



Thought Leadership

STAYING PUT: DEVELOPING DEMENTIA-FRIENDLY CARE AND SUPPORT FOR PEOPLE WITH A LEARNING DISABILITY



Leading the fight
against dementia

**Alzheimer's
Society**



foundation for
people with
learning disabilities



MacIntyre

Providing support...your way



CONTENTS

FOREWORD	1
INTRODUCTION	2
A POLICY PERSPECTIVE	4
A RESEARCH PERSPECTIVE	8
A PRACTICE PERSPECTIVE	10
A SHARED WAY FORWARD	13
FURTHER INFORMATION AND RESOURCES	14

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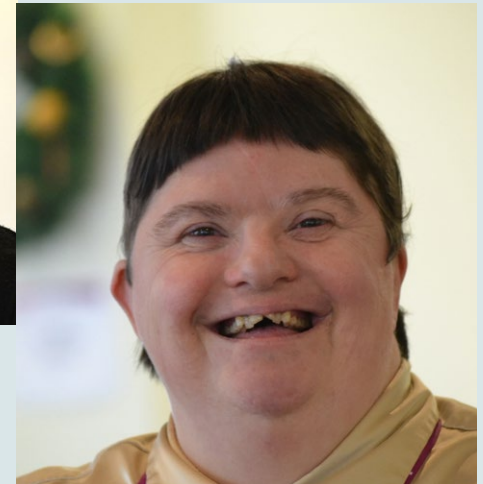
Foreword

It is important to us that all staff know about dementia and learning disability.

This is because dementia is something that can lead to people not being able to talk or even to dress or feed themselves. This can become depressing for some people (who have known the person before they had dementia).

Staff can support people and make a difference in their lives. They can do this just by being there, maybe hold their hand or even recalling events that they have done in the past.

Staff need a better understanding of what dementia is about; they just do. Our friend Alison has dementia and is 50 years old. She is a gem. We tell people about her to help people understand about dementia and learning disability.



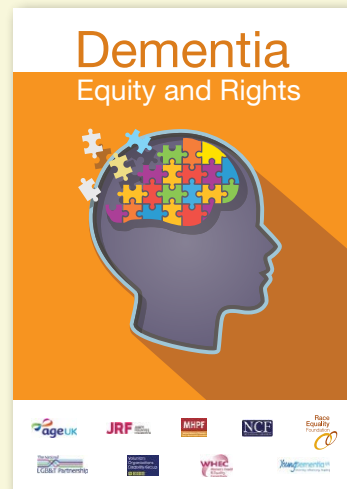
Rosie Joustra and Rachel Silver
MacIntyre Dementia Project
Self Advocates

Introduction

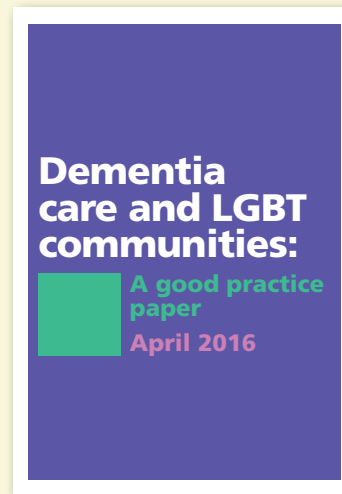
This paper explores how best to develop support, services and treatments for the growing number of people with a learning disability and dementia. It builds on earlier work¹, across the voluntary sector strategic partnership which focuses on dementia support within the context of the protected characteristics defined under the Equality Act 2010.

Dementia, Equity and Rights explores the incidence and experience of dementia for people within protected minority groups. It offers recommendations and identifies resources that promote high quality care and support to people living with dementia and their carers.

<https://www.vodg.org.uk/publications/dementia-equity-and-rights/>



This report was followed by two further papers on improving the experience of people from LGBT communities of dementia services.



http://www.nationalcareforum.org.uk/viewNews.asp?news_id=3503



http://www.nationalcareforum.org.uk/viewNews.asp?news_ID=2511§or_id=12

1 Voluntary Sector Strategic Partnership (2016) Dementia, equity and rights. Accessed: <https://www.vodg.org.uk/publications/dementia-equity-and-rights/>

To gather a range of views, knowledge and experience, we convened a workshop to explore how organisations are working to improve the quality of life of people with a learning disability and dementia and the challenges they are facing. This report addresses three key perspectives which were discussed:

- **The policy perspective** offers an introduction to the Prime Minister's challenge on dementia 2020 and what this means for service providers.
- **The research perspective** describes a study being undertaken by the University of Cambridge which aims to find a treatment that ultimately overcomes dementia in people with Down's syndrome.
- **The practice perspective** looks at how one provider is approaching supporting people with a learning disability and dementia.

Key themes which emerged from these perspectives, include:

- People can live well with a learning disability and dementia.
- Timely diagnosis is key; this helps individuals understand what is happening to them and make choices about their future; it helps health and social care organisations tailor services to meet people's changing needs.
- Remaining in a familiar environment is frequently an important factor in supporting people with a learning disability and dementia to have a good quality of life.
- Organisations need to consider service design, so that they are offering services which are responsive to the progressive nature of dementia and are fit for the future.
- Organisations and their staff teams need to develop the necessary skills to support people with a learning disability and dementia.
- Research should be integral to how health and social care organisations work; ultimately this will help in the development of treatments and provide an evidence-base for progressive, high-quality care and support for people with a learning disability and dementia.

A policy perspective

Dementia has never had such a high profile. The Prime Minister's challenge on dementia 2020² sets out a series of commitments that aim to make England the world leader in dementia care, research and awareness. This includes global recognition of dementia, the development of research through G8 activity, earlier diagnosis so that people receive appropriate care sooner and increased national awareness-raising through initiatives such as Dementia Friends and Dementia-Friendly Communities.

England already has over 1.7m Dementia Friends. These are people who have developed a basic understanding of what it is like to live with dementia and then have turned that understanding into local action. Over 200 towns and cities, with a reach of 26 million people, have signed up to become Dementia-Friendly Communities, in which local organisations and services have committed to

understanding and meeting the needs of people who have dementia. These are significant steps towards making local communities more welcoming environments for people with dementia.

The diagnosis of dementia in the general population is at its highest level. People with learning disabilities may present with behavioural changes rather than memory loss initially and this fact together with diagnostic overshadowing – mistaking dementia symptoms for symptoms of the pre-existing disability – mean that people with learning disabilities are less likely to receive a timely diagnosis. In addition, people with learning disabilities are likely

to have other health needs that may not be identified but could include high levels of unmet need as a result of health inequalities experienced in the health system.



² Department of Health, Cabinet Office and Prime Minister's Office (2015) *Prime Minister's challenge on dementia 2020*. Accessed: <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

An early diagnosis is a fundamental necessity for securing appropriate treatment and support. People with learning disabilities, especially those with Down's syndrome, are at greater risk of developing dementia at a younger age and may experience a more rapid progression of the disease. They may already be receiving social care but may be supported by staff with little knowledge or experience of dementia. Therefore, a key challenge for providers is how to adapt their services, and the environment, to enable people with dementia to remain at home. People with a learning disability and dementia are likely to need changes to their care and support package that reflect the progression of their condition, adaptations to their physical environment and access to specialist services.

Dementia has, until recently, not been described in disability terms, but it is clear that the various impairments that the condition gives rise to mean that people with dementia have protection under the law as people with disabilities. Awareness of this is growing, partly because more people with dementia are describing it in these terms.



So what can providers do to improve services?

1

Firstly, each provider should take steps to understand the scale of need within their organisation by monitoring how many people they support have a learning disability and are living with or are at risk of dementia. This will help providers plan their resources and consider where dementia sits within their overall strategy.

2

Secondly providers can best support people to live well with dementia by adopting a rights-based approach, which places the person at the centre of planning their support. The “I” statements of Think Local Act Personal’s (TLAP) *Making It Real*³ framework and those of the *National Dementia Declaration*⁴ reflect an approach which roots service delivery in the issues that are most important to the quality of people’s lives. They provide an achievable vision of how people can best be supported by services and wider society.

3

Thirdly providers can ensure that their staff have received a level of training which reflects their degree of involvement in supporting people with dementia, and those at risk of developing dementia. All frontline staff in CQC-registered services are required to have dementia awareness training. Staff who are working directly with people with a learning disability and dementia are likely to need more in-depth training in order to deliver high quality support.

³ Think Local Act Personal *Making It Real: Marking progress towards personalised community-based support*. Accessed: http://www.thinklocalactpersonal.org.uk/_assets/Resources/Personalisation/TLAP/MakingItReal.pdf

⁴ Dementia Action Alliance *National Dementia Declaration*. Accessed: http://www.dementiaaction.org.uk/assets/0001/1915/National_Dementia_Declaration_for_England.pdf

4

Fourthly, providers can encourage and support people with learning disabilities to get involved in dementia research⁵. There is a need to build relationships between researchers and providers in order to increase opportunities for people with learning disabilities to be involved in research if they so choose and subject to the right consent arrangements being in place. For example the NHS National Institute for Health Research is looking for people to be involved in a wide range of projects and the University of Cambridge is seeking volunteers to take part in their study of the causes of dementia in people with Down's syndrome.



What did people say?

“It is important to take a rights-based approach; dementia is a form of disability.”

Provider

“We need to change the way society sees people.”

Provider

“It has to be that everything we do is driven by the expressed wishes of people with dementia and their carers.”

Provider

“In tenders, dementia is getting bundled up with other needs without any recognition that it requires a skilled workforce.”

Provider

“In primary care we have a system based around episodes of disease; the G.P. does not think about the totality of your experience. This results in G.P.'s missing dementia in people with learning disabilities.”

Provider

“Where people's needs are changing, services need to change in response.”

Provider



⁵ Anyone can sign up to join dementia research at <https://www.joindementiaresearch.nihr.ac.uk/>

A research perspective

People with Down's syndrome represent the largest group of people with dementia under the age of 50⁶. While the neuropathology of Alzheimer's disease occurs almost universally in adults with Down's syndrome over the age of 40, clinical symptoms may manifest themselves many years after the neuropathology has become established. By this time treatment options are less likely to modify the disease process. A study by the University of Cambridge⁷ aims to discover the early changes in the brain which precede the clinical symptoms of Alzheimer's disease in people with Down's syndrome and to develop processes that will ultimately help identify those individuals who are likely to benefit from treatment.

⁶ Ballard C et al (2016) *Dementia in Down's syndrome*. Accessed: [http://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(16\)00063-6/abstract](http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(16)00063-6/abstract)

⁷ *Defeat dementia in Down's syndrome*. Accessed: <http://www.psychiatry.cam.ac.uk/ciddrg/research/dementia-in-downs-syndrome-dids/>

⁸ A biomarker is a biological measure (such as cholesterol is in heart disease) that when present in abnormal amounts may indicate the presence of disease.

The research is looking at how two proteins in the brain, called amyloid and tau, might cause Alzheimer's disease in people with Down's syndrome. It is testing a hypothesis which proposes that the triplication of the amyloid precursor protein on chromosome 21 leads to over-production of amyloid and this triggers Alzheimer's disease in people with Down's syndrome.

The study aims to identify a viable biomarker⁸ which can aid the development of treatments. The amount of amyloid and tau in the brain can be seen using Positron Emission Tomography (PET) scans and Magnetic Resonance Imaging (MRI). The researchers are exploring whether they can use PET and MRI scans, alongside other tests such as cognitive tests, blood tests, spinal fluid analysis, examination of the retinal nerve fibre layer and brain activity analysis using electroencephalogram (EEG), to determine who will get Alzheimer's disease in later life. The scans can also be used to measure how the levels of proteins in the brain change as people age.

As changes to the brain precede the clinical symptoms of the disease by 10-15 years in people with Down's syndrome, early diagnosis remains difficult. This creates a problem in identifying the optimum age for starting treatment, which could be as early as 15. Furthermore, people with Down's syndrome respond differently to treatment compared with the general population and consequently a targeted approach to drug development is necessary.



This research is only possible due to the participation of people with Down's syndrome. Through their involvement in ethically approved research it is hoped that safe treatments will be developed and that the project will lead to a clinical trial which will help researchers find a drug to prevent this type of dementia from developing in people with Down's syndrome.



What did people say?

"If we can demonstrate that amyloid is the protein that is causing Alzheimer's disease then there are drugs and treatments that lower amyloid and therefore might be used to prevent dementia, particularly in people with Down's syndrome."

Clinical researcher

"I enjoyed taking part in the study and I'd happily take part in any future studies."

Person with a learning disability

"We need volunteers. Up to 25% of our costs are attributable to trying to get people to take part in our study."

Consultant psychiatrist

"We can be resistant to research. We are working with people who have been poked and prodded because they have a learning disability. We need to get beyond that and promote this as an opportunity for people themselves and for generations to come."

Provider

"There should be research in everything we do."

Provider



A practice perspective

The voluntary sector strategic partnership, funded by the Department of Health (DH), has developed a clear focus on dementia and equality issues⁹, including a series of papers prepared by NCF on improving the experience of people from LGBT communities of dementia services^{10 11}.

DH is also funding VODG member MacIntyre to explore how to support people with a learning disability and dementia to live a life that makes sense to them. This work began as a special interest group which was set up to support staff teams to respond to the variety of challenges they were facing in supporting people with a learning disability and dementia. These included:

- How to support people well across a range of service delivery models and a wide geographical spread
- Developing workforce skills and confidence in supporting people with dementia
- Working with local authority commissioners, who sometimes look to move people from the security of their home environment to a specialist dementia service

The group has now run for a number of years and offers a focus for sharing best practice, developing solutions and peer support. These include 'hots tips' booklets which have been coproduced with people with learning disabilities and MacIntyre staff and are freely available via the MacIntyre website (www.macintyrecharity.org).

⁹ Voluntary Sector Strategic Partnership (2016) *Dementia, equity and rights*. Accessed: <https://www.vodg.org.uk/publications/dementia-equity-and-rights/>

¹⁰ National Care Forum (2015) *The dementia challenge for LGBT communities: a paper based on a roundtable discussion*. Accessed: http://www.nationalcareforum.org.uk/viewNews.asp?news_ID=2511§or_id=12

¹¹ National Care Forum (2016) *Dementia care and LGBT communities: a good practice paper*. Accessed: http://www.nationalcareforum.org.uk/viewNews.asp?news_id=3503



Through the DH-funded project, which began in February 2016, MacIntyre intends to build on its work in supporting people with a learning disability and dementia and to:

- Raise awareness of dementia among people with a learning disability, their families and professionals to better understand their condition and future care
- Help people with a learning disability receive a timely diagnosis of dementia
- Provide learning opportunities for professionals to support better care for people with a learning disability living with or at risk of dementia

This work is supported by the “*Keep going.....don’t stop!*” group which represents the voices of people supported by MacIntyre. Group members comment on draft resources and contribute their views and ideas about what is important to people as they get older. The dementia project is being externally evaluated and finalised resources are being made available on the MacIntyre website.



The dementia project team's top tips for providing great support to people with a learning disability and dementia are for organisations to:

- Make all staff aware of dementia, including the risks and the early indicators
- Be alert for diagnostic overshadowing
- Seek a timely diagnosis, after all other possible causes of changes in a person's condition have been explored
- Support people to live well with dementia; challenge myths and stigma; be creative and ambitious
- Celebrate best practice and share it widely
- Network with other organisations and providers to share ideas and get the inside track on latest developments
- Establish a forum for staff to share best practice and ideas
- Provide learning opportunities for people supported by the organisation

What did people say?

"The care and support we provide for people with dementia is faith-based; we believe it is good but we haven't actually produced an evidence-base to show it's good."
Provider

"We find people are being given lots of anti-psychotics to address behaviour."
Provider

"You need to look for the early signs of dementia."
Person with a learning disability

"We need a better trained workforce."
Provider

"Once you have staff on board who have an understanding of the condition, it makes a huge improvement to the person's quality of life."
Consultant psychiatrist

"We found that out of 50 people with a learning disability and dementia, not one person had been seen by a specialist in dementia."
Provider

"We want people to live well with dementia."
Provider

"Really good person-centred planning is key."
Provider

"We've found it really useful working with other providers."
Provider

A shared way forward

POLICY

VODG will include learning disability and dementia within its wider work on health inequalities.

VODG will support members to involve people with learning disabilities in the current review of the “I” statements in the National Dementia Declaration.

VODG will seek an opportunity to contribute to the examination of the UK’s performance regarding the UN Convention on the Rights of Persons with Disabilities in 2017 and will highlight the inequalities experienced by people with a learning disability and dementia.

RESEARCH

Providers offered to identify potential volunteers with Down’s syndrome who might be willing to participate in further research, including the study featured in the discussion being undertaken by the University of Cambridge. Details of how to get involved in the study can be found in **further information and resources**.

VODG will seek a dialogue with the National Institute for Health Research on what steps are being taken to support and encourage people with learning disabilities to take part in dementia research.

PRACTICE

Providers should be alert to the potential growth in the number of people with a learning disability and dementia in their organisation. How many people with a learning disability does your organisation support who have, or are at risk of developing, dementia? Once you have this data, it will help you plan services and resources.

MacIntyre will continue to make new resources available as their project progresses. Providers are welcome to attend a meeting of the MacIntyre special interest group by prior arrangement. For further information, contact dementia.project@macintyrecharity.org

VODG will seek further opportunities to address health inequalities in 2017/18.

Further information and resources

POLICY

Department of Health, Cabinet Office and Prime Minister's Office (2015) Prime Minister's challenge on dementia 2020.

▶ <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

Department of Health (2016) Prime Minister's challenge on dementia 2020: implementation plan.

▶ <https://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan>

RESEARCH

Defeat dementia in Down's syndrome website

▶ <http://www.psychiatry.cam.ac.uk/ciddrg/research/dementia-in-downs-syndrome-dids/>

To get involved in the dementia in Down's syndrome research, email dh-admin@cam.ac.uk

For a short film on the dementia in Down's syndrome research

▶ <https://www.youtube.com/watch?v=pB7iqWUXQIM&feature=youtu.be>

PRACTICE

For information about living with dementia or supporting someone with dementia, see

▶ <https://www.alzheimers.org.uk/>

Jenny's Diary, a resource to support conversations about dementia with people with a learning disability, can be downloaded at

▶ <http://www.uws.ac.uk/jennysdiary/>

For more information about the MacIntyre Dementia Project, see

▶ <http://www.macintyrecharity.org/our-work/supporting-people-with-dementia/MacIntyre-dementia-project/>

Social Care Institute for Excellence – information, guidance, resources and accredited training for anyone supporting people with dementia, see

▶ http://www.scie.org.uk/dementia/?utm_campaign=7754811_SCIE%20E%20Bulletin%2018%20November%202016&utm_medium=email&utm_source=SCIE&utm_sfid=003G000001z1pLYIAY&utm_role=&dm_i=4O5,4M7NF,FHJBVJ,H6DLZ,1

The Voluntary Sector Strategic Partnership is a partnership between VODG and NCF which delivers initiatives that support providers to improve health and wellbeing outcomes. It has published the following resources on dementia:

Dementia, equity and rights

▶ <http://www.vodg.org.uk/publications/dementia-equity-and-rights/>

The dementia challenge for LGBT communities: a paper based on a roundtable discussion

▶ http://www.nationalcareforum.org.uk/viewNews.asp?news_ID=2511§or_id=12

Dementia care and LGBT communities: a good practice paper

▶ http://www.nationalcareforum.org.uk/viewNews.asp?news_id=3503



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