

PARTICIPATORY EXPLORATION OF FACTORS INFLUENCING THE HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITIES IN AN URBAN DISTRICT: A PHOTOVOICE STUDY

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Abstract: People with intellectual disabilities (ID) may face multiple disadvantages regarding their physical and mental health. They tend to be more vulnerable to risks of illness (associated with their impairment, medication intake or social determinants, like low socio-economic status) and are confronted with various barriers in health care and health promotion (e. g. communication or programmatic barriers). This study aims to gain a better understanding of the health-relevant factors people with ID experience in their everyday life in an urban area in Germany. An inclusive research workshop was held at the Catholic University of Applied Sciences Berlin. Ten adults with ID and six members of the university (two students, four academic researchers) joined the workshop and worked together as a research group. Photovoice, a participatory research methodology, was utilized. The research group collected data by taking photographs and discussing the pictures within the group. This process resulted in a set of qualitative categories and themes. The health-relevant factors identified were multifaceted. They ranged from housing and working conditions to the effects of keeping pets or being affected by racism and discrimination. The findings were prepared in form of an exhibition, providing a basis for developing municipal strategies for inclusive health promotion.

Keywords: People with Intellectual Disabilities, Participatory Health Research, Photovoice, Municipal Strategies of Health Promotion

Introduction

People with intellectual disabilities (ID) are considered to be a vulnerable group in regard to health problems. The prevalence of ID across the world is estimated to be around 1%, with higher rates in low and middle income countries (Maulik *et al.*, 2011). ID can be described as a “group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills” (Carulla *et al.*, 2011, p. 177). Studies, mainly from high income countries in Europe, North America, and Australia, indicate that in comparison to the general population people with ID are more likely to suffer from poor physical (Cooper *et al.*, 2015; Emerson *et al.*, 2016; Walsh *et al.*, 2008) and mental health (Cooper *et al.*, 2015; Cooper *et al.*, 2007; Morgan *et al.*, 2008), and that their life expectancy tends to be lower (Bittles *et al.*, 2002; Heslop *et al.*, 2013). Some of these disadvantages may be explained through the disability itself, as for example Down's syndrome which is linked to a higher risk of congenital heart defects or respiratory tract infections (Haveman and Stöppler, 2014, pp. 212–215). In this context it should be also noted that people with ID have a relatively high and questionable medication intake that may cause additional adverse effects (Doan *et al.*, 2013; O'Dwyer *et al.*, 2016; Robertson *et al.*, 2000; Tyrer *et al.*, 2008). Recent research on the implications of certain lifestyle factors like nutrition and physical activity (Koritsas and Iacono, 2015), the perceptions of neighbourhood quality, social and civic participation (Emerson *et al.*, 2014), the experience of discrimination (Emerson *et al.*, 2014) or violence (Krnjacki *et al.*, 2016) emphasises that the health situation of people with ID is further influenced by social determinants.

Social determinants of health refer to the circumstances in which people live and the underlying systems that shape those circumstances, for example socio-economic status, experiences of social exclusion or social support, food supply, or transportation (World Health Organization, 2003). As people with ID are often excluded from regular education systems and the professional job market due to their impairments, these aspects seem to be of crucial importance for understanding the disadvantaged health situation of people with ID.

Given the problematic situation illustrated above, there is a need in many countries, including Germany, to develop appropriate and accessible health care services for people with ID (Hasseler, 2015; LGK NRW, 2013; Roser *et al.*, 2011). People with ID often experience barriers in health care settings, such as communication problems, inadequate facilities or inflexible procedures, as well as insufficiently trained health professionals (Alborz *et al.*, 2005). Also, in regard to health promotion strategies, people with ID seem to be overlooked, as there are relatively little programmes targeting or including this group of people (Burtscher, 2014).

Considering all these factors, the reasons for the poorer health status of people with ID seem to be complex and multifaceted, further indicating that people with ID may not only experience health disparities, but also health inequity (Hatton and Emerson, 2015). The participatory research project “GESUND!” is aiming at closing the gap between the people's needs and the lack of tailored health promotion strategies (Allweiss *et al.*, 2016; Burtscher, 2014). An aim of the project is to seek a better understanding of health-relevant factors which people with ID experience in their everyday life in their neighbourhood and to use these insights to develop integrated, inclusive health promotion strategies at the municipal level.

Methods

In our research we were adhering to a participatory research paradigm (International Collaboration for Participatory Health Research, 2013). That means that those people affected by the subject of the study were actively involved throughout the research process. Participatory approaches are increasingly being recognised in the field of public health, special education and related disciplines (Buchner *et al.*, 2016; International Collaboration for Participatory Health Research, 2013). Participatory health research is characterised by partnerships between academic institutions, community members (for example people with disabilities), health professionals, decision makers and other engaged stakeholders. An important goal of participatory research is the contribution to social change and broad impact (International Collaboration for Participatory Health Research, 2013). The potential positive effects of such approaches are assumed to include increased research quality, empowerment and capacity building among the persons involved, the sustainability of interventions, and the creation of systematic changes (Jagosh *et al.*, 2012).

The research method utilized in the project was *photovoice* (Wang and Burris, 1997, 1994). Photovoice is a qualitative visual research method. It is usually carried out as a group activity, in which data is gathered by taking pictures, telling narratives about the pictures and subsequent discussion. Joint analysis of the data enables a deep understanding of participants' conceptualization of a given situation, community, or problem. Photovoice was developed by Wang and Burris (1994) and aims to (1) enable communities to identify and reflect on their strengths and concerns, (2) encourage critical dialog and knowledge, and (3) reach policy makers (Wang and Burris, 1997).

Procedures and participants

The procedures of the study will be described, based on the seven phases of photovoice proposed by von Unger (2014, 71ff):

1. Planning and preparation: This phase was determined by developing an infrastructure for the study, including the recruitment of participants (in the following referred to as co-researchers) and target audience members. Research partnerships were established on two levels: (1) A community of inquiry composed of academic researchers and people with ID was organized to work together during data collection, analysis and

presentation of findings; (2) Existing partnerships between the academic institution, the local government and a sheltered workshop were used to facilitate the research process and to support the dissemination and exploitation of results. Co-researchers with ID were recruited from a cooperating sheltered workshop in Berlin-Lichtenberg. Inclusion criteria for participation were communication skills, ability to get to the workplace independently, and dependability regarding meeting attendance. Type and severity of the disability were not criteria for the selection of co-researchers. However, the inclusion criteria listed above indicated a mild to moderate ID. Most of the included co-researchers had already participated in a previous health education and research activity which was carried out within the scope of the “GESUND!” project. So, they had already gained basic knowledge about a variety of health subjects and had been trained in basic research methods. Altogether, the community of inquiry consisted of ten adults with ID (five women, five men; 26 to 65 years old) and six members of the university (two special education students and four academic researchers from the “GESUND!” team; four women, two men; 23 to 47 years old). In the group process, the co-researchers with ID assumed the roles of researchers and experts in their own lives; whereas, the students and academic researchers assumed the roles of moderators, facilitators, and researchers.

2. Training of co-researchers: In the time between October 2016 and March 2017 an inclusive research workshop took place at the Catholic University of Applied Science Berlin. The inclusive research workshop was similar to a seminar with weekly meetings and provided the setting for the entire research process. The theoretical basis for the workshop was the paradigm of participatory health research (International Collaboration for Participatory Health Research, 2013) and the Determinants of Health model by Dahlgren and Whitehead (1991). In preparation for the study, four morning seminars were held on the Determinants of Health model, the local municipality (district of Berlin-Lichtenberg) and on the correct and ethical use of cameras. Visualisation and the use of plain language was a key didactic element during the whole project. Furthermore, we clarified and discussed the objectives and questions of the forthcoming research: What helps us/ what hinder us to live a healthy life in Berlin-Lichtenberg?

3. Field phase: The study was conducted in the district of Berlin-Lichtenberg, Germany. The district has over 280,000 inhabitants (Amt für Statistik Berlin-Brandenburg, 2016) and lies in the eastern part of Berlin. Photographic data collection was mainly carried out during so called “neighbourhood walks.” Small groups, consisting of two co-researchers and an academic researcher or student, came together on two occasions to take walks through the district. The co-researchers took selected pictures according to the following instruction: Take one or more pictures of what makes you happy in your life or is good for you, what makes you angry in your life or what is not good for you, and what you think is unjust in your life.

4. Discussion: In this phase, discussions about the pictures were held in three small groups (with around 5 members each). In preparation for the discussions, each co-researcher chose five pictures most relevant for her/him and answered questions about the pictures on a worksheet. The questions on the worksheet were the same that were asked in the discussion rounds. They were based on the “SHOWeD” formula, which stands for: “What do we **S**ee here? What is really **H**appening here? How does this relate to **O**ur lives? **W**hy does this situation, concern or strength **E**xist? What can we **D**o about it?” (Wang, 1999, p. 188). After the narratives and answers of the photographer, the group was encouraged to ask questions, reflect on the picture, and to add their own experiences and interpretations. Emerging thoughts and ideas were noted. As the discussions are an important part of data collection, they have been recorded and transcribed.

5. Analysis and results: Data analysis was a two-step procedure. Subsequent to the discussions, a first coding process was carried out in the three working groups. The pictures and notes were sorted, and headings were identified and assigned to groups of similar data. This led to an initial categorisation of findings. The procedure intersected with the previous phases, as photography, discussion and categorisation comprised an iterative process. Step two was carried out solely by the academic researchers in order to combine and extend the findings of the three working groups. The original picture narratives, notes, and discussion transcripts were included in a structured, but simplified, content analysis (Kuckartz, 2016) using the software program MAXQDA. To value the work of the co-researchers and to guarantee the comprehensibility of findings, we adopted the codes of the working groups and kept to a low level of abstraction. The analysis yielded the

identification of main topics that were presented and discussed within our community of inquiry. Each co-researcher then chose the topic that was most important to her/him and another phase of exploration began: small discussion rounds about the topic, including narratives about the co-researcher's personal relationship to the issue, and a review of the previously collected data on the topic. This process allowed for a deeper understanding of each topic and provided the basis for the presentation of our results in the form of a poster exhibition.

6. Presentation and use: Each co-researcher was responsible for the presentation of one main topic. With the assistance of the academic researchers, every person created her/his exhibition poster using photographs and texts from the preceding phases. The posters, the main result and product of the study, combined both, (a) the findings from the participatory research process and (b) the author's personal relationship to the topic. To date, the exhibition has been shown on three different occasions (the research workshop closing ceremony, an exhibition at the cooperating sheltered workshop, and during the health campaign days in a local shopping centre) to a diverse audience, including local citizens, representatives of local government and service providers.

7. Evaluation: The following questions provide the focus of the project evaluation: Were the objectives achieved? How satisfied were the people involved with their participation? What impact did the photovoice project have on politics, policy-making, living conditions, community health and other possible areas of influence? (Unger, 2014, p. 76) The evaluation is still in progress and is mainly based on interviews conducted with the co-researchers and the field notes taken at every workshop meeting and exhibition event.

Results

Table 1 summarises the health-relevant factors people with ID had identified in their everyday life in Berlin-Lichtenberg. The findings are presented as they were shown in the poster exhibition.

Table 1 Findings as presented in the "GESUND!" poster exhibition

Title	Main topic and related categories	Description of findings as presented on the posters
Christian, the mobile man	Public transport, comprehensibility of information	Trams and trains are Christian's hobby. On his poster he complains about the information given at stations, which are sometimes confusing or non-existent. He also reports that there are still old trams in use which have steps and are not easily accessible; that some public transport connections are not matched well; and that the traffic light cycles are often too short.
Christiane's crime story and poems	Road safety for pedestrian	Christiane was hurt in a road accident when she was little. Since then, she has problems walking. Tripping hazards, like potholes, and pedestrian unfriendly traffic light cycles impede her mobility.
My block of ice	Managing life with little money, housing conditions, self-determination	The author of this poster describes his housing situation in an apartment block that is in poor condition (broken windows, malfunctioning heating system, and a lift, which is regularly out of order). On the poster, he reproduces a discussion with his peers about his rights as a tenant and the difficulties he has encountered with his landlord. He states that it is very difficult to find an affordable place to live.
How I live	Self-	Independent living and self-determination are very

Title	Main topic and related categories	Description of findings as presented on the posters
	determination, living and support arrangements	important subjects for the author who lives alone with her dog and gets assistance from her brother-in-law. But she also recognises that every person is different and needs different living arrangements and levels of support.
Animals are man's best friend	Keeping pets, dealing with loneliness, managing life with little money	Her own pets, as well as animal welfare, are essential aspects of the author's life. She describes that her pets are helping her feel less lonely and stay psychologically stable. However, she also remarks that keeping pets requires money and effort, and that pet owners also have to handle the illness and death of their beloved animals.
My work life	Working conditions, subsidised and regular labour market, managing life with little money	The author of this poster chose the topic work because he really likes his job as a handyman in a sheltered workshop. On the basis of his own workplace, he describes some assets and drawbacks of work, like social bonding vs. social conflicts, or assistance and support vs. control and authority. He further addresses the issue of working in subsidised labour and points out that although his job is secure, his income is very low.
From hobbies and passions	Recreation through hobbies, managing life with little money, education	Nicole is a passionate cook. For her and her co-researchers hobbies are an important source of relaxation. Nevertheless, for Nicole it is sometimes difficult to follow her passion with her little income. She is further missing educational offers in plain language.
Relaxing in the neighbourhood – Sven's story	Recreation in nature, environmental protection, keeping pets, social interactions	Sven is a dog lover and enjoys being at his dog place in nature. It is his way of relaxing and meeting up with his friends. He is worried about pollution and garbage disposal in the green areas of his neighbourhood.
From art and smearings	Appearance of living environment, aesthetics	This poster is a narrative on the living environment of the author. The big prefabricated buildings in her neighbourhood are often grey and smeared. Paintings and artworks are a welcome feature of a more colourful and pleasant environment.
Wake up!	Peaceful coexistence, experience of racism and discrimination	The author of this poster sees himself as interested and vigilant in regard to politics. He is concerned about discrimination, racism and right-wing violence. He points out that next to foreigners and other minority groups also people with disabilities can be affected. Tolerance and peaceful co-existence are important to him. Remembering German history is one way of dealing with this issue, he states.

Discussion

This participatory research project explored the perspectives of ten persons with ID on their health-related needs, experiences and perspectives regarding their life in the urban district Berlin-Lichtenberg. The results

show what they considered to be important factors for their health and well-being. The emphasis lay on a safe and satisfying life in regard to mobility, housing, work, leisure activities, living environment and societal interactions. The right of the individual to self-determination had a high priority, being addressed in discussions about the different housing situations of the co-researchers and about the advantages and disadvantages of the subsidised vs. the regular labour market. An aspect that was considered as challenging, being raised in different contexts, was living with little money. All our co-researchers were dependent on some kind of income support because they were working in a sheltered workshop (subsidised labour market). Further, a specific barrier related to the ID of the co-researchers came to light: the need for information which is easy to understand, as reflected in complaints about confusing information at train stations or the lack of educational offers in plain language.

Although the results of the photovoice study clearly reflect the specific local situation and the unique perspectives of our community of inquiry, some of the findings reflect the broader literature on the social determinants of health and people with ID. For example, the importance of peaceful coexistence and prevention of discrimination, which was identified as one health-supporting factor in our research, was also identified by Llewellyn *et al.* (2015). On basis of their literature review, the authors report that people with ID seem to be more likely to experience discrimination, and that those experiences may correlate with poorer health outcomes (Llewellyn *et al.*, 2015). Social interactions and loneliness, also identified as factors influencing the health of our co-researchers, has also been identified in other studies (Emerson, 2010; Gilmore and Cuskelly, 2014; Stancliffe *et al.*, 2007), indicating that people with ID are highly vulnerable to loneliness. However, the scientific evidence on experiencing discrimination or loneliness is limited and the association between exposure to these factors and the health of people with ID has been rarely investigated directly.

As our findings identify concrete issues which people with ID face in their everyday lives in Berlin-Lichtenberg, we suggest using our research as a basis for developing municipal strategies for inclusive health promotion in the district. An initial step in this direction has already been taken through the public exhibitions of the photovoice project that were attended by local politicians and stakeholders from services for the disabled. A recent invitation to show the exhibition at the city hall of Berlin-Lichtenberg might further raise awareness about the situation of people with ID among local policy makers. However, at this point in time, it is not possible to anticipate the impact of the photovoice project on politics, policy-making, living conditions, community health or other possible areas of influence.

In regard to effects at the individual level, it is possible to state some preliminary findings: First of all, the co-researchers' feedback on their participation has been very positive and they seemed to be very proud about the poster exhibition and the responses of the audience. As stated in the methods section, participatory research has the potential to initiate a growth in professional capacity and competence in the persons involved (Jagosh *et al.*, 2012). A process of empowerment and gains in competency were observable among the co-researchers (e. g. sharing information and experiences with peers, speaking in front of the group, presenting one's views publicly). Further, an increased awareness about a healthy lifestyle and other determinants of health (e. g. a growth in environmentally conscious behaviour) were identified by the co-researchers. We believe that the co-researchers may have experienced a valorisation of their social role (Wolfensberger, 1999) by participating in the project. Particularly, the egalitarian relationship and cooperation between academic and non-academic researchers seemed to play an important role in this context.

Photovoice is a highly accessible approach that has been shown to be an appropriate methodology to conduct research together with people with ID. The different phases, steps and tasks during the research process are adjustable to different skills and levels of competency, and thus enable the involvement of people with ID. Reading and writing skills are, for example, not necessary. Another strength of the methodology is the visibility of the results, as they are not only theoretical constructs written down in an academic journal, but also objects to see and to touch. Nevertheless, there are also limitations. Photovoice is a qualitative approach, its local dimension and the emphasis on participatory process limits the transferability and representativeness of the results. Furthermore, it cannot be answered to what degree the data may have been influenced by the research context. In regard to the visibility and public nature of the approach, there may be the risk of

reinforcing the social stigmatisation of persons with ID, especially when the expectations of the audience about scientific complexity or high gloss presentations are not met.

In conclusion, the research project provided a framework for people with ID to reflect on their lives and gave them a voice to draw attention to their opinions and concerns. New perspectives on a vulnerable group were offered which show that participatory processes are able to empower people with ID in various ways.

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