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Nursing Practice
Discussion
Learning disability

People with learning disabilities are not always actively involved in research, but inclusive studies can generate findings that are representative of this group of people

Research with and by people with learning disabilities

In this article...

- › How people with learning disability are excluded from research
- › Consequences of this group's exclusion
- › Characteristics of inclusive learning disability research

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Abstract Durell S (2016) Research with and by people with learning disabilities. *Nursing Times*; 112: 7, 15-18.

Many people with learning disabilities are frequently excluded from active involvement in research and, as a result, along with researchers, have questioned research processes. These discussions have influenced how research is undertaken by, and with, people who have learning disabilities. Learning disability research is now increasingly framed as inclusive. This article explores the development of inclusive learning disability research by tracing its background and influences, identifying key characteristics and highlighting some of the challenges in its application. It demonstrates how inclusive research can give people with learning disabilities a voice that will help to inform practice.

Many people with learning disabilities have been, and are still, regularly excluded from being actively involved in research. This situation has become increasingly challenged by self-advocacy groups and the researchers who work with them (Johnson, 2009).

The Department of Health's (2006) national research strategy stated that the engagement of "patients and members of the public leads to research that is more relevant to people's needs and concerns, more reliable and more likely to be put into practice". This is particularly relevant for people with learning disabilities, as

concerns about their experiences of healthcare have been raised for many years (Mencap, 2007). As stated by Northway (2010), strategies must therefore be developed to promote their inclusion in healthcare research, so "their views and experiences shape the development of more appropriate services".

Background and influences

The development of an inclusive approach to learning disability research was considered by Walmsley (2001), who found no evidence of any research that attempted to access or represent the opinions of people with learning disabilities before Robert Edgerton's study in the 1960s. She concluded that these people "were tested, counted, observed, analysed, described and frequently pathologised, but never asked for their views".

Normalisation

Walmsley (2001) attributed the rise of normalisation (Box 1) as a major influence on researchers, who started to acknowledge people with learning disabilities as potential active contributors of research.

These principles were instrumental in the provision of a humanistic value set, which asserted that people with learning disabilities "should have a voice in events that affect their lives" and enabled to do so (Gilbert, 2004); this included their inclusion in evaluation and research processes (Walmsley, 2001). However, normalisation has focused on service reviews and is accused of being professionally driven (Walmsley and Johnson, 2003); it also does not, generally, ascertain the views of people with learning disabilities themselves or critically analyse the question of

5 key points

1 Many people with learning disabilities are excluded from active involvement in research

2 Research processes have been questioned by people with learning disability, as well as researchers

3 Increasing numbers of people with learning disabilities are now actively involved in research

4 Normalisation principles, the social model of disability and self-advocacy have influenced the development of inclusive research

5 Inclusive learning disability research findings can inform and improve evidence-based nursing practice



Including disabled people in healthcare research leads to more appropriate services

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social norms and what it can mean for people with learning disabilities to follow them (Chappell, 1999).

However, with their emphasis on according individuals valued social roles and “the duty of non-disabled people to work for the interests of devalued people, particularly as advocates”, normalisation principles did pave the way for people with learning disabilities to be taken seriously as potential research participants (Walmsley and Johnson, 2003).

It also supplied “the conditions to make speaking out possible” and supported the development of inclusive learning disability research in the late 1980s and early 1990s (Walmsley, 2001).

Social model of disability

Another important influence on inclusive learning disability research was the emergence of the social model of disability. This focuses on the barriers that can be experienced by disabled people, including those that are environmental and societal, and the impact of anti-discrimination legislation (Barnes and Mercer, 2006). This approach had a powerful effect on disabled people, their representative organisations and disability politics, and “underpinned the growth of academic teaching and research on disability in Britain” (Barnes and Mercer, 2004). If social-model thinking perceived disability as the societal response to impairment, therefore, it followed that:

“...research should switch from the ‘problems’ created by impairment to changing society in order to increase disabled people’s opportunities for full inclusion.” (Walmsley, 2005)

From the early 1990s, some researchers tried to go beyond participatory practices and meet the more rigorous demands of emancipatory disability research. As Walmsley (2005) explained:

“This raised the stakes considerably in terms of what some learning disability researchers began to demand of themselves and their work. The type of research characteristic of normalisation-inspired models – that the research should demonstrate ways in which a ‘normal life’ could be promoted – was not enough. Somehow, the researcher was expected to find ways of giving control to people with learning disabilities, and of being accountable to them.”

While their applicability to people with learning disabilities and its translation to inclusive learning disability research have

BOX 1. KEY POINTS ABOUT NORMALISATION

Normalisation principles

- People with learning disabilities are undervalued by society and receive second-rate services
- Providing high-quality services can improve their lifestyles and enable their integration with “socially valued” non-disabled people
- Normalisation principles were developed in Scandinavia and the US in the 1960s and 1970s

Development

- In the early 20th century, in Western Europe, North America and Australia, large institutions were seen as the solution to the assumed “problem” of “mental deficiency”
- Normalisation ideas were a response to the poor standards of care at these long-stay hospitals
- They were developed with no direct input from people with learning disabilities, but at this time their voices were “universally silenced”, so it would have been difficult for them to promote widespread changes other than through non-disabled advocates/allies (Walmsley, 2001)

Concerns

- The focus on integration can lead to the identification of other people with learning disabilities as “the problem to be avoided”
- This undermines the possibility of collective political action, based on commonality of experience’ (Chappell, 1997)

been questioned (Riddell et al, 1998), emancipatory principles have influenced and developed the ways in which research is undertaken by, and with, people with learning disabilities (Learning Difficulties Research Team, 2006).

Self-advocacy

Another significant influence on inclusive learning disability research is self-advocacy. This is recognised by Walmsley and Johnson (2003) as playing an important role in the facilitation of inclusive research principles because, without it, there would be “no possibility” of organising groups of people with learning disabilities so they can work collectively on research projects. Walmsley and Johnson (2003) observed that self-advocacy groups are vital if researchers are to be accountable to learning disability organisations, identifying self-advocacy as the form for “speaking up and out” within learning disability circles.

However, concerns have been raised that:

- » Involving self-advocates in research can be perceived as tokenistic (Aspis, 2000);
- » People with learning disabilities have too little control over the research agenda (Aspis, 2000);
- » Self-advocacy has not affected the lives of different groups of people with learning disabilities equally (Walmsley and Johnson, 2003);

- » More needs to be done to include people with “severe” learning disabilities (Walmsley and Downer, 1997).

Despite these concerns, individual self-advocates and self-advocacy groups have successfully participated in research, enabling insights into the views of people with learning disabilities to be achieved (Nind and Vinha, 2012).

Characteristics of inclusive research

Inclusive learning disability research has been described as a flexible approach that is firmly based on the experiences of people with learning disabilities (Williams et al, 2008). It has also been observed as research in which people with learning disabilities “are active participants, not only as subjects, but also as initiators, doers, writers and disseminators of research”, and which embraces a range of research traditions, including emancipatory and participatory (Walmsley and Johnson, 2003).

However, it is important to differentiate between emancipatory and participatory approaches to disability research, and the relations between disabled people and researchers; Chappell (1999) makes the following differentiation:

“In the former, researchers are accountable to the organisations of disabled people; in the latter, the relationship is looser and is based on alliances.”

BOX 2. CHARACTERISTICS OF INCLUSIVE RESEARCH

- The research problem must be one that is owned (not necessarily initiated) by disabled people
- It should be collaborative; people with learning disabilities should be involved in the process of doing the research
- People with learning disabilities should be able to exert some control over the process and outcomes
- It should further the interests of people with a disability; researchers without a disability should be on the side of people with learning disabilities
- The research question, process and reports must be accessible to people with learning disabilities

Source: Walmsley and Johnson (2003)

Walmsley and Johnson (2003) believe that if a research project is to be perceived as inclusive, either from an emancipatory or participatory approach, it must exhibit the characteristics outlined in Box 2.

Challenges

A number of institutional barriers to people with learning disabilities working with academics as co-researchers in participatory research practices have been identified.

Academic qualifications

Universities' general academic prerequisites for research-grade appointments effectively exclude people with learning disabilities. While this should not prevent their employment in other positions in academic/university departments, it raises questions of fairness in terms of status and income (Ward and Simons, 1998).

Abell et al (2007) also observed that, although they aim for all researchers in their group to be equal, "the academic structure around researching is far more easily accessed by professionals".

Time pressures posed by funding bodies and publication schedules can also affect the opportunity for people with learning disabilities to participate in research, in particular as working with them "or, at least, doing it properly - takes time" (Stalker, 1998).

Imbalance of power

The role of the inclusive research supporter has also been described as contentious (Williams et al, 2005) and can be compared with that of advisers of self-advocacy groups, who do not themselves have a learning disability (Goodley, 1997). From a self-advocacy perspective, a non-dominating supporter has been identified as a fundamental feature of good research support (Tarleton et al, 2004). Involvement in research by people with learning disabilities has led to the growth of sympathetic alliances with people who do not have learning disabilities (Gilbert, 2004). However, this has been identified as more

closely related to participatory rather than emancipatory research (Walmsley, 2001). While participatory research may offer a feasible way for people with learning disabilities to participate, it can uphold the authority of non-disabled researchers and institutionalise the relative power positions of researchers and the people they study (Chappell, 1999).

Kiernan (1999) observed that people with learning disabilities should be meaningfully included, and in control, throughout all stages of the research process if it is to be truly emancipatory. However, as research is reliant on intellectual skills, it is less accessible for people with learning disabilities than for those with physical impairments only, and Kiernan argued that people with learning disabilities need substantial support from researchers to participate. This raises concerns as to whether such research truly represents the views of people with learning disabilities as "the influence of the research supporter cannot be detached from the research process". If most researchers with learning disabilities need some form of support, it is important to

explore how those who give that support can contribute to the research process without, as Williams et al (2005) described it, "taking it over". Moreover, "inclusive research" can refer to varied levels of involvement so, as Chapman and McNulty (2004) explained, "it is important to be really clear about how the research is being done, who wants to have it done in the first place and how it is used".

Inclusive learning disability research has generally taken for granted the functions and skills of research supporters. The imbalances of power between people with learning disabilities and researchers "continue to be camouflaged by a rhetoric of participation"; a way forward is to clarify what roles inclusive research supporters can play, so their existing skills and those of new entrants to the field can be developed (Walmsley, 2004).

Reflexivity can be described as "the process associated with researchers' self-awareness - of how they impact and transform the research they undertake" (Kingdon, 2005) - and is central to inclusive learning disability research (Walmsley, 2004). Chapman (2005) acknowledged the need for reflexivity and awareness of issues of power in research teams composed of people with learning disabilities and non-disabled supporters.

Overcoming the challenges

Several inclusive learning disability research projects have overcome some of these challenges. Box 3 summarises two examples. The Learning Difficulties Research Team (2006) investigated the involvement of people with learning disabilities in 12 Department of Health (DH)



People with learning disabilities should be meaningfully included throughout the research

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research projects and described their project as groundbreaking, “because the research and the management were done by people with learning difficulties”. The study was funded and supported by the DH through the Learning Disabilities Research Initiative (LDRI) to challenge the traditional ways of working with people with learning disabilities, and demonstrated that they can be full and effective partners in academic research. The study report highlighted good practice and revealed where commitment to involving people with learning disabilities in research “did not go beyond the words in the application process” (LDRT, 2006).

In its concluding recommendations, the Learning Difficulties Research Team (2006) asserted that inclusive learning disability research projects must think outside the box, be prepared to change, plan together, get the right funding and get better at producing accessible information.

Conclusion

The application of inclusive research principles enables people with learning disabilities to be actively involved in research. Findings drawn from the growing body of literature can then inform and improve evidence-based practice that focuses on person-centred care. Nurses must critically appraise inclusive learning disability research before implementing findings in their practice, and must ascertain the extent of its “inclusiveness” of people with learning disabilities. This is vital if inequalities in healthcare are to be addressed by, and with, people with learning disabilities, because when they have a say in the production of knowledge, “this leads to better research, better data and the chance of real change” (Learning Difficulties Research Team, 2006). **NT**

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BOX 3. INCLUSIVE RESEARCH PROJECTS

Building Bridges Training Research Group (2014)

A group of researchers with learning disabilities presented an overview of their group meetings and discussions. Their report highlights the big issues that mattered to them (and other people with learning disabilities), as well as their thoughts on what should change. They worked in close partnership with a non-disabled researcher, whom they knew well and trusted. She supported them throughout the project, for example, by helping them to put their words and thoughts into a report, and beyond – for example, by helping members to complete benefit forms.

Blunt et al (2012)

One inclusive group of researchers wanted to go beyond involving people with learning disabilities in research and co-writing research papers/articles, to instead develop a working partnership approach, so that they would be actively involved in “the whole process of peer review and publishing research”. The result was a special edition of the *British Journal of Learning Disabilities*, in which this group of researchers, as partners, peer reviewed all articles and wrote the editorial.

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