Engaging service users in identifying priorities for research on intellectual disabilities

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Self-advocates and supports with Katrina Scior and Angela Hassiotis during consensus meeting on 8th October 2014

Executive summary

Although there is a wealth of research on intellectual disabilities (ID) in the UK, researchers and funding bodies typically choose the topics without prior consultation or involvement of people with ID themselves in the early stages of the research. Accordingly, people with ID are only very rarely involved in defining research priorities or conceiving and designing specific studies.

Researchers at University College London (UCL) engaged service users with ID across London as participants and consultants to develop a research proposal based on a service user generation project. Reflection meetings and a final consensus-building meeting were held to achieve this.

- Service users concluded that inclusion, health and housing were key priority areas for future research.
- Service users reached consensus that housing was the most important of the three topics identified.
- An application for research with a focus on housing will be produced for research funding jointly with service users with intellectual disabilities by July 2015.
- Capacity for public engagement was built by engaging with members of established community self-advocacy groups at their usual meeting place, and subsequently bringing them together at UCL to be centrally involved in defining research priorities.
- Service users valued the process, the platform for social interaction and the sharing of different ideas. Feedback indicated that they particularly enjoyed meeting service users from different parts of London and contributing to discussions about matters close to their heart.
- A running theme that cut across all the identified topics throughout the project was poor communication, poor accessibility of a range of services, and not being involved in and/or told about events or decisions that affect people with ID.

Background

While there has been much research in the UK on the needs of service users with ID, as well as participatory research internationally that takes the perspectives of people with ID into account, this often takes the form of *consultation* in response to predefined research topics (Ramcharan, Grant & Flynn, 2004). As part of UCL's public engagement work, this project sought to enhance the involvement of people with ID to identify priority areas for research and engage people with ID as potential co-researchers in future funding applications.

A previous project that engaged people with ID in defining research priorities (Williams, Marriot & Townsley, 2008) consisted of a scoping review and workshops with various stakeholders, including people with ID and their family members, ID professionals and researchers. The project aimed to reach consensus on priorities for ID research in England over the ten years following its publication. The authors reported these six most important areas of concern for people with ID: getting good support, the right to relationships, housing, access to health care, inclusion in the community and work and personal finance. They also found that people with ID above all want research about action so that changes can be made.

What we did and what we found

The project was presented to members of three self-advocacy groups across London through liaison with each group's facilitators. Group members who were interested in taking part in the project attended one three-hour reflection and discussion meeting co-facilitated by the first two authors, and supported on each occasion by an assistant. The advocacy groups were Camden SURGE, the Islington Elfrida Power and Control (PAC) group and Speaking Up Southwark (SUS); these initial meetings were held for each group separately and the number of self-advocates present ranged from three to ten, with 17 self-advocates taking part in this initial stage across all three groups. Each group was supported by their usual group facilitator/supporter. During these meetings, it was discussed what research is, and what research group members had taken part in previously. The self-advocates had a good understanding of research and its purpose. This was followed by presentation of the six topics identified by Williams and colleagues (2008) as suggestions and those present were invited to discuss their opinions on the topics suggested, as well as forward other topics seen as important. For the two larger groups, these discussions were held in smaller groups of three to five individuals, before each group fed back to the larger group. The meetings with the three self-advocacy groups concluded with all present reaching a consensus on what they viewed as the two or three most important topics for research.

Service users from SURGE prioritised getting good support and housing, PAC prioritised access to health care and inclusion, and SUS prioritised access to health care, inclusion and getting good support. Service users discussed a wide range of concerns that they believed called for more investigation and evidence, such as stigmatising attitudes and employment opportunities.

These conclusions were used to structure a subsequent four-hour consensus meeting that brought together all self-advocates from the three groups interested in taking part. In the event 16 attended, supported by their usual group facilitator. A brief presentation was given to remind service users of the aims and objectives of the project. Volunteers from each group, supported by their peers, then summarised which topics had been chosen by their group in the initial meeting. This was a highly interactive task, and was followed by a subsequent plenary discussion which led to the self-advocates agreeing on three topics as most important for future research: inclusion, health and housing. The self-advocates then split into three groups

to have a further in-depth discussion about these three topics, each joining the discussion on the topic they were most interested in. All present were brought together for a final plenary, where they fed back on their discussion, before voting on the most important topic they would like to see more research on. The final topic that emerged was **housing**.

With regard to housing, self-advocates expressed concerns about point systems used for housing allocations, and felt that people with ID should be given priority in housing allocations. The group discussed examples of good practice, such as a housing sub-group of the Islington Learning Disability Partnership Board, headed by the Director of Housing, and felt there should be more instances of careful consideration of the needs of people with ID in relation to housing. The group noted that little seems to be known about the sort of housing that people with ID actually need or want. Those present felt that people with ID are not involved in thinking about processes and in decision making, and that accessibility to services and having choice in relation to housing are real concerns.

Lack of communication and involvement in decision-making was a running theme throughout the meetings that cut across all topics. Participants felt that they were very often not involved or told about big decisions, despite many of them acting as representatives for their groups/organisations at local, regional and national forums. It did not come as a surprise, therefore, that the final research topic chosen relates to wanting more involvement for people with ID in decisions about housing that have a real impact on the lives of people with ID.

How this relates to the available evidence

A systematic review on housing options in the UK for people with ID, conducted as part of Williams and colleagues' (2008) project, identified 43 relevant papers published between 2001 and 2008. Of those, only five involved hearing directly from people with ID to determine their housing preferences and choices (Barr, McConkey & McConaghie, 2003; Forrester-Jones et al., 2002; Gorfin & McGlaughlin, Mezza & Wilson, 2003; McConkey, McConaghie, Mezza & Wilson, 2003; McGlaughlin & Gorfin & Saul, 2004). The lack of involvement of people with ID in processes relating to housing is evident both in research and in real life.

A study in Northern Ireland found that people with ID were usually placed in residential accommodation according to availability of places, rather than in relation to their needs (McConkey, 2006). This resonates with group discussions during the current project regarding the allocation of homes reserved for people with ID by Islington council, many of which are not being filled and remain empty, possibly because they do not meet the needs and preferences of people with ID.

In the workshops run by Williams and colleagues' (2008), in relation to housing, family members expressed concerns about people with ID being included in their own local communities. People with ID noted that living near their families helped with local connections and opportunities for more activities and choices and social networking. Abbot and McConkey (2006) found that people with ID felt that the location of a house together with skills and knowledge needed for making connections and using community facilities were two key barriers to social inclusion.

Williams and colleagues (2008) identified gaps in research regarding where people with ID are actually living, what experiences they have in certain neighbourhoods and whether local housing departments are routinely taking the needs of people with ID into account. Their project concluded that research on how best to support people in having a choice over where they live should be prioritised.

In order to identify additional relevant research on housing since 2008, Google Scholar was used to generate all published articles citing each of the five relevant papers. The

lists were hand-searched to identify relevant papers. Although no relevant studies involving people with ID were found since 2008, three additional relevant papers were found during the period covered by Williams et al. (Abbot & McConkey, 2006; McConkey, Sowney, Milligan & Barr, 2004; Gorfin & McGlaughlin, 2004). Although not inclusive research, one study assessed barriers to achieving genuine house choice using focus groups with family carers and professionals and identified barriers such as risk, the need to make informed decisions and involvement during housing plans (Bowey & McGlaughlin 2005). Therefore the research priorities and suggestions set by Williams and colleagues (2008) are still relevant and applicable today, as there has not, to the authors' knowledge, been research directly involving services users and addressing the issue of housing options and accessibility.

In line with concerns noted by self-advocates during the current project, a report on housing by Mencap (2012) found that people with ID and their families identified lack of information, advice and advocacy as some of most common barriers to independent living. There seems to be a gap in the literature regarding accessibility of housing services and how people with ID can be included in housing decisions.

Furthermore, meeting the housing needs of people with ID is not only relevant to service users themselves, but also affects local authorities. 94% of local authorities agree that more needs to be done on meeting housing needs (Mencap, 2012). Furthermore, recent reductions in funding from central government have led to budgets focusing on efficiency savings rather than on meeting demands. However, if various stakeholders, including service users themselves, come together to identity and document needs and preferences in a systematic way through published research, it could help to guide authorities in their allocation of housing. This would empower, involve and meet the needs of service users as well as lead to greater efficiency by minimising wasted resources caused by unfilled housing.

A participatory workshop recently conducted in Wales by Northway and colleagues (2014) with people with ID, utilised similar methodology to the current project and also determined priority areas for research. In their project, after voting, a consensus was reached on the following three top priorities: communication with health professionals, parents with learning disabilities and independence. The issue of independence was related to the tension between needing support whilst wishing for independence. This links to the chosen topic of the current project, in that people with ID would like to have the access and option to make decisions regarding housing; living independently while having links and being near to their family (Williams et al., 2008).

The participation of people with ID in setting research agendas is empowering in itself. It provides a platform to fulfil their democratic right to speak up in a process that ultimately aims in involving them centrally in decision-making concerning their lives and needs. The very positive feedback of participants on the current project confirms this. The intrinsic value of empowerment was also highlighted in a comparison of two inclusive research studies involving people with ID, albeit not in the area of housing (Johnson, Minogue & Hopklins, 2014).

Next Steps

The aim of the present project was to involve self-advocates in the early stages of research, namely identifying research priorities. As the next step, it is planned to involve self-advocates in designing and applying for funding on the priority topic(s) identified, as well as engaging them as co-researchers.

Involvement of service users in the design and conduct of research is especially important, considering that people with ID are one of the most socially excluded groups. Furthermore, the chosen research topic of housing with reference to having access and

involvement in the processes involved in selecting housing is in line with the crucial component of local community participation that has been highlighted in Valuing People (Department of Health, 2001) and Valuing People Now (Department of Health, 2007).

Ultimately, to meet the needs of service users it is effective to use a bottom-up approach that makes their ideas, needs and preferences central to the setting of research agendas, rather than conducting research in the perceived interests of service users yet without their involvement at an early stage. The relative lack of research conducted in this way may be related to a perceived difficulty of conducting research with service users with ID due to barriers in communication. However, in line with previous similar research (Williams et al., 2008), we found that people with ID have an adequate understanding of research, and are well able to articulate their views. Furthermore, a review on methodological challenges of conducting research with people with ID addresses such challenges and illuminates promising developments (Nind, 2011).

Conclusion

Many of the proposals made during meetings as part of the present project, as well as in other participatory projects (Abbott & McConkey, 2006), are in line with current government policy and good practice guidelines. Involving individuals with ID more centrally in research is not only empowering but also has the potential to identify changes in processes and systems that required to make services accessible and appropriate to their users' needs.

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