



Proposing an Academic Space of Autism and Profound Learning Disability

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Plain English Summary

1. Introduction

This paper looks at reasons people with complex needs are often excluded from research. One reason is to do with how researchers use diagnostic labels. Autism researchers often exclude people with severe and profound learning disabilities from their research. Learning disability researchers often exclude autistic people from their research. But no matter their diagnosis, people with complex needs have a lot in common. They share characteristics such as sensory differences and learning difficulties. They communicate in similar ways such as through vocalisations and body language. They share schools and support services. So, is it ok for researchers to exclude people with complex needs because of a diagnostic label?

2. How the research was carried out

To answer the above question, the paper explores three topics:

- i. How people with complex needs are described by their diagnostic labels. This focuses on autism, severe learning disabilities and profound learning disabilities. Descriptions from a diagnostic manual and researchers are explored.
- ii. How people with complex needs are understood in everyday contexts. Are there differences between how we think about people in this group if they are diagnosed with autism or with severe/profound learning disabilities?
- iii. How people with complex needs are represented in research. Do autism and learning disability researchers represent this group differently?

3. How people with complex needs are described by diagnostic labels

This section explores whether autism and severe or profound learning disabilities are described differently in people with complex needs. The DSM-5 is a diagnostic manual (American Psychiatric Association, 2013) that describes what a diagnosis means for a person. It describes autism across three levels. 'Level 3' describes autistic people with the most complex needs. The description of level three autism is very similar to the description of severe and profound learning disabilities. For example, they both refer to impairments in communication and the use of nonverbal communication. The DSM-5 states it is difficult to separate the diagnosis.

Bellamy et al. (2010) say community members and professionals think autism is different to profound learning disabilities. However, they only asked learning disability community members and professionals and not autism community members or professionals. Hoevenaars-van den Boom et al. (2009) say you can tell if a person should have an autism diagnosis and not a profound learning disability diagnosis because they would



have fewer social skills. However, their study was designed badly and based on old understandings of autism in males.

The above analysis suggested researchers should not exclude people with complex needs because of their diagnostic label.

4. How people with complex needs are understood in everyday contexts

This section focuses on whether people with complex needs are considered people of value. It also looks at the stories people tell about this group. Finally, it discusses how support service understands their behaviours. Its purpose is to explore whether diagnostic labels make a difference in how this group are known.

Philosophers sometimes say people with complex needs are worthless. They say this because they think this group doesn't know how to communicate or socialise. This relates to autism and severe/profound learning disabilities. However, people that spend time with this group know this is not the case. They see them communicate and socialise. They see their worth.

Stories about people with complex needs often see them as victims. However, when stories are made with them, their lives and characters are seen as rich and diverse. This diversity makes it difficult to say what is autism and what is severe/profound learning disabilities.

Support services sometimes characterise people with complex needs according to their behaviour. They do this whether they have an autism or learning disability diagnosis.

This section's analysis suggested people with complex needs are known in similar ways, no matter their diagnostic label.

5. How people with complex needs are represented in research

Autism and learning disability researchers have not been very good at including people with complex needs in research. Often when discussing this group, autism researchers do not talk about people with learning disabilities. Similarly, often learning disability researchers do not talk about autistic people. This means the views and experiences of the autism or learning disability communities are not recognised or promoted. A way to help this could be for people with complex needs to have their own research field.

6. Implications

It is probably not a good idea for researchers to separate people with complex needs through diagnostic labels. It should not matter if they have a diagnosis of autism or severe or profound learning disabilities. Instead, researchers could view them as a group who have a lot in common. These commonalities include the ways they communicate, their support circles, the services and schools they share, their sensory experiences, and their support needs.

Bringing together people with complex needs in research can be termed 'opening a new academic space.' The purpose of an academic space is to improve an area of research. This would be called the 'academic space of autism and profound learning disability.' Its purpose is to improve the representation of people with complex needs in research. This group could be termed 'autistic people with profound learning disabilities.' However, these terms need consideration and input from the learning disability and autism communities. Further purposes of the space are:



- To find out what this group think are key research topics and issues
- To share ethical and inclusive ways of researching with this group
- To promote the views of this group in policy about education and health and social care

Author bio

Ned Redmore is a researcher at the Open University. His research focuses on autistic people and people with profound learning disabilities and how support services can better include them. He also researches ways this group can be better included in research.