Goethals, Tina; Van Hove, Geert; Van Breda, Lien; De Schauwer, Elisabeth

Researching together: voice as a guide in research

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Kontakt / Contact:

peDOCS
DIPF | Leibniz-Institut für Bildungsforschung und Bildungsinformation
Informationszentrum (IZ) Bildung
E-Mail: pedocs@dipf.de
Internet: www.pedocs.de

Mitglied der Leibniz-Gemeinschaft

Tobias Buchner
Oliver Koenig
Saskia Schuppener
(Hrsg.)

Inklusive Forschung

Gemeinsam mit Menschen mit Lernschwierigkeiten forschen

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Buchner / Koenig / Schuppener

Inklusive Forschung

Tobias Buchner
Oliver Koenig
Saskia Schuppener
(Hrsg.)

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Methodologische Reflexionsansätze

Tina Goethals, Geert Van Hove, Lien Van Breda und Elisabeth De Schauwer

Researching together: voice as a guide in research

Summary

This chapter seeks to explore the many meanings attached to 'voice' in research, with a particular emphasis on the different modalities voice can have in the field of inclusive disability studies. The interpretation of the six different perspectives of voice is based on the framework of Lawrence-Lightfoot and Davis (1997) and is contextualized within the work and engagement of the self-advocacy network in Flanders. The combination of these six aspects of voice led to the construction of a particular research design where voice is manifested through the chosen methodology, the various roles and various selves of the researchers and the subjects, the research tools and analysis. Drawing on the ideas and insights from a research project about political participation of persons with an intellectual disability in the self-advocacy network, tensions in the research process are explicated and research choices are discussed.

1 Context

This chapter was born out of a critical qualitative study on the political participation of persons with intellectual disabilities in Flanders, the Dutch-speaking part of Belgium. In this study, we attempt to explore and support the political and civil participation of such persons with regard to their involvement in political discussions. Concretely, by political participation we mean the participation in municipal, provincial and national policy bodies and politics, and not in councils of service providers or non-governmental organizations for persons with a disability. In a recent collaborative research project (Goethals & Van Hove 2011) it was found that persons with intellectual disabilities want to participate in political discussions and decision-making. Despite this statement, we were unable to find Flemish citizens with an intellectual disability who were 'politically active'. Political involvement, when existing, was limited to gettinging out a vote during the elections (ironically, the Dutch translation of 'to vote' is 'stemmen' or 'voices'). These findings led to the Flemish self-advocacy movement 'Our New Future' (ONT vzw, Onze Nieuwe Toekomst) setting up a concrete project which started at the beginning of 2012 to ensure that barriers to participation could be tackled. Within this study we organized a follow-up of this project, following a dozen persons with intellectual disabilities and the advisors who support them in different local participation projects. Experiences and perspectives were gathered through multiple data sources, making use of a variety of qualitatively adapted methods, such as photo voice, portraiture, observations, case studies and interviewing. Following the principles of collaborative research (Gibbs 2001), much attention was given to critical success factors, strategies and barriers that support or hinder participation.

2 The meaning of voice in research

One of the leading questions within Disability Studies is how to capture and fully include the voices of persons with disabilities and how to create opportunities for traditionally marginalized perspectives to be heard (Ashby 2011, Barton 2005,Garland-Thomson 2005, Goodley & Van Hove 2005). To respond to this need, Disability Studies introduces, inter alia, the use of different approaches such as narrative methods and dialogue in research (Booth & Booth 1996, Goodley 1996, 2000, Atkinson & Walmsley 1999, Nind 2012)

> *"in order to understand the social production of life, we need people who story their lives to structure and give meaning which lends some insight into the experiences and realities of people as active human subjects"* (Roets, Van de Perre, Van Hove, Schoeters & De Schauwer 2005, 104f.).

However, due to the almost universal and enduring silencing of the voices of persons with intellectual disabilities, it is difficult to see how Disability Studies researchers can give meaning to the different modalities that voice can have in research. As Walmsley and Johnson (2003) state, clearly articulated voices and roles are often camouflaged in inclusive research, making "the research itself becoming blurred and subject to misinterpretation." (201f.)

At the same time, according to Lawrence-Lightfoot and Davis (1997), voice is everywhere in research: "overarching and undergirding the text, framing the piece, naming the metaphors, and echoing through the central themes." (85f.) The researcher's imprint is always visible in the choice of theoretical framework, the selection of the research questions, the methodology, the choice and collection of the data, interpretation and assumptions. "The researcher's hand – revealed in the conceptual orientation, the disciplinary lens, the methods and design [and probably in personal disposition] – is certainly present and shaping the work"

(86f.). Pure objectivity with a rigid detachment of the researcher from the 'subject' does not exist, and more and more is replaced in much contemporary feminist research, by an ethic of involvement (Wilkinson & Kitzinger 1996): "clarifying and being 'up front' about one's stake replaces the notion that one should have no stake." (50f.)

In considering this ubiquity of voice, an initial and pertinent question concerns the involvement of the researcher. The research project described in this chapter, where the political participation of persons with intellectual disabilities is studied in the context of the Flemish self-advocacy network, for a number of reasons involves the active association of the researchers instead of the more classical stance of objectivity which researchers in the traditional modernistic approach hold dear (English 2003). Firstly, the research is imbedded in the self-advocacy movement where vivid dialogue and close collaborative relationships between researchers and self-advocates are an essential and omnipresent feature. Shared participatory knowledge production and collaborative research methods serve here as natural allies of self-advocacy (Atkinson 2002). Secondly, through working with different narrative methods in this study, Booth (1996) argues that this implies intimate (research) relationships between the researcher and the subjects, and an intertwining of the cultural, political and theoretical background of the researcher in the study. Thirdly, multiple data (voices) challenges the position of the researchers in relation to voice since such data accentuates the movement of language and voice as a performative act that destabilizes the real. Hence, the researchers and participants engaged in on-going, long-term research relationships and conversations within which actions and discourse are shared, openness is negotiated and opportunities created whereby processes of de- and re-construction of alternative truths and identities are strengthened (Braidotti 1994). Consequently, conducting this inclusive research on the political participation of persons with an intellectual disability, presented a number of ethical and methodological challenges.

In this chapter, we would like to take the audience from ideology to research reality. The work of colleagues who we see as 'role models' when talking about inclusive/collaborative/cooperative research projects (Goodley 2000, Walmsley & Johnson 2003) has provided a solid basis of support in this process. Starting with a concrete research project on the political participation of persons with intellectual disabilities, we took it as a challenge to take a stance as researchers and to examine how we can deal with 'voice' in research and handle the relationship between researcher and participant (see Tregaskis & Goodley 2005, Atkinson 2005, for facing similar areas of tension). We will illustrate and discuss some central topics about voice, starting with the conceptual framework of Lawrence-Lightfoot and Davis (1997) who identified six aspects of voice that might be useful for the clarification of the research steps, the search for adapted methods and ethical positioning. Lawrence-Lightfoot and Davis take portraiture – a qualitative research methodology that bridges science and art – as a starting point for exploring subjects' human experiences and complexities within a particular context, so as to identify several ways in which the researcher's and subject's voices are important for the research project. In portraiture, the making of the portrait is shaped through rich dialogue and collaboration between the portraitist and the subject in an effort to grasp the complexity and dynamics of human experiences. In particular, Lawrence-Lightfoot recommends that the researcher attend to six different aspects of voice: voice as witness, voice as interpretation, voice as preoccupation, voice as autobiography, listening for voice, and finally, voice in dialogue. Similarly, they caution the researcher on the manner of handling all these dimensions of voice in this complex and nuanced balancing act:

> "Each of these modalities of voice reflects a different level of presence and visibility for the portraitist in the text, from a minimalist stance of restraint and witness to a place of explicit, audible participation. In each modality, however, the chosen stance of the portraitist should be purposeful and conscious. Whether her voice – always dynamic and changing – is responding to or initiating shifts in dialogue, action, or context, she should be attentive to the ways in which she is employing voice. And although it is always present, the portraitist's voice should never overwhelm the voices or actions of the actors. The self of the portraitist is always there; her soul echoes through the piece. But she works very hard not to simply produce a self-portrait." (Lawrence-Lightfoot & Davis 1997, 105f.)

All of these dimensions of voice introduced by Lawrence-Lightfoot and Davis speak to the research used in this chapter. The research steps will be clarified and discussed through all these six categories of voice. Each layer of voice will be introduced by a quotation from Lawrence-Lightfoot and Davis to define the main aspects of the specific level of voice.

Voice as Autobiography

> "*The researcher brings her own history – familial, cultural, ideological, and educational – to the inquiry. Her perspective, her questions, and her insights are inevitably shaped by these profound developmental and autobiographical experiences. She must use the knowledge and wisdom drawn from these life experiences as resources for understanding, and as sources of connection and identification with the actors in the setting, but she must not let her autobiography obscure or overwhelm the inquiry.*" (Lawrence-Lightfoot & Davis 1997, 95f.)

Lawrence-Lightfoot calls this layer of voice "voice as autobiography". In this step it is recommended to share those aspects of the researcher's story that have direct relevance to the research project. We begin with voice as autobiography because it includes our history far beyond our work as researchers in the field of Disability Studies. As part of our unmasking of our choices and perceptions, we portray a brief overview of the personal and academic backdrop of the first author, as an introduction and invitation to this autobiographical aspect of voice.

> “I was raised in a small rural village in the countryside, with my two sisters, my father as a doctor and my mother as a medical assistant. Our house was situated on the hillside, and my father’s surgery was part of our house. Down the road, there was a big residential institute where a hundred people with disabilities lived. My father was the doctor for all the people living in that institute. As a child, I had no contact with those people with a disability. The only thing I saw was that there was often a specially adapted bike parked in front of our house; it belonged to the people with a disability who cycled up the steep road from the institute to see my father for a medical consultation. My only perception was that those people needed a lot of medical care, and I felt pity for them. Around the same time in nursery class, I had a friends called Iris, and she had a disability. I remember the game of climbing up the wheelchair with as many children as we could, and then Iris would turn in circles really fast. Iris was also my classmate in secondary school. She studied really hard, took the prettiest and most colourful notes, had a lot of fine humour and enjoyed it when we went shopping together after school. In contrast to the people from the institute who visited my father for a medical consultation and who – from my perception as a child – only needed medical care, Iris showed me that she was able to do something, to have preferences and dreams. Years later, I took this experience with me and started my academic studies at the University of Ghent studying Special Education. I also worked as a personal assistant to Sofie, a young woman with a disability. I look back on a warm summer day in the city, where Sofie and I were celebrating the end of the exams with a drink on a sunny terrace. A French family was having a chat with us, and was baffled by the way Sofie answered with ‘oui’ & ‘non’, by shaking her head and talking with her eyes focused on her communication book. The family was astonished that Sofie could understand them, that she could understand the French language, and moreover, that she went to a regular school where she learned that language. A lot of people are even more surprised that Sofie is now studying at the University and has a lot of friends. While I was studying and working with Sofie, I also got to know some leading and respected self-advocates within Our New Future, a self-advocacy group in Belgium, through volunteering as an advisor over the past six years. I discovered everyday life in collaboration and working on several projects on human rights. In sharing their stories, struggles, joys and dreams, we aim to “give voice” as a way to providing an alternative to the dominant discourse of disability and hope to bring positive shifts in beliefs and attitudes of society.“ (Tina’s research diary, 2012)

A number of “selves” come together in one person and in this study: the self who is a researcher, the self who was in the same class as a girl with a disability, the self who is an activist, the self who is a mother, the self who is a friend, the self who is a community member… All these multiple “selves” influenced the research and the voice as autobiography threads through the work, as revealed by the intensity of our dialogues, the nuances of our interactions, the questions we had in store, and our raucous laughter. Based on all these intensive shared experiences and dialogues, the stories of persons with disabilities in this study call up powerful responses within us, shaping our thoughts, interpretations and constructions. By engaging in the on-going process of situating ourselves and acknowledging our own filters, we realized that we conducted this study with the recognition that we live in an inherently "ableist" society, and so made the choice that one of the primary goals of the research agenda is to bring the perspectives of persons with a disability, who are all too often silenced within the community and within the political decision-making process, to the forefront. Our intention here is to unfold several aspects that are very important for our position today in working as researchers. Being introduced to 'real' persons and the confrontations with different relationships in working with and looking at people with a disability made small ruptures in our everyday habits of thought. These confrontations with the Other imposes becoming and demands the boundaries to become blurred and breached (De Schauwer & Van Hove, 2010). By never-ending learning through working together with people, listening to their stories and actively engaging with Iris, Sofie and many self-advocates, we were afforded endless opportunities for ongoing engagement and becoming. We were privileged to encounter a multiplicity of positions and relations that oriented, attracted and affected us. By going into and out of, and back and forth between these positions and encounters, we continually construct and deconstruct our own understandings. The knowledge and wisdom drawn from these experiences serve as resources for understanding and as sources of connection with the people with whom we work, and must be elucidated for every individual researcher.

Voice as Witness

> "*This use of voice underscores the researcher's stance as discerning observer, as sufficiently distanced from the action to be able to see the whole, as far enough away to depict patterns that actors in the setting might not notice because of their involvement in the scene. We see the portraitist standing on the edge of the scene – a boundary sitter – scanning the action, systematically gathering the details of behaviour, expressions, and talk, remaining open and receptive to all stimuli*" (Lawrence-Lightfoot & Davis 1997, 87f.)

This component of voice is identified by Lawrence-Lightfoot and Davis as that of the witness. It is used to express the outsider's stance "which looks across patterns of action and sees the whole" (Lawrence-Lightfoot & Davis 1997, 87f.). In doing so, we took advantage of our privileged position as eye-witness, volunteer advisor and researcher in and around the self-advocacy network. Locating ourselves in Disability Studies in Flanders, over the last years we became more sceptical observers of political participation, critical success factors and barriers that support or hinder the participation processes of persons with disabilities. During our participatory observations of self-advocates participating in political discussions and decision making, we were sometimes “able to perceive and speak about things that often go unnoticed by the actors in the setting because they have become so familiar, so ordinary” (Lawrence-Lightfoot & Davis 1997, 88f.). From a position on the boundary, we were able to witness the flow of conversation and grasp the continual interplay and interactions in which different mechanisms of professional and oppressive powers were at work. We will illustrate this with an extract from our field notes based on an event where Steven and Daniel, two self-advocates from around fifteen other persons with disabilities, were invited by a municipal servant, to give their opinions on how the city hall could be made more accessible for people with disabilities.

> „…We move in and out the corridors of an immense building. We pass elevators, staircases, rooms, offices, and a hundred help desks. Everybody is scanning and looking for opportunities to enhance the accessibility of the city hall and its service provision. Steven and Daniel identify particular difficulties regarding the intellectual demands on participating as a citizen with intellectual disabilities, looking for accessible text and signs, scanning the accessibility of the floor plan, checking whether the icons of the elevators and emergency exits are understandable and clear. The municipal servant records scrupulously what she sees and hears from the participants, and gives them each time positive feedback. Yet, every time Steven and Daniel give some advice to the city servant, she does not record anything. Nor does she give them any answer of value. Meanwhile she mumbles to others that accessibility for people with intellectual disabilities is not yet an issue. Then, looking back on the event with Steven and Daniel and trying to strike up conversation, I ask them how they felt about it. They answer that they are honoured and pleased about it, ‘glad that the servant will make a change’. I am surprised because I had the opposite feeling.“ (Tina’s field notes, March 2012)

From our privileged but challenged position of witness and advisor, we witnessed how Steven’s and Daniel’s voices and opinion were silenced, and their actions disqualified. Different mechanisms of oppressive powers were operating, often in a tricky and hidden way, bringing challenges into focus for self-advocates participating in a respectful way and for our delicate positioning as combined witness, advisor and researcher. In our research these critical events sensitized our queries and influenced our recognition of the fact that people with the so-called label of ‘intellectual disabilities’ are often denied recognition as citizens, infantilized, and tied into conventional, often subordinate roles. Furthermore, due to these incidents, the complexity of the claims for equality and full participation of self-advocates fascinated us, and will be a source of inspiration for the rest of our research queries. Nevertheless, sharing and verifying our observations, feelings and learning from the activity continues to be an important process in this research step; the views, feelings and experiences sometimes do not reflect the self-advocates opinions and experiences.

Voice as Preoccupation

> "*With increasing presence in the text, the portraitist's voice as preoccupation refers to the ways in which her observations and her text are shaped by the assumptions she brings to the inquiry, reflecting her disciplinary background, her theoretical perspectives, her intellectual interests, and her understandings of the relevant literature.*" (Lawrence-Lightfoot & Davis 1997, 93f.)

This layer of voice is identified by Lawrence-Lightfoot and Davis as "voice as preoccupation". In this layer, voice not only seeks to witness the participant's stance, and through new eyes, but also is used as preoccupation, or the "lens through which she [the portraitist] sees and records reality." (ibid., 93f.) This component of voice is "more than interpretive description". (ibid., 93f.) It is the theoretical framework underlying the work that defines "what she [the portraitist] sees and how she interprets it". (ibid.)

The life trajectories and ideas of self-advocates moved us towards a search for a theoretical framework capable of seeing human subjects as no longer divided from others and grasping the complexities of their identity and actions, drawing on disability activism, disability studies and intersectional perspectives. A crucial component in all our research and practice is the dialogical exchange by means of 'modest relations' (Goodley & Van Hove 2005). The commitment to engage in relationships between people with/out the label of disabilities is central in our perspective on Disability Studies. These intense encounters form the basis of the methodology for this research. They also provide the basis for thinking and practising in terms of possibilities for the multifaceted nature of self-advocacy support (Goodley 1998) and participation in 'real' contexts. These theoretical resources, in combination with our involvement in the self-advocacy movement, shifted us towards a deeper understanding of the beautifully illustrated work of Martha Nussbaum (2006, 2009, 2010) who in her "capability theory" (expanding on the work of Amartya Sen) tries to correct the social contract theory of Rawls. Nussbaum takes as a starting point the notion that people with an intellectual disability, if we truly regard them to be citizens of equal value, are a challenge to philosophical theories of justice. Even the extremely broadminded social contract theory of John Rawls does not manage to hide the fact that the citizens who enter into such a contract with the State are expected to have quite a few skills (Stark 2007). With her theory Nussbaum tries to develop an alternative that uses ten central capabilities which can be seen as substantial freedoms, and which all governments should guarantee to their citizens. The ten capabilities that, according to Nussbaum, should be supported by all democracies are (for our subject we pay special attention to the last capability):

- being able to live to the end of a human life of normal length (life)
- being able to have good health (bodily health)
- protection of bodily integrity (bodily integrity)
- being able to imagine, to think, and to reason (senses, imagination and thought)
- being able to have attachments to things and persons outside ourselves (emotions)
- being able to form a conception of good and to engage in critical reflection about the planning of one‘s own life (practical reason)
- being able to live for and in relation to others (affiliation)
- being able to live with concern for and in relation to animals, plants, and the world of nature (other species)
- being able to laugh, to play, to enjoy recreational activities (play)
- being able to control one‘s environment. (A) Political: being able to participate effectively in political choices that govern one‘s life; having the rights of political participation, free speech and freedom of association. (B) Material: being able to hold property (both land and movable goods); having the right to seek employment on an equal basis with others.

The capability approach uses the idea of a “threshold” (Nussbaum 2010, 78ff.): for each important entitlement there is an appropriate level beneath which it seems right to say that the relevant entitlement has not been secured, and as a result human dignity is bound to be compromised. When Nussbaum evaluates the situation of people with disabilities she finds “mixed results“: although in many Western countries progress has been made in a number of areas (people with an intellectual disability are often accepted in schools and participate via inclusive education in mainstream education and many specific support services for people with disabilities are operational), we still see hesitation on many fronts (partly for budgetary reasons, partly because persons with intellectual disabilities are often still regarded as charity cases instead of citizens with rights). This spurred Nussbaum on to call for going one step further: “Now we have to take the most controversial step of all: giving people with cognitive disabilities political and civil rights on a basis of genuine equality...” (Nussbaum 2009, 350f.; 2010, 94f.). She tries to illustrate this herself by considering the right of people with intellectual disabilities to vote, or the right to serve on a jury. In this context, we take up the challenge as formulated by Nussbaum and explore in the research the political and civil participation of persons with intellectual disabilities with regard to their involvement in political discussions.

In this light of voice as preoccupation, working in the natural environment of the self-advocacy movement felt like a balancing act where we continuously sought to accommodate the theoretical predispositions and the subjects’ realities, and tried to reveal the connections (and disconnections) between scientific abstractions and the subjects’ empirical categories. Moreover, our preoccupation with different qualitative research ventures, in terms of being motivated to experiment with more creative ways of capturing the complexity and the richness of the lived experiences of the self-advocates, also contributed to our interactions with the participants in this research. The enterprise was uncertain: it took us in many directions with sometimes dead ends and it kept us searching and moving. These interactions in the form of interviews, observations, and shared interactive space are aspects of "voice in dialogue".

Voice in Dialogue

> "*With voice in dialogue, the portraitist purposely places herself in the middle of the action (in the field and in the text). She feels the symmetry of voice—hers and the actor's—as they both express their views and together define meaning-making.*" (Lawrence-Lightfoot & Davis 1997, 103f.)

In this active positioning of voice in research, we see the developing relationship between the researchers and participants, with their voices in dialogue as an "ongoing construction of the story that happens in the two-way interviews and multivocal conversations" (Chapman 2005, 38ff.). This "voice in dialogue" has a prominent place in the work within the self-advocacy movement and grows out of our volunteer engagement as advisors of members of Our New Future, informing our work as researchers and providing us a basis for acting and dealing with uncertainties. In this framework of the self-advocacy network, professionals do not take over, but are constantly reminded to engage in a genuine dialogue and to strive for a searching process that respects the complexity of practical and professional knowledge (Van Hove, Roets, Mortier, De Schauwer, Leroy & Broekaert 2008). Our encounters are experimental. In Rinaldi's words, by engaging in dialogue we enter "a process of transformation where you lose absolutely the possibility of controlling the final result" (Rinaldi 2006, 184f.) This dialogue and listening turns the known into the unknown and opens up new modes of knowing and being (Davies 2014). Parallel to Freire's (1972) contribution of dialogical relationships, self-advocates, advisors and researchers consistently try to establish horizontal and not vertical relationships between the persons involved; based on empathy, respect, tolerance towards diversity and listening to each other's life experiences. Through this joint research and shared experience, we try to embrace and value the insider perspectives and ideas of the self-advocates in a workable dialogue. However, in this balancing act, the researcher's "soul echoes through the piece" (Lawrence-Lightfoot & Davis 1997, 105f.) from his activist and constructivist position, but he needs to works "very hard not to simply produce a self-portrait" (ibid.). Hence, we spontaneously strove to foreground self-advocates' long-silenced voices and experiences and tried to create a discursive space where we could think and act with one another, doing research with rather than on or for people with disabilities. They made us look at the world through their eyes and invited us to see their struggles and experiences and, at the same time, our own evolving "selves" (as described earlier) resonated with theirs, all involved in a process of mutual recognition and co-understanding. Through dialogue, we grew through an exchange of viewpoints between self-advocates, advisors and researcher(s), which dissolves the distance between those labelled and categorized as 'them' or 'us'. We worked as a team and shared laughter and struggles, which automatically led to communal activism and resistance in order to cultivate a desired social change (Freire 2004). In this way, our research is not neutral and becomes a political act, as illustrated in this sparkling dialogue between two self-advocates, an advisor/ the researcher. Reflecting together on the participation of Louisa in a local city council, Steven, Paul, Thomas and the researcher give meaning to and become increasingly conscious of the precarious situation of Louisa:

> Thomas explains the claims of the city council for the participation of Louisa: 'The council wants that Louisa justifies her value, before she can enter the council. They wonder if Louisa can deliver a useful contribution to the board. They don't give her the right to participate, they first want proof.'
> Steven: 'This is barbaric!'
> Tina: 'She first has to prove herself before she gets the chance to be heard, to give voice.
> Paul: 'We feel put aside, as if we are a group of people who doesn't know anything.'
> Steven, pounding on the table: 'We are self-advocates. Do we want to have to prove ourselves in this way? Like they want us to? Or are we doing it our way? They disregard our rights!'

This example of collaborative reflection was one of the many ways in which the researchers were active by the side of and part of the team of self-advocates and advisors. We held conversations that were often spirited and lively, shared observation notices, gave mutual feedback, conducted group and individual interviews, participated together in the staff meetings, evaluated and refocused the project goals, made together sense of our experiences. Our relationship evolved through the vivid display of our dialogue, ever struggling to find a place of balance and symmetry, and provided meaningful insights into our communal engagements and experiences.

Voice as Interpretation

> "*Here we not only experience the stance of the observer and her place of witness, we also hear her interpretations, the researcher's attempts to make sense of the data. She is asking, ‚What is the meaning of this action, gesture or communication to the actors in this setting?' and ‚What is the meaning of this to me?'*" (Lawrence-Lightfoot & Davis 1997, 91f.)

In this phase, acting as researchers who act and interpret actions, we will lay bare a critical incident about the participation of self-advocate Robert, based on encounters with him and some of his professional support workers. Nevertheless stories like these are able to stir up a multiplicity of interpretations, and we discovered that our research activity provided opportunities to better understand individual and collective politics of resilience and resistance of self-advocates.

Robert [a respected member of Our New Future] wants to join the new project of the self-advocacy movement [where local political participation of people with 'intellectual disabilities' is supported]. He notifies that he learnt from the stories and experiences of other self-advocates participating in local boards and that he is interested in more local policy participation. He asks Our New Future to give him an overview of all the local community and policy organizations in his town, so he can have a look. On Tuesday, we get a call from his support worker of the institute where he lives. She asks upset: "What did you do with Robert? He suddenly knocks on the table and says that he wants to participate in the local community board!" Additionally, she states on the telephone that the participation on the local board is way out of Robert's league. "He is not able to do that", she declares. We propose to meet Robert and the support worker two days later. At the meeting, the support workers are in the majority and argue with a series of arguments ("yes, but… no, because") that it is better for Robert not to participate ("you have to be elected in a board like that, not everyone is welcome there, it is far beyond your capacities, you will not understand what they say"). After the meeting, Robert says to the advisor that it is still his dream to participate. He shows his interest in the local sports council and together we contact them with some questions. Surprisingly, a little later we receive a positive answer from the sports functionary and we make a call to Robert with this good news. Suddenly, the telephone disconnects. When calling back, we only can reach the support worker, not Robert, who says that we cannot talk to Robert anymore about this. According to her, Robert has to focus on other important things in life, such as his possible relocation.

We are painfully aware of the risk of leaving these research notes open for power takeovers and interpretations of any kind, since we experience here that Robert's human rights, and especially the opportunities to actualize them, are not safeguarded when comparing this incident with the international human rights discourse, in particular with the UN Convention on the Rights of Persons with Disabilities. Mirroring these guidelines, we could say that Robert is denied the opportunity to participate in political and public life on an equal basis with others. What equally strikes us is that any symmetrical and reciprocal dialogue is relinquished and the knowledge and dreams of self-advocates are buried under expert truth and power. Their lived knowledge, resistance, ambition and moments of desire are silenced and disqualified and can be the reason why they feel alienated and excluded. In our eyes, Robert is caught in a politics of segregation and exclusion, and in a taken-for-granted system of professional discourse that tends to control his everyday life. These professional experts deny Robert being grown-up with dreams and desires, and continually create barriers and requirements so it is impossible for him to participate. Although self-advocates like Robert show us that they need interdependent, supportive relationships to be able to exercise their citizenship, support is often considered less important than quality of care (De Waele, Van Loon & Van Hove 2005). Traditional notions of independence, self-determination and autonomy are leading principles in many forms of institutionalized care in Flanders in which moments of reciprocal and genuine dialogue are nigh on impossible to ever happen.

Voice discerning other voices, listening for voice

> "*When a portraitist listens for voice, she seeks it out, trying to capture its texture and cadence, exploring its meaning and transporting its sound and message into the text through carefully selected quotations.*" (Lawrence-Lightfoot & Davis 1997, 99f.)

In this final exploration of voice in research activities, the researcher must address and pay attention not only to what actors say with words, but also to what Lawrence-Lightfoot and Davis call "mixed feelings" (ibid., 100ff.), in particular what they say with body language, hesitations in speech, timbre, tone and silences. When discerning other voices, the researcher makes a critical distinction between "listening to a story" and "listening for a story" (Lawrence-Lightfoot 2009, 17ff.), where the former implies a "more passive, receptive stance in which the interviewer waits to absorb the information and does little to give it shape or form" (ibid., 17f.); the latter suggests a much more engaged and active role for the researcher in which she or he searches for the story, while creating and moulding it as a constructivist activity, involving action instead of passive observation.

In this research project on political participation, the researchers played an active listener role in the self-advocates' storytelling. In collaboration with these self-advocates and their advisors, the experiences on participating in local policy-making processes were composed, which offered an in-depth understanding of their lived knowledge, the multiplicity of their selves and the complexities of their lives and contexts. In attempting to jointly capture and interpret these glimpses and slices of their lived experiences of oppression and resistance, we understood more completely both others and ourselves. Through cooperatively articulating our experiences and following each other's footsteps, self-advocates, advisors and researchers got to know each other's interests and pluralist meanings while at the same time creating new ones. Self-advocates used, for example, photographs, portraiture, object constellations, poetry, symbols, video and visual metaphors to foreground their voices in a variety of ways. These methods were used as a medium for dialogue and to chronicle the self-advocates' experiences and selves so as to facilitate the story-telling process. They were key for developing a fully nuanced story and co-constructing a narrative that becomes their own. They require, most importantly, time and an absolute commitment to listening, to interpreting the communications and the silences, and to supporting the process of reflection. By holding to the language of the actors and entering their story, we co-constructed narrative and together discovered new ideas and worlds, rather than assuming to already know what we were going to find. For example, the experiences of self-advocates about political participation were collaboratively revealed by developing vivid portraits which presented joint research activity and cooperative processes of composing lay-out, pictures, text and metaphors. A translation of self-advocates stories and worldviews resulted in a shared development of these artistic portraits, and we experienced that some self-advocates were first-class developers of imagery language. Moreover, these portraits were vital illustrations of accessibility and dialogue, for which the self-advocates' aim was to affect the wider society through presenting their artistic and performative work to a wider audience in an exhibition at the end of October 2012. Self-advocates wanted to create a medium for dialogue and invited visitors to explore their portraits, to make time for confabulation, reflection and on-going interpretation and meaning making. In the collaborative process of composing the portraits, many metaphors were used to illuminate their struggles and wishes. These metaphors had rich connotational meanings and unveil a profound recognition of power dynamics in the field of self-advocacy, participation and support. Simultaneously, they indicate the complexities of people's lives and the contexts influencing them. As it is the researcher's responsibility to watch for the ways in which the actors' movements and gestures speak much louder than words (Lawrence-Lightfoot & Davis 1997), the imaginative thinking of self-advocates offered us ways to elicit these complicated set of dynamics and the various subtle and overt, or sometimes contradictory- meanings. It asked for an engaged position and a listening for meaning, for the "through" line and for what is genuinely human.

3 Concluding thoughts

In this study, it is clear that a variety of voices of the researchers and self-advocates are omnipresent. Multiple and overlapping facets of voice co-exist and are heard through different mediums and texts, framed within the cultural, political and historical context of this research. Along with Lawrence-Lightfoot and Davis (1997), we would like to acknowledge the researchers' political role in making meaning of texts and shaping research being presented to the world. Nevertheless, we do not want to underrate the voice and actions of subjects with disabilities as critical agents and meaning-makers in research. Their lived experience must be honoured and must be seen as revealing counter-narratives towards resisting dominant and oppressive disability discourses (Ware 2002), challenging hegemonic discourses and enabling us to discover their activist potential and resistance towards modernist misconceptions (de Lauretis 1987; Goodley 2007). Both portraiture and Disability Studies recognize that these voices and counter-voices need to be embraced to dispel powerful myths and defy current stereotypes and dominant ableist assumptions (Linton 1998; Charlton 1998; Fisher & Goodley 2007). Similarly, we suggest, together with Reason & Torbert (2001) and Nind (2011), that we need to accept that human persons are agents who act in research on the basis of their own and mutual sense-making and (collective) action, and thus it is no longer possible to conduct research on persons, but with persons, involving them in each of the research phases.

The plurality of voices implied a balancing between multiple positions, a messy struggle with tensions and challenges. The processes and different layers of voice we engaged with are complex and interwoven. Working together and actively doing and being involved with people, was interwoven with the work at the university: by reading, discussing with colleagues and working with students. Our need to search for meaning only increased, while our meaning making and knowledge construction also occurred in relational activity, in a continuous process of formulation and reformulation, testing and negotiation" (Dahlberg & Moss 2005, 102). Our process as researchers was constructed through simultaneous approaches and withdrawals, choices and standstills, that took us in many different directions. In an ongoing search process we tried to find theoretical concepts and frameworks that could help us to make sense of and re-think what we experienced in working with people, as a witness, and in our own history far beyond our work. These processes are ongoing, never-ending, and ungraspable as a 'whole'. When bringing al the different layers of experiences and voice together, the notion of 'becoming-minoritarian' of Deleuze and Guattari is appropriate, as suggested by De Schauwer and Van Hove (2011), it "can help me to understand how I as a multiple identity am relating to other humans, non- humans and to the world. I can take the freedom to become an 'activist' and 'partner' and 'researcher' and 'mother' all at once and negotiate these different identities in encounters with the Other" (18ff.). Becoming indicates a process that destabilizes solid identities and facilitates a potential creation of entirely new and multiple identities embedded in variable and discontinuous fluxes of living. It leads you away from a stable and universal identification as a researcher, activist, friend, witness, mother and advisor. It gives you endless opportunities to cross borders and categories.

Besides, along with Ashby (2011) and Mazzei and Jackson (2012), we believe that the challenges inherent in an uncritical construction of giving voice are indispensable. While it is important to conduct research that aims to give voice, it is essential to simultaneously problematize the premise of giving voice: "Was I really giving voice? Was it mine to give? Whose voice is it really? Who benefits from the telling? Is spoken voice preferable?" (Ashby 2011, 1732f.) Longing to give voice can cause different strains. It can lead to oversimplified knowledge claims that attempt to offer an authentic essence or voice that is present and stable (Mazzei & Jackson 2012). It can assume that the experiences and perspectives are inherently distinct from those of others. It can be supposed that the people being researched have no voice and need an external impulse to reveal their experiences. In this way, "it denies that these individuals have their own voice and can (and do) choose to exercise it, although admittedly people with disabilities are often denied the opportunity to do so" (Ashby 2011, 1732f.).

Because the research discussed in this chapter implies, among others, a far more interactive process than the classical stance and is no neutral activity, but culturally and politically embedded, we insist on the importance and even ethical-deontological imperative of engaging with questions of voice, power and injustice issues. As a result, as it is unnecessary and even dangerous to assume that there is only one voice; one must be conscious and clear about the myriad ways voices are operating and coexisting in research and of the parts all the actors, including the researchers, play in shaping the research process and outcomes.

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Autorinnen und Autoren

Biewer, Gottfried, Prof. Dr.
Universität Wien, Institut für Bildungswissenschaft, Heilpädagogik und Inklusive Pädagogik.
gottfried.biewer@univie.ac.at

Buchner, Tobias
queraum. kultur- und sozialforschung.
buchner@queraum.org

Carlisle People First Research Team Ltd.
Cambeck Bridge Cottage, Brampton, Cumbria, CA8 2AU, UK.
cpfrt.research@yahoo.com

Curdt, Wiebke
Bremen
wcurdt@gmx.de

de Schauwer, Elisabeth, Dr.
Universität Gent, Department of Special Needs.
Elisabeth.DeSchauwer@UGent.be

Egloff, Barbara
UNiversität Zürich, Institut für Erziehungswissenschaft, Sonderpädagogik: Gesellschaft, Partizipation und Behinderung.
begloff@ife.uzh.ch

Fleischanderl, Ulrike
queraum. kultur- und sozialforschung.
fleischanderl@queraum.org

Flieger, Petra
Absam.
petra.flieger@pflie.at

Goeke, Stephanie, Dr.
Böblingen.
stephaniegoeke@gmx.de

Goethals, Tina
Universität Gent, Department of Special Needs.
Tina.Goethals@UGent.be

Goldbach, Anne, Dr.
Universität Leipzig, Erziehungswissenschaftliche Fakultät, Institut für Förderpädagogik, Pädagogik im Förderschwerpunkt Geistige Entwicklung.
goldbach@uni-leipzig.de

Grubich, Rainer
Pädagogische Hochschule Wien, Büro für Inklusive Bildung.
Rainer.Grubich@phwien.ac.at

Hauser, Mandy
Universität Leipzig, Erziehungswissenschaftliche Fakultät, Institut für Förderpädagogik, Pädagogik im Förderschwerpunkt Geistige Entwicklung.
mandy.hauser@uni-leipzig.de

Johnson, Kelley, Prof. Dr.
University of New South Wales, Social Policy Research Centre.
kelley.johnson@unsw.edu.au

Moser, Vera, Prof. Dr.
Humbold-Universität zu Berlin, Kultur-, Sozial- und Bildungswissenschaftliche Fakultät, Institut für Rehabilitationswissenschaften, Pädagogik bei Beeinträchtigungen des Lernens/Allgemeine Rehabilitationspädagogik.
vera.moser@hu-berlin.de

Murphy, Tomás
Tomás Murphy, is a Graduate of "The CERTIFICATE in CONTEMPORARY LIVING" Trinity College Dublin. He is now working two days a week in A&L Goodbody in the General services Department, they are based at IFSC North Wall Quay Dublin 1.

Kellett, Mary, Prof. Dr.
The Open University Milton Keynes, Dean and Director of Studies Faculty of Education and Language Studies.
mary.kellett@open.ac.uk

Klauß, Theo, Prof. Dr. i.R.
Pädagogische Hochschule Heidelberg, Institut für Sonderpädagogik, Pädagogik im Förderschwerpunkt geistige Entwicklung, Mitglied Bundesvorstand der Bundesvereinigung Lebenshilfe, Stellvertretender Vorsitzender der Deutschen Gesellschaft für seelische Gesundheit von Menschen mit geistiger Behinderung (DGSGB).
Theo.Klauss@urz.uni-heidelberg.de

Koenig, Oliver, Dr.
Universität Wien, Institut für Bildungswissenschaft, Heilpädagogik und Inklusive Pädagogik.
oliver.koenig@univie.ac.at

Kohlmann, Karen
Diakonie am Thonberg Leipzig, Berufsbildungsbereich.
kohlmann.karen@dat-leipzig.de

Kremsner, Gertraud
Universität Wien, Institut für Bildungswissenschaft, Heilpädagogik und Inklusive Pädagogik.
gertraud.kremsner@univie.ac.at

Kubiak, John, Dr.
Trinity College Dublin, School of Education.
kubiakj@tcd.ie

Nind, Melanie, Prof. Dr.
University of Southhampton, Education School.
M.A.Nind@soton.ac.uk

Nösterer-Schreiner, Sylvia
Pädagogische Hochschule Wien, Institut für Hochschulmanagement.
Sylvia.Noesterer@phwien.ac.at

O´Doherty, Siobhain
Siobhain is a PhD student in Mental Health and Social Research Unit, Department of Psychology, Maynooth University, and a SPHeRE programme scholar (Structured Population Health Services Research Education). Her contribution to the chapter arose from her previous work in the School of Social Work and Social Policy at Trinity College, Dublin.

O’Keeffe, Molly
Trinity College Dublin.
MOOKEEFF@tcd.ie

Schönwiese, Volker, Prof. Dr. i.R.
Absam.
Volker.Schoenwiese@uibk.ac.at

Schuppener, Saskia, Prof. Dr.
Universität Leipzig, Erziehungswissenschaftliche Fakultät, Institut für Förderpädagogik, Pädagogik im Förderschwerpunkt Geistige Entwicklung.
schupp@rz.uni-leipzig.de

Seifert, Monika, Prof. Dr.
Deutsche Heilpädagogische Gesellschaft e.V., Vorsitzende.
monikaseifert@gmx.de

Terfloth, Karin, Prof. Dr.
Pädagogische Hochschule Heidelberg, Institut für Sonderpädagogik, Pädagogik bei schwerer geistiger und mehrfacher Behinderung und Inklusionspädagogik.
terfloth@ph-heidelberg.de

Wagner-Willi, Monika, Dr.
Fachhochschule Nordwestschweiz, Institut Spezielle Pädagogik und Psychologie, Integrative Didaktik und Heterogenität.
monika.wagner@fhnw.ch

Williams, Val, Dr.
University of Bristol, Norah Fry Research Centre.
val.williams@bristol.ac.uk

van Hove, Geert, Prof. Dr.
Universität Gent, Department of Special Needs.
Geert.VanHove@UGent.be

van Breda, Lien
Universität Gent, Department of Special Needs.
Lien.VanBreda@UGent.be

von Unger, Hella, Prof. Dr.
Ludwigs-Maximilian-Universität München, Sozialwissenschaftliche Fakultät
Institut für Soziologie, Lehr- und Forschungsbereich für Qualitative Methoden der empirischen Sozialforschung.
unger@lmu.de

Walmsley, Jan, Dr.
Jan Walmsley Associates, Wingrave.
janwalmsleyassociates@gmail.com

Zahnd, Raphael
Universität Zürich, Institut für Erziehungswissenschaft, Sonderpädagogik: Gesellschaft, Partizipation und Behinderung.
rzahnd@ife.uzh.ch

Zehle, Jana, Prof. Dr.
Hochschule Hannover, Fakultät V – Diakonie, Gesundheit und Soziales
Heilpädagogik.
jana.zehle@hs-hannover.de

klinkhardt

Inklusive Forschung stellt einen Ansatz dar, in dem Menschen mit Lernschwierigkeiten über den gesamten Forschungsprozess hinweg eine aktiv gestaltende Rolle einnehmen. Sie verkörpert somit eine *gemeinsame* Forschung von Menschen mit und ohne akademischen Bildungshintergrund. Während sich dieser Forschungsansatz in den letzten drei Jahrzehnten in vielen englischsprachigen Ländern zunehmend etabliert hat, begann ein vergleichbarer Prozess im deutschsprachigen Raum erst ab den frühen 2000er Jahren – hat aber seitdem eine interessante Entwicklung erfahren, die bislang kaum dokumentiert wurde. Dieses Buch hat daher das Ziel, einen Überblick zu aktuellen und bisherigen Bemühungen im Kontext von Inklusiver Forschung in Deutschland, Österreich und der Schweiz zu geben. Zudem werden hier die gesammelten (Forschungs-)Erfahrungen sowie die damit verbundenen Diskussionen und Herausforderungen kritisch reflektiert.
Zudem finden sich in dieser zweisprachigen HerausgeberInnenschaft Beiträge von VordenkerInnen aus der internationalen Forschungscommunity.

HerausgeberInnen

Tobias Buchner ist Wissenschaftlicher Mitarbeiter in der außeruniviersitären Forschungseinrichtung „queraum. kultur- und sozialforschung“ in Wien.
Dr. Oliver Koenig ist Wissenschaftlicher Mitarbeiter im Bereich Heilpädagogik und Inklusive Pädagogik im Institut für Bildungswissenschaft der Universität Wien.
Dr. Saskia Schuppener ist Professorin für Pädagogik im Förderschwerpunkt geistige Entwicklung im Institut für Förderpädagogik an der Erziehungswissenschaftlichen Fakultät der Universität Leipzig.

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