

# Meeting the challenges of dementia for people with learning disabilities

*Roundtable discussion briefing paper*



National Dementia Action Alliance

## INTRODUCTION TO CAMPAIGN

This briefing paper has been produced to launch the National Dementia Action Alliance's (NDAA) campaign to improve care and support for people affected by dementia from seldom heard groups.

## ABOUT THE NDAA

The NDAA is a network of organisations who commit to taking action on dementia. Through our work, we aim to improve health and social outcomes for people affected by dementia. The NDAA was set up in 2011 following the government's National Dementia Strategy of England, to bring together key organisations to gain their commitments to achieving the outcomes outlined in the strategy. Since then it has gone from strength to strength and we now have over 150 members.

The role of the NDAA is to bring together our members to connect, share best practice and take action on dementia. We also campaign on key issues affecting people with dementia and their carers. Past campaigns we have organised have improved dementia care within hospital settings, reduced anti-psychotic drug prescriptions and improved support for carers.

Our 2017 campaign will focus on improving care and support for people affected by dementia who come from seldom heard groups. The campaign has three primary objectives:

1. Raise awareness of the challenges faced by people with dementia from seldom heard groups
2. Influence system wide change
3. Bring about organisational change

As part of the campaign we will hold a series of roundtables, each focusing on a specific seldom heard group. Through the roundtables we will explore areas where progress is needed and where the NDAA, through the influence of its members, can affect wider change.

We will run roundtables focused on dementia in the following groups:

- Prisons
- Lesbian Gay Bisexual & transgender
- Learning disabilities

## DEMENTIA AND LEARNING DISABILITIES

### Overview of main issues

This paper will seek to outline some of the main challenges affecting people with dementia and learning disabilities. Through it, we hope to identify a specific area where change is needed and then through the roundtable to explore a desired outcome and way of achieving this.

People with a learning disability are at greater risk of developing dementia at a younger age. Studies have shown that one in ten people with a learning disability develop young onset Alzheimer's Disease between the age of 50 to 65. The number of people with Down's Syndrome who develop Alzheimer's disease is even greater with one in 50 developing the condition aged 30-39, one in ten aged 40-49 and one in three people with Down's Syndrome will have Alzheimer's in their 50s.

Someone with a learning disability may not fully understand a diagnosis of dementia or what it will mean for them. Even after a diagnosis of dementia, a person with a learning disability will have other existing health care needs plus those associated with ageing. For example, older people with learning disabilities have higher rates of arthritis and other problems that impair mobility. Health and social care policy for older people does not always take into account the specific needs of people ageing with a learning disability. Instead, needs are absorbed into the larger population of older people for whom disability is typically seen as an inevitable part of ageing.

### Receiving a diagnosis

People with learning disabilities often struggle to access appropriate treatment particularly for conditions considered to be unrelated to their learning disability, which is why early recognition and diagnosis of dementia is crucial. 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.

People with learning disabilities may present 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.

### Responsibility and accountability for delivering care

The Voluntary Organisations Disability Group (VODG) report "Developing dementia friendly care and support for people with a learning disability" stated that providers should take steps

to understand the scale of need within their organisation by monitoring how many people they support who 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.

There are complex health needs and a lack of joined up working, with the pathway often unclear.

### The right care

Organisations and their staff need to develop the necessary skills to support people with a learning disability and dementia. Dementia navigators are not trained to help people with a learning disability and people in learning disability services are not trained to work with people with dementia. Someone who understands the impact of both dementia and learning disabilities is needed.

### Dementia and human rights

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. People with a learning disability and dementia are more likely to need a change in their support package and adaptations to their environment.

A key issue for people with a learning disability is avoidable death. The figures are high with learning disabilities as people are not getting good quality healthcare and reasonable adjustments are not being made in their care. Judgements are made about quality of life and treatments.

People can't always access services as they haven't been told their diagnosis. If they have been given a diagnosis and are accessing services, they don't always know why they are doing so.

### Conclusion

There are a number of issues facing people with a learning disability and dementia. People with a learning disability are developing dementia in a higher number and from a younger age, therefore the appropriate diagnosis and post diagnostic support needs to be in place. People need to be told of their diagnosis in order to be able to have equity of access to services and understand their diagnosis. They need an honest explanation from the professionals, and for this there needs to be a change of attitude. There needs to be choice

of treatments and opportunities so that the person and their friends and families can be supported by professionals. In addition to this, information needs to be accessible.

A strategy in social services aimed specifically at people with dementia and a learning disability is needed. To make sure people are not absorbed into the larger older population for whom disability is typically seen as an inevitable part of ageing. A shared working model exists and this needs to be made available to GPs, memory clinics and social services. People with a learning disability should have the opportunity to see an old age or dementia specialist and have reasonable adjustments made by the services to ensure equity of access. Social care is absolutely key to ensuring people don't fall through the cracks.

Good practice does exist and it is important that through this campaign we highlight the specific things that can be done, whilst at the same time pushing for wider changes that need to be made.