenda for change. As our population ages, there is an urgent need to ensure our communities and services are equipped to be flexible and responsive to individuals' changing needs while ensuring that they receive the support needed to remain connected to their communities and live well into old age. While health and social care services are evolving at a rapid pace, policies need to catch up to address needs of individuals with both a learning disability and dementia.



Photo: Macintyre Charity

35. The British Psychological Society. (2015). Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia. Leicester: British Psychological Society.

Further information

Dementia Organisations

Dementia Action Alliance (DAA)

2nd Floor,
43-44 Crutched Friars,
London EC3N 2AE

www.dementiaaction.org.uk

Alzheimer's Society

Devon House
58 St Katharine's Way
London E1W 1LB

Telephone: 0300 222 11 22

www.alzheimers.co.uk

Learning Disability Organisations

Foundation for People with Learning Disabilities

Colechurch House
1 London Bridge Walk
London SE1 2SX
United Kingdom

www.learningdisabilities.org.uk

VODG (Voluntary Organisations Disability Group)

www.vodg.org.uk

MacIntyre

602 South Seventh Street,
Milton Keynes,
MK9 2JA

www.macintyrecharity.org

Down's Syndrome Association

Langdon Down Centre
2a Langdon Park
Teddington
Middlesex
TW11 9PS

Telephone: 0333 1212 300

www.downs-syndrome.org.uk

Scottish Down's Syndrome Association

158/160 Balgreen Road
Edinburgh EH11 3AU

Telephone: 0131 313 4225

www.dsscotland.org.uk

MENCAP

123 Golden Lane
London EC1Y 0RT

Telephone: 020 7454 0454

www.mencap.org.uk

Publications

- Supporting Derek (Watchman et al., 2010)
<http://www.jrf.org.uk/publications/supporting-derek>
- Watchman K (2017) Intellectual Disability and Dementia: A Guide for Families. London: Jessica Kingsley Publisher.
- Down's Syndrome and dementia-a resource for carers and support staff (Dodd et al., 2009) <http://www.bild.org.uk/our-services/books/bestsellers/downs-syndrome-and-dementia/>
- Down's Syndrome and dementia workbook for staff. (Dodd et al 2006)
<http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-professionals/1091-downs-syndrome-and-dementia-workbook.html>
- About Dementia- The journey of life /About my friend (Dodd et al., 2005)
<http://www.bild.org.uk/our-services/books/health-and-well-being/about-dementia/>
- The Simplicity of Dementia. (Buijsen 2005) Jessica Kingsley Publishers. London.
- Understanding Learning Disability and Dementia: Developing Effective Interventions. (Kerr 2007) Jessica Kingsley Publishers. London.

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Please download the report and Easier to Read summary here:

mentalhealth.org.uk/dementialearningdisability

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