

Consensus Statement of the International Summit on Intellectual Disability and Dementia on Valuing the Perspectives of Persons with Intellectual Disability

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Abstract

The International Summit on Intellectual Disability and Dementia held in Scotland in 2016 covered a range of issues related to dementia and intellectual disability, including the dearth of personal reflections of persons with intellectual disability affected by dementia. This paper reflects on this deficiency and explores some of the personal perspectives gleaned from the literature, from Summit attendees, and from the experiences of persons with intellectual disability recorded or scribed in advance of the two-day Summit meeting. Omission of the perspectives of persons with intellectual disability in both policy and practice limits understanding of the experience of dementia. It leads to an overreliance on proxy reporting; something considered by the Summit to be a backwards step in person-centred work. The Summit recognised that the perspectives of persons with intellectual disability must be considered whenever interventions and supports are discussed with planning required at an earlier stage for advance directives that guide medical treatment, and for advice or counselling around relationships, the continuity of social networks, and when securing dementia-friendly housing. Systemic recommendations included reinforcing the value of the involvement of persons with intellectual disability in (a) research alongside removing barriers to inclusion posed by institutional/ethics review boards, (b) planning groups that establish services and supports for dementia, and (c) peer support efforts that help adults with intellectual disability who are affected by dementia (either directly or indirectly). Practice recommendations included (a) valuing personal perspectives in decision-making, (b) enabling peer-to-peer support models, (c) supporting choice in community dwelling arrangements, and (d) wider availability of materials for persons with intellectual disability that would promote understanding of dementia.

Introduction

While the general dementia-related literature contains work on the perspectives of adults who are diagnosed with dementia, with reflections on experiences and on what the progression of dementia may mean (Botek, 2016; Desai et al., 2016), most of the literature on dementia-related experiences in the intellectual disability field is drawn from the perspectives of proxies, such as family or staff carers (Bowers, Webber, & Bigby, 2009; Carling-Jenkins, Bigby, & Iacono, 2014; Hammond & Benedetti, 1999; Lin et al., 2014). Limited subjective experiential information is available from the perspectives of adults with intellectual disability (Blackman & Thompson, 2014; Bowey & McGlaughlin, 2005; Lloyd, Kalsy & Gatherer, 2007;

Watchman, 2014) and almost none is available drawn from research on personal perspectives. On October 13-14, 2016, a group of researchers, workers, and family members met at the International Summit on Intellectual Disability and Dementia held in Glasgow, Scotland¹ and discussed a range of issues related to dementia and intellectual disability, including the dearth of personal reflections of persons with intellectual disability affected by dementia. Summit participants noted the lack of such subjective experiential information, whether through having a diagnosis, or having a friend, partner, or family member with an intellectual disability and dementia. The Summit recognised that there are differences in such perceived experiences between persons with intellectual disability in contrast to adults with dementia in general. One such difference was understanding how each may communicate their feelings and thoughts about having dementia given the nature of intellectual disability. Another, was that the existing evidence base that includes people with intellectual disability has been drawn from adults in early stages of dementia and has focused primarily on adults with Down syndrome, which may bias interpretations of findings noted in the literature. Yet another was that the dearth of personal perspectives' information about dementia may adversely impact maintaining relationships and friendships. Lastly, was the question of how environments for living and day care provision are perceived and coped with as dementia progresses. The Summit recommended that these differences (or deficiencies) be examined and rectified. This consensus statement reflects on such deficiencies. It explores some the personal perspectives gleaned from the literature and from the experiences of persons with intellectual disability scribed in advance and shared at the two-day event through pre-prepared vignettes (comments from which are included in Table 1).

The inherent value to having and understanding the subjective perspectives of any group that is being aided or supported is that it enables planners and public policy makers to more aptly define needs and more appropriately allocate resources and tailor services. It

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enables social care and support workers to gain a better understanding of how their services and actions affect the people they work with and gives a more reliable perspective on the impact of their work. In the case of researchers, it enables greater accuracy in answering questions asked and studied, and it provides a basis for the evaluation of the impact of services and a context for understanding the nuances of quality of life. In this case, the Summit noted the dearth of first-person information that might inform all these functions and outcomes, and proposed a review of some of the salient issues. What follows is a summary of the main issues debated and the recommendations that emanated from those discussions.

Insert Table 1 about here

Reflections on critical areas

Finding the voice and identifying individuals. Rather than referring to individuals with an intellectual disability and dementia as a ‘hard to reach’ group, the Summit instead proposed that the term ‘under-researched’ is more appropriate. Here, the onus is on the researcher and practitioner to facilitate inclusion rather than the standpoint that, as a group already marginalised by others’ perception of their intellectual disability, this is not achievable. A recurring theme in the literature is of not seeking the perspective of the person with intellectual disability with a diagnosis of dementia, not knowing how to do so, and not recognising the potential for naturally occurring activities that may facilitate conversations. Hence, the need identified by the Summit was for greater awareness of tools and resources that are available, and of data collection methods that might be appropriate for gleaning this type of information. Further, the Summit recognised the need for greater awareness among researchers as to valuing and finding informants among people with intellectual disability who may be able to relate their personal experiences.

Whilst this is not unique to people with intellectual disability (other marginalised groups are often excluded from studies) it presents a challenge to researchers in a field where historically inclusion of people with intellectual disability was not the norm. Presently, the person-centred movement continues to emerge and grow, as does the self-advocacy movement seen in both dementia (DAI, 2017; Swaffer, 2013) and intellectual disability populations (The Arc, 2016). Recently, this has extended to consideration of dementia as a disability under the Convention for the Rights of Persons with Disabilities (Shakespeare, Zeiger & Mittler, 2017) and global action plans (WHO, 2017), although not with unanimous support largely due to concerns over further labelling (Whitman, 2015). Yet, whichever approach is favoured, such generic

dementia self-advocacy has not yet advanced to include people who have both an intellectual disability and dementia. Given this, finding persons who can relate their experiences may be limited when seeking informants from among self-advocates with dementia.

Expanding impact via self-advocacy. The shift in culture in intellectual disability services over the past decades has resulted in a rise in self-advocacy by individuals and disability organisations. More recently, there has been a rise in formal self-advocacy among people with dementia who do not have an intellectual disability as shown in Table 2. This level of self-advocacy is reflected by increased inclusion of adults with dementia on planning groups, on boards of dementia organisations, and as sought-after representatives at public policy forums (DAI, 2017). This extent of self-advocacy is not yet expressed by the population of people with intellectual disability affected by dementia or their families, nor has it been evident in decision-making levels within advocacy or national third sector or non-government organisations (Watchman et al., 2017). The Summit recognised this deficit and supports the greater inclusion of the perspectives of adults with intellectual disability on local, regional and national planning and policy advisory boards, groups, and panels. People with an intellectual disability and their families have a well-established history of advocacy and consequently they should and could be an excellent resource and partner within the self-advocacy movement for people with dementia.

Insert Table 2 about here

Speaking to be heard – existing evidence. The evidence base that is available in relation to the perspective of people with intellectual disability who also have dementia is largely representative of people in the early stage who have the verbal capacity to talk about their experience (Lloyd et al., 2006; Lynggard & Alexander, 2004). Additionally, it is generally drawn from people with Down syndrome, rather than other types of intellectual disability (Watchman, 2016). Furthermore, it is recognised that the opinions and preferences of the person with intellectual disability may differ from that of proxies, such as family members, who may speak for the person. Such second person commentary is valuable but is also compromised by the bias or perception of proxies. See for example a series of comments by persons with intellectual disability and other persons involved in their lives in Table 2.

Expressive language factors. The Summit concurred that language processes are linked to primary and secondary language facility – which has particular resonance in nations or sub-national geographic areas with language diversity. Research findings in dementia show

that the facility of a second language is lost prior to the loss of facility in a first language (McMurtray, Saito & Nakamoto, 2009). Attempts to communicate with adults who are bi-lingual and to gain their perspectives should recognize regression (or reverting) to the first language and ensure that queries and discussions to gain perspectives are carried in the language in which the adult maintains proficiency. Similarly, attention should be paid to the use of Makaton (or similar) sign language when the person was younger. Makaton is often taught to younger children in advance of verbal communication developing and it is not known how far this is retained into adulthood if not used, or if there is long-term recall with cognitive changes. The Summit contends that in interview or other subjective data gathering consideration be given to language skills, both verbal and non-verbal, and the challenges some adults with intellectual disability affected by dementia may have in expressing themselves either due to their role in a family, or due to the neuropathology. Examples of tools to facilitate non-verbal interactions include Talking Mats (Murphy & McKay, 2015) and multi-sensory storytelling (Matos et al., 2015; Young, 2016)

Impact of relationships and friendships. In the UK, the Joseph Rowntree Foundation identified priority issues on aging from the perspective of persons with an intellectual disability (Wade, 2012) as including: having an opportunity to speak for oneself, companionship, having a home and feeling secure in it, being listened to, and having choices. This should not be different for people who also have dementia; indeed, some of these issues will increase in prominence rather than change. Whilst family members may know the person with an intellectual disability best, this does not always mean that there is agreement among extended family members about what is a ‘best interest’ decision, and it is often in this dialogue that the voice of the person with dementia becomes lost. Professionals may be fleetingly in and out of lives and often rely on what they see or are told by others, which again may not reflect the wishes or support needs of individuals. In other instances, support staff may be the primary carer over extended time periods in the absence or lack of a geographically close family. This can lead to tensions as to who is the primary decision-maker: the parent or carer, the person with intellectual disability, or another person who may have decision-making authority, depending on the extant legal framework. The Summit contends that emphasis should be given to ensuring that any negotiations over decisions include the perspective of the person with an intellectual disability with preferences ideally being known in advance of dementia as part of routine care planning and conversation.

Enabling help by peers. Another consideration is when seeking advice or counsel about dementia or life choices. Peer support models prevalent in the general population also apply to adults with intellectual disability (Mental Health Foundation, 2017). Peer support efforts are social, emotional or practical help that people affected by dementia can give to one another. Such models can facilitate understanding and provide support when the effects of dementia are discussed within the context of what adults with intellectual disability experience. Peer support efforts can also apply to aiding adults with intellectual disability who have become the carers for aging parents, spouses, and friends. The Summit contends that support provided by services ought to be extended to the development and maintenance of peer-to-peer supports among adults when they, and their families, are affected by dementia.

Ascribed carer roles. Often adults with intellectual disability may also gain the status of carer, when a parent, older sibling, or other person in their life is diagnosed with dementia (Blackman & Thompson, 2014) and they become the primary carer. This can pose some challenges as navigating services to help someone who is a primary carer can be problematic, but can be made even more difficult if the services don't recognise that person's role or efforts simply because they are marginalised because of intellectual disability. Forward looking providers can be enablers in such situations, but such awareness is not always the case. Heller (2017) has provided us with anecdotal information about a woman with Down syndrome in her 40s who was on the advisory committee of a university centre for disabilities and aging in the USA. She was an articulate self-advocate who inherited the role of carer for her aging mother who was in the early stages of dementia. She related the problems she experienced in attempting to access services for her mother, as many providers were patronising and refused to accept her role as a carer. Such difficulties will become more prevalent as more adults with intellectual disability are placed into primary carer roles in the absence of any other involved family members. The Summit noted that it is important for services to recognise the role of carer that be undertaken in some situations and provide specialised support to enable these roles to be undertaken.

Appropriate environments

A further area where we know little of the preferences, perspectives, and experiences of people with intellectual disability and dementia is in housing, particularly after a diagnosis of a dementia. Depending on the country, public policy mandates, and services availability, people with dementia who do not have an intellectual disability typically have access to: specialised dementia care settings, home care, and access to retirement homes, as well as counselling for

financial management or to help with downsizing their property – access to which is for the most part contingent upon their financial resources and informal support systems. In many countries, specialised dementia-related in-home support and carer assistance to adults with dementia are the purview of the private sector and are provided subject to their financial resources or of their families. In contrast, whilst a range of such options are also in place for people with an intellectual disability, they are generally an extension of publicly supported services to dependent populations and are limited by availability. In many instances, the specialised dementia-related supports and services are a transitional extension of services already being provided, especially if the adult is already known to intellectual disability services. Rarely, are the higher-level services, generally self-funded, available to adults with intellectual disability. However, even when such options are available, it is unclear how much choice is given to the individual, and the assignment is more likely made based upon on local availability and cost.

Housing options include: shared group living arrangements that may offer more of an opportunity to remain at the setting due to existing staff supports; living with family members which may also offer access to support depending on the service previously used; specifically developed housing for people ageing with both an intellectual disability and dementia; and in some countries aged care services (typically residential care homes). The latter often pose dilemmas particularly for individuals with Down syndrome as they are typically considerably younger than other residents and simultaneously staff often feel, whether accurately or not, that they are ill-equipped to support someone with an intellectual disability (Cleary & Doody, 2016). The dearth of research on housing preferences and perceived satisfactions among adults with intellectual disability and dementia limits knowing more fully how well these housing options meet needs and contribute to perceived quality of life. Further when residential or care homes are used, there is increasing concern that people with intellectual disability and dementia are becoming ‘lost’ in such services (see Thompson, Ryrie & Wright, 2004). How, this ‘integrated’ housing is perceived by the residents with an intellectual disability is a void in the research literature. The Summit contends that both researchers and practitioners should actively seek to hear the voice of such residents and provide a research basis for policy determinations.

Institutionalisation has not just take place in large out-of-area facilities but it has occurred in any place where people are isolated, segregated, and do not have control over their day-to-day lives (People First, 2016). Given most countries’ historical policies of institutionalising children and adults with intellectual disability (Braddock et al., 1991; Johnson

& Traustadottir, 2005), the oldest-old among adults with intellectual disability are more likely to have a history of institutionalisation – which has led to self-advocates strongly voicing their opposition to being re-institutionalised due to aging-related issues, such as diminished abilities due to dementia. In 2004, self-advocates with intellectual disability participating in a Canadian conference agreed with this statement, “I’m worried that people will make decisions for me...and will place me in an institution” (L’Institute Roehrer Institute, 2004, pg. 24). For the most part, younger adults with intellectual disability in many, although not all, countries are less likely to have experienced institutional care, and entering an institutional-type environment in later age may be traumatic and against their wishes. The Summit, in accord with policy statements of a range of national advocacy groups, supports, as a universal principle and human right, the preclusion of any form of inappropriate non-health-related institutionalisation arising because of dementia (see for example, NTG, 2012; WHO, 2012).

Aging-in-place is not necessarily the appropriate option for everyone; some individuals may need or want to move to alternative settings. This may be for a variety of reasons, such as the need for barrier free design, desire for a new home, need for staff supports with different skill sets or the simultaneous move of a long-term friend or partner). In such instances, planning for transition with the person becomes more important than supporting them to remain where they are, either after a diagnosis, or as dementia advances. Involving the person in the planning and decision-making is critical and understanding their perspectives on the move and possible alternatives for a new home should ease the transition. With progression of dementia, a transition, such as a change in accommodation, requires a different process to transitions generally. As an example, if the visits and overnight stays in advance may be anticipated to be stressful, procedurally support staff should visit the person in their current accommodation prior to a move, or family stay with individuals when they first move. Alternatively, the décor and physical contents of a person’s room might be ‘moved’ before they do so that the new environment has a familiar appearance. In such situations, conferring with the person and appreciating his or her fears, wants, and other perspectives prior to organising a move would reflect a reciprocal planning approach. The Summit, in accord with sound practice principles, supports the use of familiar designs for enabling transitions to alternative living settings, with consideration given to dementia- and aged eye-design principles of colour contrast and lighting to aid transition.

Strategies to including personal perspectives

The Summit proposes that every effort should be made to understand the wishes and preferences of the person with intellectual disability from as early as possible, albeit with the understanding that wishes may change later as dementia progresses. The concerns and emotional needs of adults with intellectual disability upon recognising that they have dementia warrant careful exploration. Sometimes this may be difficult as many adults with intellectual disability lack awareness of their diagnosis of dementia and what this may mean to their lives on a day-to-day basis. Materials that can help convey what dementia means are limited, and when available are mostly in English and may not always reflect linguistic or cultural differences. The Summit supports the development and dissemination in various media of materials that would help promote understanding of dementia and its nuances, as well as what might be of expectations for change in the future. This includes the translation of existing resources to spread their reach and promote wider accessibility. Examples of such resources include Dodd, Turk, & Christmas (2005), Watchman, (2007), and Watchman, Quinn and Tuffrey-Wijne (2015).

Reflection and reminiscence. The Summit recognised that various techniques can help in enabling people with intellectual disability to reflect upon their lives and that these techniques may be valuable in eliciting perspectives. One such technique is life story work (whether in photographic form, video, or a memory box) which should be viewed as an ongoing process through life, not as a finished product. The benefit of such activities may only be apparent later should the person be deemed to have incapacity and compromised decision-making abilities, although there is a need to be aware that recall of unhappy or disturbing events such as past trauma or bereavement can cause distress (Lloyd, 2015). The Summit supports the use of techniques and aids that can help with reflection and reminiscence to compensate for losses in memory because of dementia, although it recognises that research is needed to develop the evidence base of such dementia-related supports among people with intellectual disability.

Advance directives and similar instruments. As we recognise a lack of understanding of how dementia among people with intellectual disability is experienced in the early stages, so it is to be expected that this does not improve as dementia advances – and only becomes more challenging. The Summit recognised that there exist a range of issues stemming from the poor availability of information about later life medical care when dementia is present and lack of planning for the future as dementia progresses. An important aspect is ensuring that aged persons with intellectual disability have a planning instrument in place that defines

their preferences for medical care in general (e.g., NDSS, 2012; Ross & Olsen, 2014) and as dementia progresses (Evenhuis, 1999; Prasher, 2005). While the legal framework for later-life medical care planning for this will vary among nations, adults with intellectual disability should be included in relevant conversations about their care choices using whatever approaches and communication methods that are appropriate for the individual, recognizing that these may not always be verbal. This planning includes establishing living wills, advance directives, and durable powers of attorney or healthcare proxies or agents. In the UK, power of attorney can enable a proxy to express the adult's wishes and make health care decisions for him or her if the person becomes incapacitated. There is a need for greater awareness of use of advance directives and other instruments, which govern care and treatment in circumstances when dementia is suspected or present. The supportive role of a health passport and community learning disability nurse in supporting the wishes of the person with intellectual disability and dementias around health interventions is crucial, in addition to any legal framework such as powers of attorney. The Summit recommends that such arrangements be undertaken and, to the fullest basis possible, be based upon the wishes and perspectives of the person with intellectual disability. Ideally, such arrangements should be undertaken early in adulthood and not after health needs change and cognition deteriorates.

Maintaining relationships and friendships. The Summit further recognized that there exist a range of issues stemming from the lack of focus on maintaining relationships and friendships when dementia is present. The consequence here is that little is known about how dementia is experienced from the perspective of a peer or partner with an intellectual disability. The Summit proposed that this is consistent with issues facing people with dementia without intellectual disability but is compounded by the progression of dementia creating complexity of care and support needs. Companionship for many increasingly comes from people who are paid to provide support and proactive support is required to maintain relationships. This can involve a change in the approach to support that may have previously been provided by staff or family. Whereas the social model of disability has typically been advocated, we will see a shift towards increased medical needs as a dementia progresses – not just dementia-related, but the same age-related health problems as other older adults. The danger here is moving too far away from the principles behind the social model of disability at a time when the importance of relationships and the need to 'know the person' increases, making use of life story work and recognising the importance of previous experiences. Provision of appropriate health/medical interventions as dementia progresses, a medical approach, should not be to the neglect of the social model and all that has been achieved, but should recognise the complexity of needs with

a changing emphasis from promotion of independent living towards increased reliance on others for care. People with an intellectual disability have expressed worries around losing friends and family as they grow older and they have noted the importance of having a circle of friends (L’Institute Roeher Institute, 2004). The Summit contends that as with any social capacity building efforts, lifelong emphasis on assisting people to develop rich and engaged support networks can help to address concerns about deficiencies in social relationships.

Other factors. The Summit also proposed that several other areas warrant consideration, including how language is used. Inappropriate language usage can lead to further stigmatisation. It is preferable to use ‘people first’ language, such as ‘diagnosed with’ or ‘affected by dementia’ (Alzheimer’s Australia, n.d.). The Summit, consistent with many others (e.g., Shakespeare, Zeilig & Mittler, 2017), contends that use of respectful language will go far to minimize further stigmatisation of people with intellectual disability affected by dementia. There are also barriers posed by research ethics (or institutional) board reviews – in particular, where ethics boards may not recognize the value – and ability – of adults with intellectual disability to be informants in studies or by imposing over-protective conditions in the conduct of research which impede the involvement of adults with intellectual disability in studies. With respect to research protocols, consideration should be given to the appropriateness of measures and tools for persons with intellectual disability who are experiencing declining cognition and assuring that bias of floor effects does not cancel the value of the measures. Further, studies concerning dementia in general should include in their research populations a sample of adults with intellectual disability, acknowledging that some measurement tools for people with dementia are not appropriate, or may need to be adapted (Wilkinson et al., 2002). Similarly, such studies need to make research outputs accessible to people with intellectual disability. Limited communications skills should not be a barrier to participation and the onus is on researchers to address this. The extensive range of ‘deficit-focused’ tools for people with dementia generally does not offer a strong starting point for research, for example when seeking the impact of positive interventions. The Summit contends that in addition the involvement of persons with intellectual disability affected by dementia in research studies as informants providing evaluation of supports and services, they should also be included as members on dementia research planning teams, and as co-researchers (see Gove et al., 2017; Watchman et al., 2017b). Lastly, given their particular life experiences, adults with early stage dementia or who have been impacted by family members or friends with dementia, should be drawn upon to serve on advocacy and planning bodies that create national plans or advise on public policy and services development (See Watchman et al., 2017a)

Summary

The Summit recognised the imperative to include the views and perspectives of persons with intellectual disability with respect to dementia, and recognised the problems posed by limitations placed on services for dementia, involvement in research, evaluation of services, and membership on dementia advocacy and planning bodies, as well as restrictions in medical settings, and ill-prepared care workers. Summit members have produced a series of statements to guide actions with respect to the perspective of adults with intellectual disability affected by dementia. Overall, adults with intellectual disability should be included in conversations on their life and care choices - using whatever approaches and communication methods are appropriate for the individual, recognising that this may not always be verbal. The Summit also notes that a primary purpose of engaging the perspectives of adults with intellectual disability is linked to avoiding institutional-like settings as dementia progresses and providing care environments that optimise autonomy, respect the individual's wishes, and provide for quality of life. With this in mind, the Summit offers the following set of recommendations in the areas of policy, practice and research.

Recommendations

Recommendations for policy and practice

- Include adults with intellectual disability with and without dementia in planning groups
- Commit to equality of access to supports and services offered within the community
- Expand peers support mechanisms when supporting people with intellectual disability.
- Undertake consultation for future dementia plans and strategies and reviews of current iterations that are inclusive of people with an intellectual disability affected by dementia.
- Forge partnerships between existing self-advocacy groups for people with an intellectual disability and dementia advocacy organizations, recognizing the significant experience of the self-advocacy movement.

Recommendations for research

- Develop and test a quality of life tool or measure for people with intellectual disability and dementia that includes self-report, in addition to carer perspective (that may be

drawn and adapted from available measures and tools already existing in both the general dementia and intellectual disability fields).

- Establish an international review group to examine the barriers to inclusion in research studies posed by research and ethics review boards that do not recognise the value offered by the presence and perspectives of participants with intellectual disability.
- Conduct research to better understand and address issues experienced by people with intellectual disability who find themselves providing support to someone else at different stages of dementia, typically either a parent in a family home context or a peer in group home setting.

References

- Alzheimer's Australia. (n.d.). *Dementia language guidelines*. Accessed from: <https://www.fightdementia.org.au/files/NATIONAL/documents/language-guidelines-full.pdf>
- Alzheimer Europe. (2016). *Personal experiences of living with dementia*. Accessed from: <http://www.alzheimer-europe.org/Living-with-dementia/Personal-experiences-of-living-with-dementia>
- Alzheimer Europe. (2016). *European Working Group of People with Dementia – EWGPWD*. Accessed from: <http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia>
- Alzheimer's Society of Canada. (2011). *Guidelines for care: Person-centred care of people with dementia living in care homes*. Accessed from: http://www.alzheimer.ca/~media/Files/national/Culture-change/culture_change_framework_e.pdf
- Aminzadeh, F., Byszewski, A., Molnar, F.J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging & Mental Health*, 11(3), no page numbers. <http://dx.doi.org/10.1080/13607860600963695>
- Blackman, N., & Thompson, D. (2014). The perspective of people with intellectual disabilities. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 114-125). London/Philadelphia: Jessica Kingsley Publishers.
- Botek, A-M. (2016). *Another world: People with Alzheimer's share their perspectives*. Alzheimer's & Dementia: AgingCare.com. Accessed from <https://www.agingcare.com/articles/alzheimers-patients-share-their-experiences-153702.htm>

- Bowey, L., & McGlaughlin, A. (2005). Adults with a learning disability living with elderly carers talk about planning for the future: Aspirations and concerns. *British Journal of Social Work*, 35(8), 1377-1392. DOI: <https://doi.org/10.1093/bjsw/bch241>
- Bowers, B., Webber, R., & Bigby, C. (2009). Aging and health related changes of people with intellectual disabilities living in group homes in Australia. *Journal of Policy and Practice in Intellectual Disabilities*, 6(2), 98.
- Braddock, D., Fujiura, G., Hemp, R., Mitchell, D., & Bachelder, L. (1991). Current and future trends in state-operated mental retardation institutions in the United States. *American Journal of Mental Retardation*, 95(4), 451-462.
- Carling-Jenkins, R., Bigby, C., & Iacono, T. (2014). Family experiences of supporting a person with Down syndrome and dementia in Australia. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 145-160). London/Philadelphia: Jessica Kingsley Publishers.
- Cleary, J. & Doody, O. (2016). Nurses' experience of caring for people with intellectual disability and dementia. *Journal of Clinical Nursing*, 26, 620–631, doi: 10.1111/jocn.13431
- Davis, D.R. (1999). A parent's perspective. In M.P. Janicki & A.J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities* (pp. 42-50). Philadelphia: Brunner-Mazel.
- Desai, A.K, Galliano Desai, F., McFadden, S.H., & Grossberg, G.T. (2016). Experiences and Perspectives of Persons with Dementia (pp. 151-166). In M. Boltz & J.E. Galvin (Eds.), *Dementia care: An evidence-based approach*. Basel, Switzerland: Springer.
- Dementia Engagement and Empowerment Group. (n.d.). *What is DEEP?* Accessed from: <http://dementiavoices.org.uk/>
- Dementia Advocacy and Support Network International. (n.d.). *Main page*. Accessed from: <http://www.dasninternational.org/>
- Dementia Alliance International. (2015). About *DAI*. Accessed from: <http://www.dementiaallianceinternational.org/>
- Dementia Alliance International. (2017). Our *core beliefs*. Accessed from: <https://www.dementiaallianceinternational.org/about-dai/core-beliefs/>
- Dodd, K., Turk, V., & Christmas, M. (2005). *About dementia for people with learning disabilities*. Birmingham, UK: BILD. Accessed from: <http://www.bild.org.uk/our-services/books/health-and-wellbeing/about-dementia/>
- Down's Syndrome Scotland. (2016). For *Parents of Adults – Living with dementia*. Edinburgh, Scotland: Author. Accessed from: <http://www.dsscotland.org.uk/resources/publications/for-parents-of-adults/>
- Evenhuis, H. (1999). Associated medical aspects. In M. P. Janicki and A.J. Dalton (eds.), *Dementia, aging and intellectual disabilities* (pp. 103-118). Philadelphia: Brunner/Mazel
- Gove, D., Diaz-Ponce, A., Georges, H., Moniz-Cook, E., Mountain, G., Chattat, R., Øksnebjerg, L., & The European Working Group of People with Dementia. (2017). Alzheimer

Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging and Mental Health*, 0(0), 000-000.

Hammond, B., & Benedetti, P. (1999). Perspectives of a care provider. In M.P. Janicki & A.J. Dalton (Eds.), *Dementia, Aging, and Intellectual Disabilities* (pp. 32-41). Philadelphia: Brunner-Mazel.

Johnson, K. & Traustadottir, R., (Eds.) (2005). *Deinstitutionalization and people with intellectual disabilities: In and out of institutions*. London, UK: Jessica Kingsley.

Lin LP, Hsu SW, Hsia YC, Wu CL, Chu C, & Lin JD. (2014). Association of early-onset dementia with activities of daily living (ADL) in middle-aged adults with intellectual disabilities: the caregiver's perspective. *Research in Developmental Disabilities*, 35(3), 626-631. doi: 10.1016/j.ridd.2013.12.015.

Lloyd, J. (2015). The role of objects in supporting older adults with dementia to tell stories about their lives. *Journal of Applied Arts and Health*, 6(2), 171-186.

Lloyd, V., Gatherer, A. & Kalsy, S. (2006). Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research*, 16(10), 1386-1404.

Lloyd, V., Kalsy, S., & Gatherer, A. (2007). The subjective experience of individuals with Down syndrome living with dementia. *Dementia*, 6(1), 63-88.

L'Institute Roehere. (2004). Coming of age: Securing positive futures for seniors with intellectual disabilities. outcomes of the coming of age dialogue. Toronto, Ontario: Author. Accessed from: <http://www.winnserv.ca/Winnserv-Aging.html>.

Lynggard, H. & Alexander, N. (2004). Why are my friends changing?' Explaining dementia to people with learning disabilities. *British Journal of Learning Disabilities*, 32(1), 30-34.

Matos, A., Rocha, T., Cabral, L., & Bessa, M. (2015). Multi-sensory storytelling to support learning for people with intellectual disability: an exploratory didactic study. *Procedia Computer Science*, 67, 12-18. doi.org/10.1016/j.procs.2015.09.244

Mental Health Foundation. (2017). Peer support. Accessed from: <https://www.mentalhealth.org.uk/a-to-z/p/peer-support>

McMurtray, A., Saito, E., & Nakamoto, B. (2009). Language preference and development of dementia among bilingual individuals. *Hawaiian Medical Journal*, 68(9), 223-226.

Murphy, J & MacKay, M. (2015) *Will anyone listen to us? What matters to young people with complex and exceptional health needs and their families during health transitions: Final Report*. Edinburgh: NHS Health Scotland.

NDSS. (2012). *Health care guidelines (Adult)*. Accessed from <http://www.ndss.org/Resources/Health-Care/Health-Care-Guidelines/>

Nolan, M.R., Brown, J., Davies, S., Nolan, J., & Keady, J. (2006). *The senses framework: improving care for older people through a relationship-centred approach*. Getting Research into Practice (GRiP) Report No 2. Project Report. Sheffield, UK: University of Sheffield. Accessed from: http://shura.shu.ac.uk/280/1/PDF_Senses_Framework_Report.pdf

People First Canada. (2016). Institution watch. Accessed from: <http://www.peoplefirstofcanada.ca/wp-content/uploads/2016/04/Institution-Watch-Newsletter-Spring-2016.pdf>

Prasher, V.P. (2005). *Alzheimer's disease and dementia in Down syndrome in intellectual disabilities*. Oxford: Radcliffe.

Self-advocacy.net *Links to self-advocacy groups*. Accessed from: <http://www.selfadvocacy.net/groups-by-country/>

Ross, W.T. & Olsen, M. (2014). Care of the adult patient with Down Syndrome. *Southern Medical Journal*, 107(11), 715-721,

Shakespeare, T., Zeilig, H. & Mittler, P. (2017). Rights in mind: Thinking differently about dementia and disability. *Dementia* 0(0), 1-14. DOI: 10.1177/1471301217701506.

Swaffer, K. (2013). Advocacy as an intervention for dementia. Accessed from: <https://kateswaffer.com/2013/06/20/advocacy-as-an-intervention-for-dementia/>

The Arc. (2016). *Self-advocacy position*. Accessed from: <http://www.thearc.org/who-we-are/position-statements/rights/self-advocacy>.

Thompson, D. J., Ryrie, I., & Wright, S. (2004). People with intellectual disabilities living in generic residential services for older people in the UK. *Journal of applied research in intellectual disabilities*, 17(2), 101-108.

Ward, C. (2012). Perspectives on ageing with a learning disability. York, UK: Joseph Rowntree Foundation. Accessed from: <https://www.jrf.org.uk/report/perspectives-ageing-learning-disability>.

Watchman, K., Quinn, S. & Tuffrey-Wijne, I. (2015). *Jenny's Diary: supporting conversations about dementia with people who have a learning (intellectual) disability*. Accessed from: <http://www.learningdisabilityanddementia.org/jennys-diary.html>

Watchman, K. (2014). Towards understanding individual experiences of people aging with an intellectual disability and dementia. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 126-144). London/Philadelphia: Jessica Kingsley Publishers.

Watchman, K. (2016). Investigating the lived experience of people with Down syndrome and dementia: overcoming methodological and ethical challenges to inform policy and practice. *Journal of Policy and Practice in Intellectual Disability*, 13(2), 190-198.

Watchman, K., Janicki, M.P., Splaine, M., Larsen, F.K., Lucchino, R., & Gomiero, T. (2017a) International Summit Consensus Statement: Intellectual Disability Inclusion in National Dementia Plans. *American Journal of Alzheimer's Disease and Other Dementias*. DOI: 10.1177/1533317517704082

Watchman, K. (2017b) Helping people with learning disabilities to access non-drug treatments for dementia symptoms [Online]. Accessed from: https://www.alzheimers.org.uk/info/20053/research_projects/817/helping_people_with_learning_disabilities_to_access_non-drug_treatments_for_dementia_symptoms

Webber, R., Bowers, B. & Bigby, C. (2014) Residential aged care for people with intellectual disability: a matter of perspective. *Australian Journal on Ageing*, [online]
<http://onlinelibrary.wiley.com/doi/10.1111/ajag.12086/full>

Whitman, L. (Ed.) (2015). *People with dementia speak out*. London: Jessica Kingsley Publishers.

Wilkinson, H. & Janicki, M.P., & Edinburgh Working Group on Dementia Care Practices (EWGDCP). (2002). The Edinburgh Principles with accompanying guidelines and recommendations. *Journal of Intellectual Disability Research*, 46(3), 279-284.

World Health Organization. (2012). *Dementia: a public health priority*. Geneva, Switzerland.

World Health Organization (WHO). (2017). Draft global action plan on the public health response to dementia. Accessed from:
http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/

Young, H. (2016) Overcoming barriers to grief: supporting bereaved people with profound intellectual and multiple disabilities. *International Journal of Developmental Disabilities*. 0 (0), 1-7 <http://dx.doi.org/10.1080/20473869.2016.1158511>

Table 1: Comments and Perspectives of Persons with Intellectual Disability and Others

Issues	Speaker	Comment
Speaking to be heard – existing evidence	Sister of Lewis, a 49-year-old man with Down syndrome diagnosed with dementia)	<i>“He knew the tablets were making him worse, he told us in no uncertain terms and of course he was right, we should have listened sooner.”</i>
	Elias, father of a man with Down syndrome and diagnosed with dementia	<i>“I feel we could have told him more in the early stages about why he was struggling to do some things like get dressed and cook meals. We also missed opportunities as a family to talk about end of life care and funeral arrangements, this definitely could have come up naturally when we were watching television, but to be honest we shied away from it.”</i>
Impact of relationships and friendships	Sara, aged 58, a woman with Down syndrome and dementia	<i>“I wanted to go to the day centre. My friends were there. But I didn’t like the noise. I got lost. They said I had to stop.”</i>
	Lucas, a friend of woman with intellectual disability and dementia	<i>“I didn’t understand why she didn’t come anymore. I missed her. Then they said she died. I didn’t get to see her first. I would have got the bus if I knew.”</i>
	Steven, a friend and housemate of woman with intellectual disability and dementia	<i>“I know about dementia. I’ve seen it before. I wish I had known she had that. I feel quite bad about it.”</i>
Appropriate environments	June, a friend and housemate of woman with Down syndrome and dementia	<i>“I knew she wanted to live here, I helped. She moved somewhere else, no one asked us what we thought.”</i>
	Sofia, the sister of a woman with Down syndrome diagnosed with dementia living in residential care home for older people	<i>“There was no other bed for her when I went into hospital, I didn’t know what to do.”</i>

Table 2: Self- and General Advocacy Organizations for People Affected by Dementia

Organization or Group	Function	Source for contact
Dementia Engagement and Empowerment Project (DEEP, 2016),	Supported groups of people with dementia in the UK strive to support the involvement and inclusion of people with dementia by creating a series of guides for individuals and groups.	Source: http://dementiavoices.org.uk/
Dementia Advocacy and Support Network International (DASNI, 2016).	An internet based support network designed to promote respect and dignity for individuals with dementia, provide useful information and resources and advocate for people with dementia	Source: http://www.dasninternational.org/
Dementia Alliance International (2017)	Established with the aim of supporting, educating and representing people with dementia.	Source: http://www.dementiaallianceinternational.org/
Alzheimer Europe	Pan-European organization with over thirty personal stories of people with dementia and carers on their website, however, none have an intellectual disability and only one is representative of a 'marginalised' group	Source: http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia
Scottish Dementia Working Group	National campaigning group led by people with dementia. Currently, no members with intellectual disability	Source: http://www.sdwg.org.uk/
European Working Group of People with Dementia.	Launched by Alzheimer Europe in 2012 and composed entirely of people with dementia, although none with an intellectual disability	Source: http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia