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TMA 04

Critically discuss the advantages and disadvantages of disabled people undertaking disability research. Illustrate your answers with material from Chapter 13 by Lewis and Kellet in Reader B and the research paper by Monteith in chapter 9 of Reader A.

In considering what are the advantages and disadvantages of disabled people undertaking disability research, it is first necessary to define what disability research is; what are the main issues concerning this type of research and whether there are advantages or disadvantages in disabled researchers undertaking such research.

Issues in Disability Research

The word disability has a multitude of meanings. The term used to describe different disabilities can often convey a particular attitude towards people with disabilities. There are terms that are frequently used in the past, and still used by some people in the present day which are derogatory and convey a negative image of disabled people. It is important for all researchers undertaking disability research to consider how they talk about disabled people, because the terms used may be perceived by others including people with disabilities in a different way from that intended (Lewis and Kellet 2004). Generic umbrella terms imply a degree of similarity between individuals and others within the same disability group. Many families with disabled children have been joined by professionals and academics in emphasising the need to see the child first and the disability second.

However, there are differing degrees of disabilities particularly with regard to blindness; the term visually impaired is used in preference to blind, because some

children who are considered for educational purposes as blind can often see light and dark or even vague shapes, so these children can be thought of as having different degrees of visual impairment. Similarly hearing loss can vary from profound to mild. Around 10% of deaf children have a deaf parent, and the use of sign language within these children's families makes them a cultural minority. Many deaf people categorise themselves as "Deaf" with a capital D and see themselves as having a distinct and separate identity in the hearing world. Thus children born into families with deaf parents are more likely to see themselves and to be seen by their families as Deaf children, rather than children with hearing impairment.

Another issue in disability research particularly where children with disabilities are being compared to children who are not disabled is what to call the latter. Some researchers refer to these children as "normal". However, the use of the word normal implies that children with disabilities are not normal. Because of this the term "typically developing" is often used to describe children without disabilities in research projects.

Children with disabilities belong to other social groups such as families, age and peer groups, cultural and /or religious groups; disability is only part of their identity and should not be allowed to overshadow other factors which construct their identity.

Research into the development of children with disabilities provides valuable information into how disabilities affect development and provide insight into developmental progress of children without disabilities. However, Unwin in (Lewis and Kellet 2004) points out those researchers must consider the development of children with disabilities with care. If their development is under calculated, the affect of their disability on their development may be over calculated. Researchers must also ensure that the affect of a disability on development cannot be attributed to another problem or difficulty that the child may experience.

Children are often grouped together and labelled because of their disability e.g. As blind or with Down's syndrome, this grouping suggests that the individuals in these

groups share certain characteristics. Obviously such children will have some features in common but the nature of their disability may be very different. This is particularly true of those with profound and multiple learning difficulties. The severity and multiplicity of such impairment makes it highly unlikely that a homogenous group can be found within a population. The same can be said to be true of any group of children or young people who are grouped together and labelled because they share certain characteristics such as the additional chromosome 21 that is present in all those with Down's syndrome. Researchers will need to assess if the primary of the disability over-rides other factors in the child's life for example the problems faced by children with disabilities are often attributed solely to the fact that they are disabled, whereas in fact other variables such as education or social environment may be in some cases contributory to their problems as much if not more than their disability. An example of this would be if a child was accommodated in a residential school away from their family and their language development was delayed, the delay may not be a direct consequence of the disability, but may in fact be due to some aspect of their residential environment. Another problem in research into the development of children with disabilities is that researchers very often use methods of research with disabled children which have been used to study "typically developing" children. However such methods may not be appropriate for children with certain disabilities. Despite all the problems which arise in research with children and young people with disabilities such research can make a marked contribution to creating a clear picture of these children's lives and experiences

Children and young people with disabilities are at an even higher vulnerability than other children. The issues of power relations become intensified. Ethical considerations need to be heightened and greater consideration given to gatekeepers in order to protect children with disabilities from becoming prey to unscrupulous researchers. Disability thinking has moved away from the medical model, where the "problem" is seen to be within the child to a social model where society is seen as disabling not the child; this has encouraged research with its focus on the social environment of the children with disabilities. There has also been an increase in educational research which places a greater importance on the quality and flexibility of teaching approaches and less on pupil disability. This has led to the development of a research base for interactive teaching approaches with children who have a

learning disability, which has replaced most behavioural research which was popular in the 1980's.

There are questions being asked as to whether able bodied researchers should be undertaking disability research. However, are there advantages in disabled researchers undertaking such research or do the disadvantages outweigh any advantages; and should research into disability issues be conducted by those best qualified to undertake it, be they themselves be disabled or able bodied.

Advantages of Disabled People undertaking Disability Research

One of the major advantages of disabled researchers undertaking disability research is their ability to empathize with the participants. They will have had many of the experiences encountered by the participants and may be able to use this experience to put the participants at ease and to go about adapting parts of the research project to include some disabled participants which able bodied researchers may not have been able to include. Monteith's research involved a young girl with disabilities at both the design stage and the writing up stage as part of the research advisory group.

Monteith's states that her advice and insight were very important throughout the project. With this girl's help Monteith was able to rework some of her questions included in the research questionnaire. This is just one example where involvement of people with disabilities in the research project can be an advantage. Disabled researchers could be regarded as experts on certain disabilities and be able to place their skill and knowledge at the disposal of those being researched. The use of disabled researchers could also help to negate power differences that might exist between able bodied researchers and their disabled participants. Although there is no evidence that there were problems with power relationship in Monteith's research, such problems do emerge in research into people with disabilities.

Many participants with disabilities may feel more relaxed with researchers who share the same or similar disabilities as themselves, and thus may be more forthcoming with these researchers who they feel may well be more sympathetic to their condition and to their opinions. Would participants with learning difficulties have been more

forthcoming had Monteith employed a research assistant with a mild learning disability and would this have meant that some of those with more severe learning difficulties would not have to have been excluded from the research. The use of disabled researchers could lead to greater inclusion by disabled people into society as a whole. Many sociologists claim that disability research is not representative of disabled people's experiences and knowledge, because the vast majority is conducted by non-disabled researchers. It is also argued that it is only disabled people who can know what it is like to be disabled and thus it is only disabled people who can truly interpret and present data from other disabled people. It is also claimed that research concerning disability is usually researcher orientated, based around the agendas of non-disabled researchers and able bodied funding agencies rather than the subjects of the research; that is disabled people. Using disabled researchers would address the criticism to some point since their interests and agendas should be more in line with the interests of the disabled subjects of the research. Gray and Denicolo (Lewis and Kellet 2004 pg 201) cite a case in which hearing researchers falsely hypothesised that the deaf children they were studying were not capable of certain behavioural characteristics of typically developing children. It could therefore be said that the inability of able bodied researchers to switch their perspective to one of disability compromises the validity of their research. It could also be argued that disabled researchers have the same perspectives as their disabled subjects, or that they find it easier to switch their perspective than do their able bodied counterparts. Monteith had little experience of disability issues and may have been greatly assisted in her research had she had disabled researchers on her team.

Disadvantages of Disabled Researchers undertaking Disability Research

There are some disadvantages to disabled researchers undertaking disability research. Firstly it is possible that disabled researchers may be too involved with the disability, particularly if they have the disability that is being researched. They may have too many preconceived ideas that they cannot overcome, they may be too subjective and not have an open minded approach. Due to their experience of their own disability they may not be able to see the bigger picture and may unconsciously transfer their own opinions and concerns onto the participants of the research.

Disabled researchers may not have the experience of able bodied researchers. To use disabled researchers in preference to able bodied researchers, simply because they are disabled may be positive discrimination, but may not be the best thing for the research project. Experienced researchers have technical skills and abilities that can be applied to new areas of enquiry and it might not be necessary for them to have specific knowledge or experience of the research subject. The inclusion of a disabled researcher in disability research may be seen as tokenism and may be resented by the disabled participants taking part in the research and seen as an attempt to con them into taking part in the research or revealing more about their opinions or feeling than they would normally have been prepared to do.

Conclusion

In conclusion I think that on the whole the inclusion of disabled researcher in projects undertaking disability research has more advantages than disadvantages. The knowledge and understanding of what it means to be disabled, that only disabled researchers can bring to a project can be invaluable. However, it would not always be practical for disabled researchers to undertake all disability research. A compromise would be to include disabled people in all stages of the research project. Monteith did this in her research by including a disabled young woman at the design stage and the writing up stage. To go further, if disabled people helped to formulate and monitor the researcher project, providing constructive criticism at all stages, but allowing the process of data generation, analysis and writing up to be undertaken by professional researchers, be they able bodied or disabled, then this would seem like the best compromise.

(2020 WORDS)

REFERENCES

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