Herron, D., **Priest, H**., & Read, S. (2015). Working alongside older people with a learning disability: informing and shaping research design. *British Journal of Learning Disabilities, 43*, 261–269. Doi:10.1111/bld.12147

Accessible summary

* This paper is about working with people with learning disabilities to develop a research (or ‘finding out’) study. We worked with people from Reach, a group-advocacy project, which is part of Asist in Staffordshire, to write clear and simple information sheets and consent forms to help people with learning disabilities and dementia to participate in a research study.
* We also worked with members of Reach to create appropriate, clear and simple interview questions to ask people with learning disabilities and dementia about their experiences
* Working alongside people with learning disabilities helps to ensure the work is fit for purpose.

There has been an increase in inclusive research in the learning disability field; however, this has not been reflected within learning disability and dementia research, where little is known from the perspective of people with learning disabilities. This paper will define inclusive research, explore reasons for the dearth of inclusive dementia research, and identify the challenges of conducting dementia research involving people with learning disabilities. Examples of working with people with learning disabilities to develop elements of a PhD research study will be detailed and discussed. These experiences aided the creation of accessible material about dementia for a research study. Subsequently, this helped to overcome challenges of communication within the research study and helped to facilitate the participation of people with learning disabilities and dementia. Sharing these ideas about how we worked together will help others who are seeking to engage and achieve more inclusive research practices with marginalised populations.

*Keywords: Learning disabilities, dementia, research design, participation, collaboration, advocacy*

**Introduction**

Historically, people with learning disabilities have not always been included in research related to them, even as participants; research was predominately conducted about them (Kiernan 1999). However, since the 1990s the UK Government has advocated service user involvement in research and evaluation (Gibbs & Read 2010), including marginalised groups such as people with mental health issues and people with learning disabilities. This has been supported by UK health policies which have aimed to strengthen public and patient involvement in the NHS (e.g. Health and Social Care Act 2001), and the English Department of Health (DH) who state that there has been a:

fundamental shift in the nature of healthcare professionals’ relationship with patients and the public, resulting in a move from a service that does things to and for its patients to one which is patient led, where the service works with patients to support them with their health needs; thus promoting a collaborative approach to care (DH 2005, p.3).

From a research perspective, this has meant enabling people with learning disabilities to have greater input into research which is related to them; this input should run throughout the research process from the design, conduct, and analysis stages through to dissemination (DH 2005). Today, increased inclusive research has enabled people with learning disabilities to have a louder voice (Nind & Vinha 2012). Methods and methodologies have been developed and adapted which facilitate active and meaningful engagement (Walmsley 2004). However, whilst greater inclusive research is becoming more established within the learning disability field, the voices of some of society’s most marginalised and difficult to reach populations are still going unheard. One such population is people with learning disabilities and dementia.

The aims of this article are to explore inclusive research; to acknowledge the challenges of including people with learning disabilities and dementia in research; and to critically describe the process of working in collaboration with a local group-advocacy organisation and its members, which sought to overcome these challenges.

**Dementia in learning disabilities**

In the past, age-related mental health problems, such as dementia, have not presented as much of an issue amongst people with learning disabilities, who tended to have a low life expectancy. Over the past 60 or so years, however, their life expectancy has increased considerably (Strydom et al. 2010), leading to a shift in the proportion of people with learning disabilities in the population from younger to older, a trend which is set to continue in the future (Janicki & Walsh 2002). It is estimated that the number of people with learning disabilities aged over 60 will increase by 36% between 2001 and 2021 (Foundation for People with Learning Disabilities 2010). Both increases are presenting new challenges within learning disabilities; one of these being an increased presentation of dementia.

People with learning disabilities have higher prevalence rates of dementia compared to the general population (Strydom et al. 2010). This is especially true for people with Down Syndrome, who are significantly more likely to present with dementia, and at a much younger age, compared to the general population and people with other types of learning disabilities (Cooper 1997; Holland et al. 1998; Alzheimer's Society 2011).

With increasing numbers of people with learning disabilities living with dementia, significant challenges to the individuals, their family, friends, support staff, and health and social care services are likely to be experienced (Watchman 2014). People with learning disabilities still face many barriers and challenges to receiving adequate care, support and access to healthcare services, as demonstrated through recent reports (Mencap 2004; Disability Rights Commission 2006; Mencap 2007; DH 2012; Heslop et al. 2013). From a research perspective, little is known about these challenges and barriers, and how people with learning disabilities and dementia experience and attempt to overcome them.

**Strategies for dementia support**

When recommending strategies for supporting individuals with dementia, the Alzheimer’s Society (2005, cited in Lloyd et al. 2007) emphasise the need to empower individuals by enabling them to have as much control as possible; trying to gain an understanding of their feelings and causes of negative emotions and/or behaviour. Within research this translates into understanding and exploring the perspectives and experiences of people with learning disabilities and dementia (Watchman 2012). This is much needed when both designing and implementing evidence based dementia practice and care.

Dementia research within learning disabilities has provided knowledge of the increased incidence and prevalence of dementia including the early signs of physical change (Watchman 2014); it has also explored the perceptions and knowledge of carers to a lesser extent (Herron & Priest 2013). However, it has not provided the same level of knowledge about the subjective experience of having dementia from the perspective of someone with a learning disability.

**Inclusive Research**

Inclusive research, in relation to people with learning disabilities, means including or involving them in a meaningful way in addition to participation as ‘subjects’. Underpinning this are a number of principles:

* Inclusive research must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them.
* It must access and represent their views and experiences
* People with learning disabilities need to be treated with respect by the research community (Walmsley & Johnson 2003, p.16)

At its most simplistic level, this entails people with learning disabilities taking a meaningful role within the research process.

Inclusive research has brought together two methodological traditions: participatory and emancipatory research (Walmsley & Johnson 2003). Participatory research involves meaningful partnership and utilising the experiences of people with learning disabilities themselves (Walmsley 2004). In this tradition, qualitative methods are used to explore the experiences of people with learning disabilities (Gilbert 2004). Emancipatory research aims to empower people with learning disabilities such that they take much more active involvement and control of the research agenda.

Bigby, Frawley, and Ramcharan (2014) have further conceptualised inclusive research, highlighting three approaches in which people with learning disabilities may be included within the research process, and which foster a ‘respectful relationship and regard for the perspective of people with learning disabilities’ (Bigby et al. 2014, p.4). The first, and most pertinent to the PhD research study in this article, is as advisors, where people with learning disabilities may be included as an advisory or consultation group, who actively input across the research process. However, the researcher determines the extent of involvement of people with learning disabilities, who have little input into the type of role they play, and whether they are included or not. The second approach is ‘leaders or controllers of research’ (Bigby et al. 2014, p.4), where people with learning disabilities take active control of research which is important to them, this involves leading across the research process from start to finish. The third approach is called ‘collaborative groups’ (Bigby et al. 2014, p.5), and refers to ‘partnerships or collaborations in which people with or without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued’ (p.8).

 Research involving people with learning disabilities is varied (McClimens 2008; Tuffrey-Wijne & Butler 2009; Nind & Vinha 2012). For instance, in Northway et al.’s (2014) work, people with learning disabilities identified priority areas for research in a participatory workshop. People with learning disabilities are also carrying out research positions, as described by White and Morgan (2012) where one of the authors, Michelle White, details her journey to becoming a researcher. These examples demonstrate the changing dynamics of learning disability research, with positions traditionally unattainable to people with learning disabilities now being obtained.

A similar picture is echoed across dementia research in the general population, where there is an increasing consensus that people with dementia should actively participate in research (Hubbard et al. 2003). Individual accounts of their subjective views and experiences have been available since the 1990s; initially through biographies (Davies 1992; McGowin 1993), and now through a growing body of research (Dabbs 1999; Tanner 2012). People with dementia in the general population are engaged in research at both a participatory and emancipatory level (Tanner 2012). This has produced benefits at an individual level; empowering individuals with dementia as they take on roles traditionally held by researchers and thus enhancing self-confidence, self-esteem, dignity, and the feeling of being valued (Barnett 2000; Aggarwal et al. 2003; Hellstrom et al. 2007). It has also enhanced their feeling of being recognised as capable of engaging in research (Kapp 1998), and has played a part in challenging marginalisation and improving social inclusion (Cantley et al. 2005).

 Benefits also extend to the research, where the inclusion of people with learning disabilities in designing research can lead to improved outcomes, can help the research team to meet their objectives, and can ‘improve the quality of … data by reducing the risk of excluding groups on interest’ (The Office for Disability Issues 2011, p.10).

 There are, however, a number of challenges to achieving such benefits for both participants and research in the learning disabilities and dementia field.

**The Challenges of Dementia Research with People with Learning Disabilities**

Recruiting people with learning disabilities and dementia to participate in research requires careful and early consideration around a number of issues, such as: identifying the population, gaining ethical approval, establishing and maintaining informed consent, and defining their role within the research process itself. Within the literature these challenges are not explicitly explored in relation to dementia research in learning disabilities; however, one challenge which may cross boundaries from dementia research in the general population to people with learning disabilities is communication. This is pertinent throughout research, especially within the consent process.

It is reported that more than 50% of people with learning disabilities have some form of impaired communication skills (Kerr et al. 1996). This may be further compounded for people with dementia as it progresses and the individual’s communication skills begin to further deteriorate (Beuscher & Grando 2009). Therefore, research teams need to be flexible and creative; utilising communication aids as required to enable inclusion (Gibbs & Read 2010).

A small body of research has demonstrated that the challenges of communication can be overcome in qualitative research, and in so doing, the collection of rich data can be aided. This research has demonstrated that the participation of people with learning disabilities and dementia is both possible and desirable. Additionally, it is important to engage people through an individualised approach, enabling the exploration of once unexplored experiences and perceptions. For example, Lloyd et al. (2007) explored the perspectives and subjective experiences of six people with Down syndrome and dementia through individual interviews. This qualitative methodology provided the most appropriate context for facilitating and ‘including the perspectives of vulnerable people’ (Gibbs & Read 2010, p. 233). Part of their success lay upon prior meetings with participants in order to establish and build a rapport and level of trust; also enabling the researchers to judge the communication level of participants.

 Watchman (2014) further demonstrated the importance of a flexible and individualistic approach to facilitate active engagement and participation of people with learning disabilities and dementia. She developed case studies with three individuals with Down syndrome and dementia to understand their lived experiences of dementia. Watchman conducted ethnographic research, drawing on observations, field notes, recorded conversations and interactions. Differences in participants’ abilities and preferences were acknowledged early, and communication was adapted when/if necessary, utilising methods such as Talking mats (Murphy, Gray & Cox 2007) and Makaton (Walker 2000) to enable the perspectives of those who had limited or no verbal communication skills to be included. Watchman’s methodology and flexible, personalised approach enabled participation.

 These researchers have demonstrated that early planning can help to overcome communication challenges, which underpin the consent and research processes. However, the involvement of people with learning disabilities within the research process can also help to overcome these challenges. What follows are two examples of collaboration within a PhD research study which have tried to overcome these challenges and facilitate the participation of people with learning disabilities and dementia. These examples had a common theme of working collaboratively with the same local group-advocacy organisation and people with learning disabilities to increase inclusivity and quality of research.

**Collaboration in a PhD Research Study**

 In 2013, the first author started a PhD study. This research study aims:

* to explore the experiences and journeys of people with learning disabilities living with dementia.
* to explore the experiences and journeys of their family and professional carers.
* to critically explore how Dementia Care Pathways and the support systems in place influence these journeys and experiences of holistic care and support.

These aims reflect a combination of the concerns and questions of people with learning disabilities with and without dementia and their carers, and the researcher’s knowledge and experiences. They provide an opportunity to help people with learning disabilities and dementia to use the research process as a platform to have their voice heard. This represented the start of a research study which progressively developed through experience into a piece of work which advocated more engagement and greater involvement of people with learning disabilities. This research study is positioned in the participatory tradition on the inclusive continuum (Walmsley 2004). More specifically, it takes an advisory approach (Bigby et al. 2014) as it utilises the expertise of an advisory group, or as referred to throughout this paper, a consultation group.

What follows is an account of collaboration used to help overcome the challenges of communication throughout the consent and interview process for participants with learning disabilities and dementia. This shaped, defined, and developed the design of the current study and its materials.

**Challenges to the Consent Process**

One area of the research process where communication has the ability to include or exclude people with learning disabilities and dementia is the consent process.Challenges may be experienced around gaining, and maintaining informed consent. Capacity to consent is always assumed (The Mental Health Act 2005); however, people with dementia, like people with learning disabilities, are often considered a vulnerable population, and may need support through this process. This may mean researchers having to adapt the consent process. This may be further compounded by the cognitive decline experienced when dementia is present, which eventually compromises decision making. Additionally, where participation in research occurs over a period of time, protocols need to be in place to take account of possible changes in participants’ capacity to consent. Communication is an important aspect of the consent process as it consists of providing information to people, in a comprehensible manner, and ensuring that the person has sufficient information on which to base their decision (Nind 2008), weighing up the advantages and disadvantages of taking part in the research.

**Developing tools for the Consent Process**

Over a number of consultation meetings, information sheets and consent forms were constructed by accessing the expertise and facilities of Reach. Collaborating and engaging with people across this organisation and people with learning disabilities outside of this organisation, steps were taken to create information about the study in accessible formats. Initially this information was created with an employee, without a learning disability, from Reach who has expertise in creating accessible information, and access to the software, such as Photosymbols (2014) required to do this. Once the draft information and consent forms were created, three individuals with learning disabilities were consulted about their suitability. These individuals were a self- advocate from Reach, and two individuals known to the first author. Two members were male and one was female, all were Caucasian, and aged between 30-60 years old, and all had experience of caring for someone with dementia. The consultation took place over two sessions; one with a self-advocate from Reach, and the other with the remaining two members. Across both sessions members of the group meticulously critiqued the accessible information page by page; in particular, the content, mode of expression, the corresponding pictures, and whether combined they made sense to the group members.

An important aspect of creating accessible information was selecting pictures which appropriately matched the information. This was not always an easy process as certain pieces of information are difficult to sum up in one picture. For instance, within Photosymbols (2014), the photo library used to select pictures, no pictures clearly represented ‘dementia’ (**insert Figure 1 about here**). Instead, it was necessary to describe what dementia is in the text and to represent some of its more well-known symptoms, such as confusion and forgetfulness, with pictures; for example, by portraying an image of an individual looking confused with a question mark attached. While the pictures did not perfectly match the text, they did represent its underlying message. Across the consultation sessions, all group members validated the combination of text and images, especially commenting on the effectiveness of repeated information, and the presentation of information in sizable chunks.

Consistency was also highlighted as important throughout the information sheets and consent forms by consultation members. For example, it was highlighted that after the research team members were initially introduced in the material by photograph and name, it was important that their photograph was presented whenever the researcher was mentioned (**insert Figure 2 about here**). This alteration led to the same principle being applied across the information and consent forms, where images of the same people were consistently used throughout the material when presenting related information. For example, the same images are shown in the pictures which relate to ‘choosing to talk to me’ and ‘not having to talk to me’, as seen across figure 2 and 3. Consultation members commented on how this consistency made it less confusing and easier to follow (**insert 3 about here**).

Various sources of guidance are available for developing and adapting information to an easy read format, (for example, DH 2010), but it was collaborating with Reach and people with learning disabilities themselves that proved most beneficial. The end results were materials of greater quality than could have been produced without this collaboration and input. Through this work, information sheets and consent forms were created which would provide potential participants with all the necessary information about the study; allowing them to think about their participation in the work and make an informed decision about participating. The importance of communication was highlighted, but also the sharing of knowledge proved essential. Skills such as making information easy read and accessible, but also practical skills, such as using specialised software, became useful across the whole research study and will be beneficial for future research.

 **Creating Interview Questions**

In order to develop an understandable and meaningful interview schedule for participants with learning disabilities and dementia, a consultation group was convened over two half day sessions. This group consisted of three females and five males, all were Caucasian, aged between 30-60 years old, with five members having experience of caring for a family member with dementia. Those recruited also had previous experience of working on a different project about dementia with the first author. Additionally, some of the group had previous training and experience in developing interview questions through their role with Reach.

 The initial stages of this process had a number of practical considerations which included: applying for funding for the consultation sessions, which consisted of paying for the group members’ travel expenses, food and beverages, and hiring a room; advertising the sessions to Reach members; and making arrangements for the location of the session and travel for the members. This was a time consuming process which took considerable planning and organisation, due to many of these considerations.

The first session aimed to create tentative interview questions for participants with learning disability and dementia. The session started by discussing session etiquette, the aim of the research study and of the session; all of which were listed on A2 size paper and put in a visible location of the room. The Importance of and how to create good interview questions were also discussed using a document provided by Reach.

It was discovered early in the collaborative process that flexibility in how the session’s aims were achieved was needed for its success. The original plan altered early in the session, where the consultation group took the decision to firstly discuss, explore and write down their experiences of dementia on post-it notes. These were then allocated to one of four broad themes: experience of dementia; experience of dementia care and services; the current challenges; and the future. Tentative interview questions were then created from these. These questions incorporated as many of the discussed experiences as possible.

 The aim of the second session was to scrutinise and develop the questions from the first session. Like the first session, the aims of the research study and of the session were discussed. Members scrutinised the questions one by one, with any comments being written on a post-it note (by the individual or facilitator). There was much debate about the wording of some questions, for instance, some members felt uncomfortable using the word ‘illness’ when referring to dementia and wanted it changed to dementia. Others believed that there should be more of a focus on what the individual wants in order to live well. For example, the members were clear that they wanted questions about the future (or whatever) to be included; this area of questioning had not initially been considered for the interview schedule, and so a number of questions such as ‘What is the most important thing for you in the future?’ and ‘What help might you need for this to happen?’. It was important that any alterations were discussed as a group and altered based on this process.

 The end results were interview questions which reflected the interests and concerns of people with learning disabilities, who also have experience of dementia, mainly through a caring role. This process highlighted the added demands of involving people with learning disabilities within the research process. However, the final result is of greater quality than could have been produced without this collaboration. These questions will help participants with learning disabilities and dementia to understand what is being asked of them, something which may not have been achieved without the input of the consultation group.

**Reflections on Collaboration**

Both these experiences have had a great influence on the direction in which the research study will be taken. Reflecting on these experiences, it was evident that working closely with the same group-advocacy organisation and its members was beneficial. As this relationship developed, access to their expertise and resources became easier and more streamlined, which has provided further opportunities to develop the PhD research study and to make it more inclusive. Additionally, one of the major strengths of this collaborative process was the recognition of what those involved brought to the sessions. This meant building on and using everyone’s strengths and expertise whilst working towards a shared goal. This was highlighted when creating interview questions, where members were experts by experience of dementia through a caring role, as well as in the collaborative process. The questions were informed by their expertise, which gave them more meaning and reflected their concerns, ensuring the interview would be fit for purpose.

This process did have drawbacks, in particular its labour intensive and time consuming nature. The collaboration required practical and logistical considerations, such as agreeing on meeting times, and spending long periods creating interview questions. However, this commitment was entirely appropriate and produced materials across the research study which will help to facilitate the participation of people with learning disabilities and dementia; which will improve the quality of the data and producing more meaningful outcomes.

The facilitating role also proved to be challenging, at least in parts. Having eight members of the consultation group allowed for the sharing of a great depth of experiences, and the development of an excellent range of questions, however, there was a need to be firm, as some members repeatedly talked over others and it was important to enable all members’ views to be heard.

It is also important to recognise that neither of the consultation exercises included people with learning disabilities and dementia. To truly share, create and adapt materials about dementia, it would have been more representative and inclusive to have worked alongside people with learning disabilities and dementia. This is something which needs to be carefully considered in future collaboration plans.

**Conclusion**

This paper began by highlighting the limited inclusion and participation of people with learning disabilities with or without dementia in dementia research, against the backdrop of greater inclusive research in other areas of learning disability. However, there are a number of challenges to achieving inclusion, one of which is communication. Lessons about overcoming this challenge have been taken from the experiences within a PhD research study. Ultimately, these opportunities demonstrated the importance and power of communication and its role in helping to facilitate or exclude people from meaningful engagement in research.

Working in collaboration with Reach and people with learning disabilities brought together and recognised the expertise of people with various backgrounds. Collaborating in this manner created materials which improved accessibility and understanding of the content. For the research study this will allow people with learning disabilities and dementia to weigh up the information, and make their own informed decision about participation. It is hoped that this work will provide a marginalised and hard to reach population with a platform to have a louder voice in the research process; something which they may not have previously experienced. However, as has been noted, it is important to recognise that this process did have challenges which included being time consuming.

As previously outlined, research on ageing and learning disability is generally lacking, hence creating opportunities for research to be more inclusive, using strategies such as outlined in this paper, can only be beneficial. Having taken so much from this experience of collaboration, and experiencing the benefits, the authors of this paper hope that others will be informed by these experiences, and utilise or adapt these procedures in order to create opportunities for marginalised and hard to reach populations to contribute to and participate in the research process. A number of points for good practice are provided below:

* **Funding**: do not underestimate the amount that working inclusively costs. When creating interview questions, costs of two sessions alone exceeded £200. Some of the largest expenditures consisted of travel for consultation members, food and beverages, and hiring a room. Look for and secure funding early.
* **Recruitment of consultation group members**: it is important that consideration is given to the participants of the consultation group and the expertise they bring. It is not always appropriate, as Bigby et al. (2014, p. 6) state, to simply select the ‘few active or well-known self-advocates available’ or selecting members based on their learning disability alone, and believing this makes them experts by experience. In the research study, members were selected due to a combination of their learning disability and experience of dementia.
* **Getting to know the group**: understand their lives, experiences, skills and support needs within the research process itself. This will allow you to utilise their expertise and experience appropriately. For example, the lead author spent time getting to know each group member upon arriving for consultation sessions. Group members spoke of their experience of working on other projects and creating interview questions which was subsequently used within consultation sessions.
* **Prior experience of facilitation**: try to gain as much experience of facilitating groups prior to utilising the knowledge of any consultation group. Facilitating the session without experience may mean not achieving your aims and not gaining as rich outcomes.
* **Flexibility**: researchers need to be guided by the person with a learning disability, being prepared to deviate from their original plan. Within this research study, the facilitator followed the lead of the consultation group and adapted the session. This will be dependent on the situation, but by having flexibility, researchers are able to adapt to the unexpected.

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**Figure 1**- A page taken from the adapted information sheet for people with learning disabilities and dementia, from the PhD research study described in the article. This picture consists of information on the right-hand side and pictures on the left. It demonstrates the fit between images and text within the information sheet.

**Figure 2**- A page taken from the adapted information sheet for people with learning disabilities and dementia, from the PhD research study described in the article. This picture demonstrates the consistency implemented throughout the information sheet to reduce confusion.

**Figure 3**- A page taken from the adapted information sheet for people with learning disabilities and dementia, from the PhD research study described in the article. This picture demonstrates the consistency implemented throughout the information sheet to reduce confusion, with the same peoples used in pictures for similar messages.