

Service quality: dementia

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Service provision for people with an intellectual disability and dementia in  
Scotland: adherence to good practice guidelines

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## Abstract

**Background:** Good practice guidelines aim to promote equity in service provision and quality in order to improve the outcomes, experiences and quality of life of service users

**Specific Aims:** to evaluate the extent to which the practices of NHS services for people with an intellectual disability and dementia in Scotland were consistent with a range of quality indicators that covered screening, assessment, and intervention.

**Method:** Participants were staff from 10 intellectual disability services in Scotland who completed an online survey. They rated the extent to which their service met quality indicators adapted from the British Psychological Society, Division of Clinical Psychology & Royal College of Psychiatrists (2015) Good Practice Standards Self-Assessment Checklist.

**Findings:** The areas that were most commonly 'fully met' related to assessment and diagnosis, those that were most commonly 'not/only partially met' related to areas such as flexible funding, service development and monitoring and location of out of area placements.

**Discussion:** The results suggest there is some disparity in the extent to which the participating services have practices which are consistent with all of the quality indicators. The limitations and implications for nurses are discussed.

## Introduction

Providing good quality assessment, treatment, and support of people with dementia and an intellectual disability can be challenging for service providers (see McCallion et al., 2017 for an overview). There are a number of reasons for this. Firstly, people with Down syndrome are at a significantly increased risk of developing Alzheimer's disease and at a much younger age than their typically developing peers (McCarron et al., 2014). Secondly, one of the negative consequences of increased life expectancy is that people with an intellectual disability, which is not as a result of Down syndrome, are increasingly likely to develop dementia, most commonly Alzheimer's disease in older age (Strydom et al., 2010). Thirdly, the differing course and progression of dementia in people with an intellectual disability, including a more rapid rate of deterioration, can mean that service providers have, or feel they have, limited knowledge, experience, and confidence in supporting this group of people (McCarron et al., 2010; McKenzie et al., 2002). This can mean that, as with services for people with an intellectual disability in general, those for people with an intellectual disability and dementia can vary across areas,

One of the key aims of clinical guidelines is to provide an evidence-based framework to help clinicians and others promote equity in service provision and quality in order to improve the outcomes, experiences, and quality of life of service users (e.g. National Institute for Health and Care Excellence [NICE], 2018). While guidance that is specific to older people with an intellectual disability is currently being developed by NICE, the 2015 publication of joint guidelines on the assessment, diagnosis, interventions, and support of people with an intellectual disability who develop dementia (British Psychological Society Division of Clinical Psychology & Royal College of Psychiatrists [BPS; DCP, RCP, 2015]

currently provides good practice recommendations against which service providers can benchmark their own practice.

Nurses are one of the professions most commonly involved in the screening, assessment and care of people with an intellectual disability and dementia (McKenzie et al., 2018) and as such are well placed to help ensure that service provision is consistent with good practice guidelines. Such guidelines can be related to a range of positive outcomes for service users and providers, but they are not always implemented in practice or fully adhered to (e.g. McKenzie et al., 2015).

The present national study, therefore aimed to evaluate the extent to which the practices of NHS services for people with an intellectual disability and dementia in Scotland were consistent with a range of quality indicators that covered screening, assessment, and intervention for this client group. These were adapted from the BPS DCP and RCP (2015) “Good Practice Standards – Self Assessment Checklist”.

## Method

### Design

The project received ethical approval from the first author’s university. Information in relation to the quality indicators adapted from the BPS DCP and RCP (2015) “Good Practice Standards – Self Assessment Checklist” was gathered via an online questionnaire which was distributed to NHS practitioners in Scotland who provided services to people with an intellectual disability who had, or were at risk of developing, dementia. Recruitment was via the leads of clinical psychology services who were initially contacted by email, provided with information about the study and a link to the online questionnaire, and asked to distribute it to the relevant staff member(s) to complete. Each service lead covered a health board area

in Scotland, therefore a response from a service in that area represented service provision for that particular health board area.

Participants were staff from 12 intellectual disability services which covered the 11 health board areas in Scotland. While there are more than 11 health board areas in Scotland, some small health board areas receive services from neighbouring health boards. An individual response represented consultation between a number of different professionals within a service, with the team clinical psychologist responding on behalf of the service. Responses are out of 9 or 10 as 9 services fully completed the questionnaire, with an additional service answering only some sections.

#### Measures

Quality indicators: the BPS DCP and RCP (2015) “Good Practice Standards” self assessment checklist was used to enable services to evaluate the extent to which they met the standards. The wording was changed where required to reflect the relevant context and legislation in Scotland. Participants responded to items by indicating if it was ‘fully met’, ‘partially met’, ‘not met’, or ‘not known’ in relation to their own service.

#### Results

Table 1 illustrates the number of services that identified the extent to which they felt that a range of quality indicators were met within their health board area in relation to working within legal frameworks and guidance, population, care pathways, multi-disciplinary approach, and assessment and diagnosis.

<Insert table 1 about here>

Table 2 illustrates the number of services that identified the extent to which they felt that a range of quality indicators were met within their health board area in relation to policies, systems, processes, staffing, environment, residence, personalised care, and wider support.

<Insert table 2 about here>

## Discussion

### Working within legal frameworks and guidance

The quality indicator that was most frequently identified as being fully met by the participating services in relation to working within legal frameworks and guidance was being able to access a published local adult safeguarding policy. A series of abuses of people with an intellectual disability has prompted the introduction of safeguarding legislation across the UK, with Scotland having introduced the Adult Support and Protection (Scotland) Act 2007. This Act aims to prevent harm to adults who do not have the capacity to protect their own wellbeing and would be applicable to many individuals with an intellectual disability and dementia. Proactive screening of individuals with Down syndrome for dementia offers one means of highlighting previously unidentified safeguarding issues (Major and McBrien, 2011).

### Assessment and diagnosis

In relation to diagnosis and assessment, the indicators that were most frequently endorsed as being fully met related to identifying and treating other illnesses, as appropriate, as part of the dementia assessment, carrying out assessments in a timely manner, diagnosing according to established criteria, and having a written formulation. A number of health conditions, such as depression, hearing and vision problems, and hypothyroidism, can result

in symptoms that are similar to those that result from dementia (e.g. McKenzie et al., 2002). Health screens are, therefore, recommended as a key component of proactive screening and reactive assessment for dementia (BPS DCP & RCP, 2015), tend to be long-standing components of screening and assessment pathways (McKenzie et al., 2000), and have been found to be effective in identifying health issues that were previously undetected or unreported (Paxton et al., 2001). It is, therefore, unsurprising that this aspect was rated as fully met by nine out of ten services. Similarly, the evaluation of different sources of information to develop a formulation of the person's difficulties is common practice among health professionals (Holle et al., 2017) and helps inform whether a diagnosis of dementia is appropriate or not.

#### End of life care and care pathways

The indicators that were most frequently identified as not being met related to providing people with an intellectual disability diagnosed with dementia with the opportunity to plan their end of life care, the existence of a multi-agency pathway agreed at board (or equivalent) level, and a person-centred care plan for each individual. The importance of end of life care for people with an intellectual disability and dementia has recently been highlighted by the consensus statement of the International Summit on Intellectual Disability and Dementia related to end-of-life care in advanced dementia (McCallion et al., 2017). However, research suggests that specialist palliative care service providers may lack experience in discussing and planning end of life care directly with people with an intellectual disability and dementia (Ryan and McQuillan, 2005). In some cases, the limited communication skills of service users may make end of life care planning even more difficult. It has been suggested that carers can act as a conduit to help plan the end of life

care of the person they support based on their knowledge of the person and his/her preferences and in collaboration with specialist palliative care services (see McCarron et al., 2010). Both health and social care staff who work within intellectual disability services have, however, also been found to lack confidence in discussing issues related to death with people with an intellectual disability (Murray et al., 2000). This may continue to act as a barrier both to the involvement of the person in end of life care planning and to the development of a person-centred plan that reflects his/her wishes.

While many areas have had NHS care pathways for people with an intellectual disability and dementia for many years (McKenzie et al., 1998; McKenzie et al., 2000), the Public Bodies (Joint Working) (Scotland) Act 2014 introduced legislation integrating health and social care in Scotland by 2016. This has required reorganisation of services and the introduction of integrated joint boards. This may explain the low endorsement by services of the item relating to the existence of pathways that are agreed at board level.

Person-centred care, care management and review, and dying in place

The quality indicators in these categories which were most frequently identified as being fully met related to providing care which promotes social inclusion and which recognises that the person with dementia should not be moved unless absolutely necessary. The promotion of social inclusion is a long-standing value that underpins all good quality services for people with an intellectual disability (O'Brien and Tyne, 1981).

There has been a growing recognition of the need to minimise changes in the environment for people with dementia, particularly given the importance of familiarity and routines as ways of helping reduce problems associated with memory loss and that research indicates that moving is associated with more rapid deterioration (see BPS DCP & RCP,



2015). The participating services also recognised the importance of stability for the person with dementia. This recognition was not, however, always able to be reflected in practice, as shown by the low endorsement of items under the category 'Dying in place'.

Another item that had limited endorsement was flexible funding, i.e. funding that is able to be changed rapidly according to the person's needs, such as moving. Service et al. (2017) highlight some of the issues that can prevent the person with dementia from remaining at home, even if this is the preferred option. This includes the inability of family members to care for the person with dementia because of their own age, health issues, other caring responsibilities or challenges associated with the increasing physical care needs associated with dementia care. This highlights the need for flexible funding in order to ensure that support can be put in place rapidly to meet the needs of the person with dementia as they change and develop. However, few services noted that the indicators were fully met in relation to the individual if they had to move home. The new home was rarely close to the person's previous home and access to their existing day and leisure services was rarely maintained.

## Intervention

The majority of indicators relating to intervention were rated as being fully or partially met by most services. The indicators that were least frequently endorsed as being met related to the provision of certain types of intervention, such as reminiscence, reality orientation, life story books, validation therapy, and the provision of dementia care mapping. Research suggests that approaches such as the use of life story books can improve the wellbeing of people with an intellectual disability and dementia, although study sample sizes are often small (e.g. Crook et al., 2016). Approaches such as life story work can, however, be

challenging to implement (e.g. McKeowan et al., 2013) and this may deter staff from using them. It has also been suggested that, particularly for those in the later stages of dementia, more passive care such as 'simply being with the person' may be more appropriate than active interventions (Service et al., 2017).

### Dementia friendly environment

The features of the environment that are beneficial for the person with dementia include creating a calm, familiar, predictable, stress-free, and safe environment that also provides appropriate stimulation, maximises independence, promotes positive identity, self-esteem and control, and minimises the impact of the dementia and intellectual disability (see BPS DCP and RCP, 2015). This study found that all of the indicators relating to a dementia friendly environment were rated by five services or more as being at least partially met.

### Choices and rights

As with promoting social inclusion, promoting the choice and rights of people with an intellectual disability are also key principles in good quality services (O'Brien & Tyne, 1981). Most services reported that these indicators were fully or partially met, with those that were least likely to be met relating to accessible information. Information about dementia has been developed specifically for people with an intellectual disability (e.g. Down's Syndrome Scotland, n.d.), however, it may be that the reluctance to discuss death with people with an intellectual disability (Murray et al., 2000) leads to such resources not being used by services. A recent review suggested that individually tailored information that is communicated according to the needs and understanding of the individual is most effective (Chinn and Homeyard, 2016).

## Support to family carers

The importance of involving and supporting family carers from the early stages of diagnosis of dementia has been highlighted in order to help them anticipate and cope with the inevitable changes in the functioning and support needs of their family member (Watchman, 2017). Families may also need structured information and training to help them understand the processes that the person with dementia will undergo and to support future planning (Towers, 2015), particularly as some may find considering the future upsetting and be reluctant to plan ahead (Prosser, 1997).

Most of the services felt that the indicators were fully met in respect of the family carers receiving support from the community learning disability team and training sessions being offered to increase awareness of dementia and its management. By contrast, none of the services were either aware of, or felt that there was an assessment of, carer burden in their area. This may be because this aspect of support was thought to be provided by adult mental health services. Similarly, there was little engagement of family carers in the development of services for people with an intellectual disability. This finding may be particularly important as research out with the UK suggests that carers do not always find services to be supportive (Weeks et al., 2008).

## Conclusion

Overall, the results of the study suggest that there is some disparity in the extent to which services for people with an intellectual disability and dementia in Scotland adhere to the “Good Practice Standards.” The areas that were most commonly fully met related to assessment and diagnosis, while the least endorsed items related to areas such as the availability of flexible funding, service development, and monitoring and location of out of area placements. While some of these aspects are likely to be out with the direct control of

practitioners, nurses can influence practice by highlighting to budget holders and service leads any gaps in service provision, as well as making recommendations about service developments and funding priorities based on their experience and the evidence base. Other areas can be more directly addressed by nurses, such as ensuring that all people at risk of developing dementia have health action plans.

The study limitations were that not all services fully completed the checklist, therefore the picture across all of Scotland remains somewhat incomplete. In addition, some information, for example in relation to purchasing out of area services, may only be available at board level rather than to practitioners.

The results suggest the need for a more consistent approach to service provision across Scotland while allowing flexibility to meet the requirements of local areas and resources to respond to the changing needs of individuals, their families, and carers. The continuing development of the roles and remit of integrated joint boards across Scotland may help facilitate this process.

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Table 1. The number of services that identified the extent to which they felt that a range of quality indicators were met within their health board area in relation to working within legal frameworks and guidance, population, care pathways, multi-disciplinary approach, and assessment and diagnosis (checklist adapted and reproduced with permission)

Indicator	Don't Know	Not met	Partially met	Fully met
In relation to the services provided to people with an intellectual disability who have, or are at risk of developing, dementia in the area that you work...				
<b>Working within legal frameworks and guidance</b>				
There are clear health and social care pathways that incorporate assessment of capacity in line with relevant legislation, e.g. the Adults with Incapacity (Scotland) Act 2000	1	1	2	5
Local care pathways ensure compliance with NICE/SCIE guidelines and the proposed dementia strategy	0	1	5	4
All people with intellectual disabilities (PWID) who have, or are at risk of developing, dementia have a person-centred plan within your service	1	3	4	1
Health action plans are offered to all people at risk of developing dementia	4	2	1	2
PWID at risk of developing dementia are given an opportunity to plan their end of life care	0	4	4	1
There is a published local 'Safeguarding Adults Policy' that PWID, clinicians, and carers can access	2	0	0	7
Where PWID have 'out of area' placements purchased for them, the purchasing authority regularly checks that the provider also achieves these standards	8	0	0	1
There is an agreed strategy which addresses relevant intellectual disability and dementia guidance provided by the British Psychological Society	1	2	5	2
<b>Population. There is a regularly updated register/database in which all adults with intellectual disabilities are highlighted, as well as identifying those with Down syndrome</b>				
Care pathway. The care pathway provided for assessment, diagnosis, treatment, and support for people who have, or are at risk of developing, dementia is multi-agency and has been agreed by the relevant Board or its equivalent	0	3	4	3
<b>Multi-disciplinary approach. PWID have easy access to a range of suitably trained professionals and a range of specialist mainstream services, such as neurology</b>				
<b>Assessment and Diagnosis</b>				
Assessments are responded to in good time	0	0	2	8
People are diagnosed according to established diagnostic criteria and there is a written formulation	0	1	2	7

There is an established method of disseminating information regarding diagnosis to PWID and their carers	0	1	4	5
Other illnesses are identified and treated as appropriate when the dementia assessment takes place	0	0	1	9
Peers of PWID and dementia are offered support dealing with the person's condition	0	1	8	1

Table 2. The number of services that identified the extent to which they felt that a range of quality indicators were met within their health board area in relation to person-centred care, care management and review, intervention, dementia friendly environments, dying in place, choices and rights, and support for family carers

Indicator	Don't Know	Not met	Partially met	Fully met
Person-centred care				
Everyone who is at risk developing dementia has:				
A person-centred plan for future needs	1	3	3	2
Dementia care provided with the person at the centre	0	2	4	3
Care provided according to the Adults with Incapacity (Scotland) Act 2000	3	1	3	2
Care which is changed without risk or delay	0	1	8	0
Care which promotes social inclusion	0	1	4	4
Care management and review				
Everyone with an intellectual disability and dementia has:				
A named care manager	2	1	5	1
Multi-disciplinary care plan incorporating the individual's person-centred plan	0	0	7	2
Regular care reviews	0	1	5	3
A health action plan	2	0	4	3
A proactive risk assessment	3	1	3	2
Access to flexible funding to meet needs	3	4	2	0
Outcomes monitored regarding quality of life	1	0	7	1
Staffing levels increased when needed	1	2	6	0
Recognition that people with dementia should not be moved unless absolutely necessary	0	0	5	4

Intervention				
Everyone with an intellectual disability and dementia has staff who deliver:				
Medication in line with appropriate guidelines, e.g. NICE	2	0	3	4
Strategies which maintain mobility and good posture	1	0	5	3
Strategies which maintain adequate oral intake in a safe manner	1	0	4	4
Aid to maintain continence	1	0	4	4
Strategies to aid communication	0	0	5	4
Support to maintain self-care and domestic skills	0	0	5	4
Access to failure free activities, e.g. sensory stimulation	0	1	8	0
Reminiscence, reality orientation, life story books, validation therapy	1	3	4	1
Dementia care mapping	2	4	3	0
Positive Behaviour Support	0	1	4	4
Dementia friendly environments				
The environment of everyone with an intellectual disability and dementia is:				
Identified as 'dementia friendly'	1	3	5	0
Safe, stimulating, and predictable	1	2	6	0
An appropriate colour	1	2	5	1
Appropriately furnished	1	2	6	0
Appropriately adapted to suit their needs	1	2	6	0
Provided with wheelchairs, special beds, and seating when required	0	2	6	1
Provided with appropriate assistive technology	2	2	4	1
Dying in place				
Everyone with an intellectual disability and dementia is provided with the following, allowing them to remain in their own home:				
Good advance planning	0	3	5	1
Additional staff provided as required	2	3	3	1
Environments are adapted	1	2	4	2
Funding able to be changed rapidly according to needs	2	4	2	1
Good end of life care	2	0	6	1
If the person has to move to a new home, the new home...				
Is within close proximity of the old home	3	6	0	0

Is within an intellectual disability service	2	3	3	1
Allows existing day and leisure services to be maintained	2	5	2	0
Is a final move	3	2	3	1
Choices and rights				
Everyone with an intellectual disability and dementia always has:				
A regularly updated person-centred plan	2	0	7	0
A regularly updated 'Health Action Plan'	3	0	4	2
An individualised care plan developed in accordance with the services the person uses	1	0	7	1
Accessible reports about their care	1	4	4	0
Accessible information about dementia	0	2	5	2
Support for their peers with regard to their dementia	0	1	8	0
Their needs appropriately met	0	1	7	1
Support to family carers				
Family carers who support a person with an intellectual disability and dementia always have:				
An offer of a 'Carer's Assessment' in line with Local Authority Guidance	3	0	2	4
Respite care for those with dementia living with the family	4	1	3	1
An offer of accessible information on dementia alongside intellectual disability/Down syndrome	0	2	3	4
Support from the Learning Disabilities Community Team to manage aspects of their loved one's condition	0	0	2	7
An offer of training sessions to increase awareness of dementia and its management in the home	0	0	1	8
Engagement in the development of services for people with an intellectual disability in their area	3	3	3	0
An assessment of carer burden, e.g. Carer Activity Survey-Intellectual Disability (CAS-ID)	3	6	0	0