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Full Length Research Paper

More than a “Nice Day Out” – How to encourage the meaningful participation of people with learning difficulties in disability conferences

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Disability researchers recognise the significance of knowledge exchange among participants. Increasing value is attributed to the importance of life experiences. It is surprising therefore, that no literature exists about participation of people with learning difficulties in disability conferences. To address this gap, Disability Studies in Netherland (DSiN)¹ designed and implemented a ‘Buddy Project’ for a 2013 conference in Amsterdam. Relevant concepts were explored in literature, one group interview and eleven individual interviews were conducted. Participants with learning difficulties were sent a list of questions the day before. The Buddy Project assisted people with learning difficulties in both *meaning* and language *translation*. Although, people with learning difficulties had some sense of belonging at the conference, and understanding was increased, they felt they were not heard. The project was partially successful in increasing participation of people with learning difficulties, but less successful in facilitating *mutual* exchange of knowledge. If people with learning difficulties had been involved in its design, it would have been more successful, as they would have provided useful suggestions.

Key words: Inclusion, belonging; mutual exchange of knowledge, people with learning disabilities, conferences.

INTRODUCTION

Miranda-Galarza, B; Lusli, M; Zweekhorst, M. & Budge, F. state 'an epistemological shift can be brought about by recognizing the importance of personal knowledge of disabled people and its transformative social potential' (2013:85). Recognising the value of personal knowledge is fundamental when engaging people with learning difficulties in research, reflecting the notion of 'expert by experience'. Despite significant shifts that have taken place in social science, and the control of research shifting from so-called '*objective experts*' to '*subjects of research*', there is little recognition for the value of life experience in knowledge creation (Miranda-Galarza *et al.*, 2013)

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¹DSiN strive to promote Disability Studies as a field of study in The Netherlands. To achieve this, research and education are stimulated, and a knowledge network of committed people has been created. By developing, sharing and applying knowledge, DSiN want to achieve social change and contribute to a growing participation and inclusion of people with disabilities.

Disability conferences are places where recognition of such knowledge should happen. Lack of literature about engaging people with learning difficulties in conferences indicates this does not occur. Responding to this gap, Disability Studies in Netherland (DSiN) designed and implemented a ‘Buddy Project’ for a conference in Amsterdam in 2013. The project reflected the idea that research needs to include, and be driven by people implicated in research. Proponents of this notion challenge researchers to: increase collective voice, facilitate resistance of devalued social constructions of disability, affirm positions of research ‘objects’ as competent social actors and address research power imbalances (Beart, 2005; Björnsdóttir and Traustadóttir, 2010; Gilbert, 2004; Kramer and Garci, 2011; Miranda-Galarza *et al.*, 2013; Townson *et al.*, 2004; Walmsley and Johnson, 2004; Walmsley, 2001, 2004).

One way to do this is to ensure inclusive efforts do not reinforce academic agendas of exerting influence and

power in the research arena. bell hooks², a Black American feminist, familiar with processes of power and influence, eloquently, albeit somewhat sarcastically, addresses this concern in her statement:

'No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then, I will tell it back to you in such a way that it has become mine, my own. Re-writing you, I rewrite myself anew. I am still author, authority. I am still the colonizer, the speaking subject, and you now are the centre of my talk' (1990:151-2).

Disability conferences must not perpetuate colonising practices. Addressing this concern, DSiN explicitly extended an invitation to people with learning difficulties to the conference. People with and without learning difficulties were brought together with the aim of encouraging a supportive relationship. The intention was that mutual learning would take place within this relationship, and as a result it would make the conference a richer experience for both partners. All participants engaged in a voluntary basis and were encouraged to call in support if they felt it necessary.

Aims

As the theme of the conference was *'The Art of Belonging'* it would have been negligent if people with learning difficulties were unable to participate. DSiN are dedicated to the principles underlying inclusive research, and are responsive to the position *'Nothing about us without us'*. Resonating with this position, DSiN wanted to challenge the *'academic atmosphere'* of conferences, characterised by discourses, that exclude non-academics. The 'buddy project' aim was to:

- i) Increase participation of people with learning or physical restrictions.
- ii) Create a buddy relationship.
- iii) Provide support.
- iv) Facilitate mutual exchange of knowledge.
- v) Increase a sense of belonging (especially for people with learning difficulties).
- vi) Encourage expression of voice (especially from people with learning difficulties).

The project began with a two-hour training session

² The use of bell hooks in lower case is in keeping with her self-proclaimed desire to "to construct a writer-identity that would challenge and subdue all impulses leading me away from speech into silence" (1990:9)

offered by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). Training participants were paired as buddies comprising a person with and without restrictions. They were encouraged to relate conference messages to daily circumstances, leading to an exchange of knowledge. Emphasis was placed on ensuring that everyone felt included. A project organiser summarised the aims:

"... to generate knowledge ... describe ... key messages ... relate this to your life and ...think of how ... the messages could change your life".

The conference was international, and the primary language was English. Buddies also assisted with language translation.

EVALUATION METHODS

As there is no existing literature about participation of people with learning difficulties in conferences, principles drawn from 'scoping studies' were adopted. Scoping studies are recognised as an appropriate means of mapping a range of literature in order to identify gaps and innovative approaches. Furthermore, they are concerned with contextualising knowledge and as such provide a solid basis for policy and practice development (Levac et al., 2010). Results from this study served to guide the interview design and facilitate a better understanding of evaluation findings. Concepts included, 'participation', 'inclusive research', 'buddy', 'knowledge exchange', 'belonging, and 'voice'. Both Google and Google Scholar were used for the search. As this was an evaluation of a short project, and not an in-depth research, it was felt rigorous and systematic use of specific search engines unnecessary.

Interviews and group discussion

A total of 17 conference attendees were interviewed. Eleven of these were semi-structured, individual interviews. Eight of these were with people without learning difficulties and were involved as either buddies, organisers or non-project related participants. Three were people with learning difficulties, for these interviews a parent attended. Six people were interviewed in a group interview: five had learning difficulties and one was their regular 'supporter'. In total, eight men and nine women were interviewed (Figure 1).

Interviews were semi-structured and thematically determined by concepts relevant to project aims. People were asked how they felt support, participation, a sense of belonging, and mutual knowledge sharing was experienced. Additionally, questions were asked about the extent to which they felt voices were heard. A day

17 people in semi-structured interviews:

11 Individual Interviews :

8 with people without learning difficulties:

2 involved in organising the conference (1 female/1 male)

4 buddies (3 female/1 male)

1 with a physical impairment (1 male)

1 conference attendee, uninvolved in project (1 female)

3 people with learning difficulties (3 male)

6 people in group interview:

5 people with learning difficulties (4 male/1 female)

1 without learning difficulties (female)

Figure 1. Overview of interviewee's

before the interview a written question guide was sent to the support person of three individuals and people in the group interview with learning difficulties. This happened as their level of learning difficulty indicated that some time for preparation of answers would be helpful.

All interviews were immediately condensed into main highlights and a written summary was sent to the participants and, where relevant, to their supporters for comments and corrections. Interviews were later transcribed verbatim and submitted to MAXQDA, for thematic analysis. Principles guiding the project formed the basis of the analysis, but not exclusively as new themes emerged these were incorporated into the evaluation.

Findings

Findings are structured according to concepts driving the project and presented with the support of participant's narratives.

Participation

Kiernan (1999) talks about the paradigm shift, in social science, where research took place *'with'* rather than *'on'* people. This shift defied research practices reducing people to 'natural' phenomena and where researchers maintained distance from their 'objects' of study (Kiernan 1999). Miranda *et al.* believe this *"helped to challenge the hegemony of neo-positivist empiricism that, for many years, characterised social research production"* (2013:86). This shift is reflected in the Disability Movement slogan "Nothing About Us Without Us". Kiernan asserts this participatory paradigm aims to *"explicitly 'ground' studies in the experience and views of respondents"* (1999:43).

Participation opens opportunity for hearing collective voice and meeting others. Furthermore, participation in

conferences, of people implicated in research, increases their knowledge enabling them to make more informed decisions (Zakrzewska *et al.*, 2009). Zakrzewska's study about end-users participation in conferences recommended *"... supply newcomers with a vocabulary list of words used frequently by the session leaders and moderators"* (2009:489). This recommendation was reflected in the evaluation:

"... beforehand they could match the people with the sessions and just like colour codes ... relevant session themes could be indicated like ... this is more emotional or more technical for example" ...
... "... what you have to look out for is that you have to make it very clear for someone ... when there is something and they don't know what the subject is then you can do something about it ... you can make it clear what level it is ... if it is emotional or theoretical ..." [Buddy without learning difficulties].

Buddy

Most literature about buddies for a person with learning difficulties was within the context of primary school and stressed the importance of not conceptualising such people as eternal children (Björnsdóttir and Traustadóttir, 2010; Stalker, 1998). This notion was reflected in the group interview by a buddy with learning difficulties:

"In little groups you can talk very good... but uhm, it is not like children ... [like] you go to the church and then the minister sends the little children out ...
Researcher: "like Sunday school"?
"...yes then we can go in the work group ... together but not like Sunday School Children ..."

Although not explicitly mentioned, but perhaps also inferred here is that people with learning difficulties do not

want others determining if they are 'competent' enough to follow proceedings, as often happens when adults in church make decisions *'for'* children in services.

The 'buddy' concept also appeared frequently in literature about smoking cessation programmes. Here, it was implied that programmes generally overlook support needs, preferences and gender and socio/cultural status (Stewart *et al.*, 2010).

This idea of considering individual needs and preferences is reflected in the following comment:

"... if you do it with everyone [not pre-determined buddies] at the conference... they can help you ... and ... can have ... the same interest as somebody who is there ..." [Buddy with learning difficulties].

He clearly believed ensuring this 'complementary match' would create a supportive and amicable relationship.

Support

A supporter should promote a sense of security and safety and this was echoed by a buddy:

"I was only her safe point, if she didn't see anyone, she would come back to me" [Buddy without learning difficulties].

More than once the participants in this study said the supportive buddy made things a lot 'easier' as implied in the following statement:

"... level of the sessions ... sometimes it was easy to get [follow] and sometimes it was emotional and personal and that you can bring to the point easily" [Buddy without learning difficulties].

In reference to support for language and meaning translation, people with learning difficulties said this was 'essential'. Translation of 'meaning' was also important as buddies could relay information in a meaningful way for their buddy, for example through diagrams, analogies and easier language:

"It was indeed good for translation and for explanations so you could understand" [Buddy with learning difficulties].

Mutual exchange of knowledge

Mutual exchange of knowledge is important for feelings of inclusion. Despite this, most buddies felt this did not happen:

"You have a research conference ... you share ... at an intellectual level ... all the researchers they know the research they know what it was about, they can ask each other the right questions ... Who have you researched and why? ... What methods have you used? ... What measuring tools did you use? ... What were your findings, blah blah ... but... this is not interesting for clients [people with learning difficulties] ..." [Buddy without learning difficulties].

She continued:

"The key is... can you ask the clients about the research? The other thing is you have the results of the research and you can have a discussion about the results ... you can say what you found ... what you found in their neighbourhood, and then ask the clients what they think about it".

Miranda-Galarza *et al.* claim "Personal knowledge represents the embodied unique capital of each individual and when marginalized social groups become conscious of such capital, it can provoke changes in both individual and collective life" (2013:86). This highlights the importance of acquiring knowledge to create 'change' as is captured in this comment:

"I want to listen to what she [buddy with learning difficulties] has to say, and to learn from that ... I learned ... she felt like a hero ... I already thought ... you are a hero, you ... come here and ... take a step in your life and that is important for all of us, that you take steps in your life even if they are not easy... for her, it's more normal that things are not easy, and ... we get a little bit spoiled ... so that was my lesson" [Buddy without learning difficulties].

There was some scepticism about the ability of people with learning difficulties to exchange knowledge, as is reflected in the following statements from a buddy without learning difficulties:

"The clients were involved in the research but I don't know if it was interesting for the clients to hear the results... we have to search for a way to really let them be in a conversation ... otherwise it is just like tokenism ... we call that in Dutch an 'excuus Truus' ..."

"The most important thing was ... they had a nice day out ... they love it because, wow, it is interesting ... but I think deep in their hearts they must think what is in this for me other than a nice day out?"

This implies that including people with learning difficulties in 'mainstream' activities is fraught with complexity, begging the question: "what and whose needs are being

met”?

Consider this in relation to the following comment from a person with a learning difficulty the group interview about ‘presenters’ at conferences:

“They have it in there [tapping his head] but they don’t feel it here [rubbing his stomach]”

Continuing this line of thought, another participant indicated the buddy translated well but was ‘*not a bridge*’. Alluding to the perception there was no knowledge exchange, rather a one-way transfer of knowledge. This concern is reflected by Meininger (2013) who believes efforts for social inclusion often disregard ‘otherness’ and push for people to be moulded into self-confident and assertive citizens. Walmsley (2004a) warns, some ‘inclusive’ efforts towards normalization attempt to deny difference and do not result in clarity and added value. The challenge lies in striking a balance between rights for autonomy, independence and egalitarianism and searching for ways to relate interdependently. Research should lead to ‘dialogue’ between the research community and disabled people which in turn should empower people (*ibid*).

Belonging

The theme ‘The Art of Belonging’ not only reflects DSiN aspirations to encourage high levels of participation of people with disabilities, but also the centrality of this concept when engaging disabled people in research. Nind *et al.* assert “*belonging encompasses the desire for some attachment with people and spaces*” (2012: 653). The importance of relationships for processes of belonging reminds us that belonging extends beyond what identity can capture as it is both relational and contextual. Some buddies indicated that a feeling of “belonging” was not really the case:

“You come on the party with the professors and with the other people from the congress ... and then we people with learning difficulties are there ... we have a really nice party, but the professors and the other people ... talk about people but don’t go to the people” [Buddy with learning difficulties].

Meininger (2013) addresses such sentiments when exploring spaces of encounter between people with and without learning difficulties. Drawing on Foucault’s ‘*places of otherness*’, he explains the difficulty experienced by both groups. Dialogue occurs between the ‘normal’ and ‘abnormal’, ‘familiar’ and ‘strange’. The encounters occur in social spaces transcending geography or specific life domains.

These spaces will be places where people with learning difficulties are treated as ‘normal’. Meininger believes the challenge lies in creating new spaces of encounter “a

relational space where people who are ‘other’ meet and communicate” (2013: 32).

Efforts to increase a sense of belonging for people with learning difficulties in a conference setting should acknowledge differences, and offer support. The following statements about the buddy role echo this notion:

“... it was very important for the understanding of what was happening ... it gave ... some structure ... some understanding of what would happen when and how” [Buddy without learning difficulties].

“... [it] was really important for me ... to explain what was happening, to tell where things were happening ... if there was no buddy I could not have managed at the conference” [Buddy with learning difficulties].

It would be remiss to talk of participation, supportive buddy roles, knowledge transfer and belonging, without paying attention to the concept of ‘voice’.

Voice

Nind *et al.* (2011) remind us, voice is intrinsic to rights and we need to exercise caution when helping people express opinions. We must avoid tokenism and promote the right for voice, of people with learning difficulties, to be heard in a meaningful way that embraces difference. The challenge is to counter exclusionary hegemonic academic environments and promote participation in a way that does not backfire and reinforce feelings of exclusion. This is crucial when voice is expressed in unconventional ways often termed ‘deficient’. The perception of ‘deficiency’ creates barriers to listening to these voices (Nind, 2009).

Drawing on Lundy (2007), Nind *et al.* (2011) remind us “*Voice is not a panacea*” and “*enabling voice is insufficient for active participation in decision-making without that voice being accompanied by space, influence and audience*” (2011:3). This is a critical issue for this evaluation. The aim was to increase inclusion of people with learning difficulties so their voices could not only be heard, but make a valuable contribution to the conference, a space with an influential audience. Walmsley (2004) acknowledges the need for people with learning difficulties to have ‘allies’ if their voice is to be heard. This acknowledgement is reflected by one of the designers of the project:

“One of the main questions for Disability Studies is, how do we hear the voice of people with learning difficulties and how do we ensure that voice contributes to what we do”?

Two conference attending participants, uninvolved in the project, were sceptical about it. Both are involved in disability organisations and are strong proponents of

Social Role Valorisation (SRV) with considerable experience organising disability conferences. They maintain these always have a high level of participation of disabled people. Explaining their scepticism, they offered the following account, of a person with learning difficulties, at one of their conferences who was using audio-technology for translation. He removed his headset and:

"... recognized ... he [the presenter] is talking about me and about what matters to me ... we were sitting in the back and can you imagine we really spent a huge amount of money on the translation problem ... one of the presenters said "well, does anybody have a question"? ... he stood up and ... asked a quite to the point question ... there were support workers and they were really astonished ... and said a bit too loud ... "I didn't know he spoke English" ... the person with the disability looked at the support worker and said "do you know how many hours a day I watch television because I have nothing else to do?"

Another and perhaps stronger reason for the objection to the buddy project was related to their belief about the impact of such a project on people's identity:

"I think that instantly when you put a label ... there might be people with a disability who don't need it [and think] why am I offered this? Am I so special? ... And maybe just introduce some people to one another ... not in the way of I'm here to make sure that you need him and he has a disability... Please. He's just like you are, no?"

There is undoubtedly merit to these views, driven by values of social justice, that address early misconceptions about the lack of competence of people with learning difficulties. There are a few concerns, however, as they may enhance an image that denies 'differences' making it difficult for people with learning difficulties to navigate unfamiliar spaces. Furthermore, these views do not resonate with the experience of some of the buddies who acknowledged having a 'learning difficulty identity' and welcomed support from a person without this identity.

As disability researchers, sensitized to understandings of 'normalization', we need to exercise caution against denying difference (Culham and Nind, 2003; Walmsley, 2001). The challenge is to strike a balance between acknowledging the needs of people with learning difficulties to participate and contribute to work that is about them and simultaneously ensure 'help' that is offered does not threaten their integrity and dignity.

Limitations

The original evaluator of this project was unable to

complete the evaluation due to unforeseen circumstances. The replacement evaluator was less familiar with the project and its participants and had to deal with time constraints. Furthermore, she does not have a solid command of the Dutch language. The recruitment of more participants with learning difficulties attending the conference would have strengthened the evaluation. Finally, the evaluation would have been stronger had more conference attendees with no knowledge of the project been recruited.

Conclusions and lessons learned

This evaluation affirms the importance and complexity, of including people with learning difficulties in academic endeavours. Despite increasing recognition for inclusive research, nothing has been published about including people with learning difficulties in disability conferences. DSiN attempted to address this gap by designing and implementing a 'Buddy Project'. Evaluation results indicates this may not be the best way to address this issue, but nevertheless there are important lessons to be learned:

- Participants believed the project was useful for translating 'language' as well as translating the 'meaning' of content.
- It was less useful for encouraging *mutual exchange* of knowledge. It was felt transfer of knowledge was unidirectional and *exchange* was limited. As one participant with learning difficulties said, "There was no bridge".
- Efforts to involve people with learning difficulties in disability conferences is important.
- People with learning difficulties should be facilitated to engage in decisions about how this should happen.
- Collaboration is needed to ensure inclusion and participation is genuine and affords dignity and integrity for all.

We need to ensure inclusive efforts do not reinforce academic agendas of exerting power and influence in the research arena.

Four possibilities for active and meaningful participation of people with learning difficulties in disability conferences emerged in this evaluation:

- 1) Increase awareness of conference organisers about this need.
- 2) Do not organise a buddy project as this inherently implicates a 'non-inclusive' concept as, almost by definition, such a project requires 'exclusive' attention for people with learning difficulties.
- 3) Encourage people with learning difficulties to find their own buddy.
- 4) Design a buddy project for conferences but ensure full participation of people with learning difficulties in the design of the project.

- Offer everyone at the conference the opportunity to buddy someone (to increase chances for compatibility)

- Colour code sessions to indicate the level or type of session to be held

- Invite people with learning difficulties to a podium to be interviewed, so others present can have a better understanding of their lives

- Increase the number of small interactive groups

- Have a 'banner making' session prior to the conference where people with learning difficulties can make a banner about what they want to say and use these when they want to say something in a large group

Figure 2. Recommendations from people with learning difficulties

Recommendations

Inclusive conference planning must aim at bridging the gap between academic goals and the 'flesh and blood' issues of people with learning difficulties. Whichever possibility is opted, for we must create space and opportunity for people with learning difficulties to voice their ideas and act on them.

It is therefore, fitting to conclude this paper with recommendations from participants with learning difficulties (Figure 2).

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