

Dementia and Learning Disabilities: Roundtable notes

Seldom heard groups

People from seldom heard groups face barriers to accessing good health and social care, which at times fails to meet their needs. Challenges can include a lack of awareness and cultural understanding across health and social care settings. This problem has become more acute as public service budgets have been cut.

Through our diverse membership the NDAA is well placed to improve this situation by harnessing the resources and ideas of our members and of other organisations operating across health and social care.

In June 2017 the NDAA hosted a series of evidence gathering roundtables with leading stakeholders involved in delivering care and support of seldom heard groups. The roundtables covered dementia and learning disabilities, dementia within prison settings and within the LGBT+ community.

Introduction

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 one in three people in their 50s and more than 1 in 2 at age 60 and above.

Roundtable

20 people came together on 8th June in London to discuss the key issues and actions to be taken around supporting people affected by dementia and a learning disability. The NDAA hosted this four-hour roundtable, which was chaired by Christine Burke from the Foundation of People with a Learning Disability and Pat Charlesworth, an expert by experience. The attendees consisted of experts on learning disabilities and dementia, with videos being shown of people with dementia and a learning disability, which were kindly provided by the charity MacIntrye. The session consisted of small group discussions around the issues and agreeing on actions that this campaign could focus on for NDAA members to undertake.

The key themes from the Learning Disability roundtable discussions are detailed within this document.

Key themes

1. Pathways – Planning ahead

Pathways should be in place before a diagnosis, particularly as we know the risks are high for people who have a learning disability. Good life story work from birth onwards – accurate records of medical and social needs leads to health professional's signposting to

more appropriate services in the pathway. Staff who work with people with a learning disability can't assume their behaviour is part of their learning disability. GPs can often make this assumption. Joint working between health and social care professionals is key, so that medical and social history is not lost. Learning disabilities are often seen first and excuses are made for health changes, which are put down to a learning disability, so dementia diagnosis is delayed.

Simple pattern of assessment:

- Has the person changed over the course of 6 months?
- What could be the cause?
- Seek an accurate diagnosis
- Exclude other options
- Don't jump to conclusions

2. Human Rights

People should be supported in environments known to them, or this could be an infringement of their human rights. People supported should be told of their diagnosis (if they wish to know it) in a way that makes sense to them using their own preferred communication. Check they have understood - do not assume.

3. Peoples' Information and Sharing

There should be an information and consent form so that people are on a database for future assessment from age 18. Having accurate information on a database can solve sharing issues later on, and facilitate baseline assessments for people with Down's syndrome at age 30. People's history and information often doesn't transfer with them if they move homes – just one sheet of paper and the summary doesn't go deep enough. At present when a person moves, detailed health and social care notes do not move with them. It is as if their medical and social history does not matter. In order to receive a timely diagnosis, staff must take more responsibility and accountability to improve on better recording of health and social care information.

4. Involving Families in Formal Networks of Care

We must give families, carers and friends the confidence to speak up and become part of the formal network of care for their loved one. Families don't always know about the increased risks of someone with learning disabilities developing dementia. Increased communication and better health recording may help with this area.

5. Complex Needs

Complex and combined needs are not currently addressed in a sophisticated way. Some people with learning disabilities will try and cover up symptoms after a lifetime of looking foolish and feeling foolish. It is important for all to understand how to spot the signs.

6. A Right to Know

There are challenges around how to give a meaningful diagnosis. Pick a communication method that works for the person e.g. if they ask 'is my brain broken' then address this sensitively but truthfully.

7. Raising Awareness

Through being honest and open we have better conversations about dementia and learning disabilities much earlier. We can talk to people with learning disabilities about things that might happen when they are older. There is a need for better education. Most people with learning disabilities don't know the word dementia. Commissioners need to know this is an issue. They are juggling small pots of money.

8. Existing Initiatives

There are a number of existing initiatives so we should join the dots and help them work together. Organisations coming together in this way can ensure the existing work is publicised and not duplicated. As they have a Right to Know, ensure they have been told in a way that makes sense to them. Eg if the person does not use words to communicate, then have they been told in their own preferred style (e.g. pictures, photo symbols, Makaton, sequences). We need to respect their Right to Know, and inform them in a way that makes sense to them and check understanding,

Recommendations

The NDAA is asking organisations to sign up to a pledge and to take actions to support people with a learning disability and dementia. Collectively organisations are stronger. Areas we discussed at the round table were:

- Consult with people with learning disabilities and carers
- Funding – especially to meet changing needs as dementia progresses
- Education and Awareness raising. Educate providers in older people and dementia teams, as well as learning disability teams and draw together the expertise that sits in both areas
- Early intervention
- Commissioning
- Integration of health and social care
- Communication
- Promotion of existing work
- Improve health recording
- Providers to understand what they need to be doing, not to deskill people

1. Importance of an early diagnosis and person centred care

- It is important to see the person, not the learning disability or dementia

- When changes are noticed, this needs to be acted upon quickly and a timely but accurate differential diagnosis should be received
- Conversations might be difficult, but health professionals need to tell the person the diagnosis and say the word dementia. The diagnosis needs to be understood and explained in a way that makes sense to the person
- Diagnosis is followed up and the relevant professionals are involved at the appropriate times

2. Joined up working

- Diagnosis flags a need for joint working with health and social care professionals
- To involve people with a learning disability and dementia and their carers throughout the whole process
- Practitioners working in learning disabilities and dementia to understand systems and to have training
- Funding at all stage of the pathway has to be there and has to be holistic

3. Awareness and support of people outside of current system who are isolated

- 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 people with a learning disability and dementia face
- Money needs to be invested in these areas
- Need to improve access to person centred commissioning
- Commissioners to follow the British Psychological Society/ Royal College of Psychiatrists guidelines for commissioners

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

- People shouldn't have to move house following a diagnosis. Support needs to be funded to maintain people in their own homes, which would be a more appropriate care setting
- Local authorities to work closely with the person with a learning disability and dementia, their carers and their care providers to fund the most appropriate outcome changing support needs within their home

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