INCLUSIE EN PARTICIPATIE VAN PERSONEN MET EEN BEPERKING IN VLAANDEREN:

EEN PARTICIPATIEF ONDERZOEK NAAR POLITIEKE PARTICIPATIE VAN MENSEN MET EEN VERSTANDELIJKE BEPERKING

2012-2016

STEUNPUNT GELIJKEKANSENBELEID - 3de GENERATIE

ONDERZOEKER
Tina Goethals
Universiteit Gent
Universiteit Antwerpen

Promotor
Dr. Prof. Geert Van Hove
Universiteit Gent

Co-promotor
Dr. Prof. Dimitri Mortelmans
Universiteit Antwerpen

Voorwoord

In voorliggend onderzoeksrapport wordt gerapporteerd over een onderzoek naar de politieke participatie van personen met een verstandelijke beperking in Vlaanderen, als onderdeel van Werkpakket Handicap 1 (WPD1) van het Steunpunt Gelijke Kansenbeleid. In deze onderzoekslijn werd een participatief follow-up onderzoek uitgevoerd van een lokaal project van self-advoacy vereniging Onze Nieuwe Toekomst, waar enkele 'pioniers' met een verstandelijke beperking die politiek wilden participeren, samen met hun coaches, werden ondersteund.

In de inleiding wordt het onderzoek gekaderd en enkele centrale bevindingen weergegeven. Nadien volgt een wetenschappelijk artikel met enkele belangrijke bevindingen uit het project en een wetenschappelijk artikel over inclusief onderzoek en enkele uitdagingen hierbij.

Aan dit onderzoek is een (dubbel)doctoraatsonderzoek verbonden binnen de Vakgroep Orthopedagogiek van de Universiteit Gent en het Departement Sociologie van de Universiteit Antwerpen.

In Werkpakket Handicap 1 (WPD1) van het Steunpunt Gelijke Kansenbeleid zijn nog andere onderzoekslijnen verbonden die in andere rapporten worden besproken:

- het opstellen van indicatoren die de participatie van personen met een beperking in Vlaanderen opvolgen
- het verzamelen en analyseren van persoonslijke narratieven van personen met een beperking omtrent inclusie/exclusie
- het onderzoeken van de beeldvorming van personen met een beperking in de Vlaamse media

Vooraleer verder te lezen, vragen we u even stil te staan bij enkele aannames of vooronderstellingen die we vooraf formuleerden en centraal stellen in dit onderzoek,

overeenkomstig het VN-verdrag inzake de Rechten van Personen met een Handicap en overeenkomstig het kader van Disability Studies:

1. Het onderzoek dient de rechten van personen met een beperking en hun menselijke waardigheid te ondersteunen en bevorderen.

2. Personen met een beperking zijn niet langer 'objecten' die zorg ontvangen, maar 'subjecten', actieve personen met eigen mogelijkheden en rechten die eigen beslissingen kunnen nemen.

3. Disability ontstaat als een interactie tussen de persoon en de omgeving. Drempels in de maatschappij kunnen participatie in de weg staan.

4. We willen respect tonen voor het anders zijn en personen met een beperking zien als volwaardige persoon.

5. We geloven dat volledige en effectieve participatie en inclusie belangrijk zijn om mensen te laten groeien en om de samenleving te verrijken.

6. Aan alle activiteiten -ook onderzoek- moeten personen met een beperking kunnen participeren (Nothing About Us, Without Us).

Inhoudstafel

1. INLEIDING EN SAMENVATTING

1.1 Context

Beleidsparticipatie van personen met een verstandelijke beperking is een actueel, maatschappelijk en politiek thema binnen het huidige diversiteitsdebat. Uit de onderzoeksresultaten van een recente onderzoek rond beleidsparticipatie van personen met een verstandelijke beperking (Goethals & Van Hove, 2011) wordt duidelijk dat er wel degelijk personen met een verstandelijke beperking wensen deel te nemen aan beleid en politiek en dat zij beleidsparticipatie ernstig nemen. De nulmeting daarentegen leert ons dat er slechts weinig personen met een verstandelijke beperking daadwerkelijk participeren in beleid (drie personen in Vlaanderen, geen personen in Wallonië), wat onlosmakelijk samenhangt met knelpunten en barrières tot effectieve beleidsparticipatie. Er is met andere woorden nog een hele weg af te leggen om randvoorwaarden te realiseren en de politieke rechten voor personen met een verstandelijke beperking, zoals omschreven in het VN-verdrag, te laten gelden.

Ook vanuit het Vlaamse Gelijke Kansen Beleid is er toenemende aandacht voor personen met een verstandelijke beperking. Een van de drijfveren is de zorg om de kwaliteit van de democratie en de kwaliteit van bestaan van personen met een verstandelijke beperking. Beleidsorganisaties, coaches, maar ook personen met een verstandelijke beperking zelf, zijn zoekende op welke manieren de ervaringsdeskundigheid van personen met een verstandelijke beperking op een respectvolle manier kan worden ingezet, hoe personen met een verstandelijke beperking volwaardig kunnen deelnemen aan het beleid en hoe de ondersteuning er kan/moet uitzien.

1.2 Onze Nieuwe Toekomst

Dit onderzoek volgt een concreet project op van Onze Nieuwe Toekomst, een self-advocacy vereninging van, voor en door mensen met een verstandelijke beperking. Onze Nieuwe

Toekomst is een beweging van en voor personen met verstandelijke beperking die willen opkomen voor hun eigen rechten. Het is de eerste self-advocacy groep van mensen met een verstandelijke handicap in Vlaanderen. Onze Nieuwe Toekomst wordt gedragen door een kerngroep van een twintigtal kernleden. Er is een ondersteuningsnetwerk binnen de organisatie door een tiental coachen. De vereninging beschrijft als volgt haar doelstellingen:

- We strijden samen voor onze rechten als mensen.
- We willen met onze beweging vooral laten zien dat we mensen zijn met eigen mogelijkheden.
- We tonen dat we iets kunnen aan de andere mensen.
- We leren elkaar beter kennen, we leren elkaar beter verstaan.

Via het 'project beleidsparticipatie' kon Onze Nieuwe Toekomst met steun van de Vlaamse Overheid drie jaar lang personen met een verstandelijke beperking en hun coachen ondersteunen bij politieke participatie. Er werd oorspronkelijk ingezet op a) lokale beleidsparticipatie (gemeentelijk en stedelijk), b) participatie aan verscheidene beleidskanalen op 'hoger' niveau, en c) het opzetten van een coachenbureau en –vorming. Gedurende de jaren werd intensiever gewerkt aan het ondersteunen van een tiental 'verkenners' ('pioniers' met een verstandelijke beperking) die de wens hadden om heel lokaal te participeren aan het beleid van hun gemeente of stad. Hiervoor werden lokale coachen gezocht en opgevolgd.

1.3 Centrale bevindingen

Kort lichten we drie belangrijke bevindingen weer die uit het onderzoek naar voor komen. Deze worden – samen met andere bevindingen – verder uitgediept in de twee wetenschappelijke artikels binnen hoofdstuk 2 en 3.

1.3.1 Gebrek aan informatie

Doorheen dit gehele onderzoeksproces zien we telkens weer dat er een groot gebrek is aan informatie over politieke betrokkenheid en het recht op politieke participatie bij mensen met een verstandelijke beperking in Vlaanderen. Bovendien is de beschikbare informatie niet toegankelijk of hebben mensen niet altijd toegang tot internet om op de hoogte te zijn. Daarnaast fungeren zorginstellingen vaak als buffer of toegangspoort, waardoor de informatie nog moeilijker -of helemaal niet- bij de juiste persoon terecht komt.

1.3.2 Top-down

Als mensen op politiek vlak willen betrokken zijn, moeten ze zich inpassen in een top-down georganiseerde participatiestructuur. Ze moeten zich inpassen in structuren en doelen die van bovenuit bepaald zijn. Mensen mogen er zijn, maar er wordt beslist voor hen over wat ze al dan niet kunnen meepraten. Hierbij worden vaak onredelijke voorwaarden vooropgesteld waaraan mensen moeten voldoen, denk aan taalgebruik, tempo en grote hoeveelheden ontoegankelijke tekst die moet verwerkt worden in een korte tijd.

1.3.3 Presumed competence?!

Mensen met een verstandelijke beperking worden systematisch onderschat. Men gaat er niet van uit dat ze competent zijn (presumed competence) en hun mening wordt als minderwaardig beschouwd. Hierbij worden heel veel drempels gecreëerd of smoezen verzonnen zodat mensen met een verstandelijke beperking geen actieve rol kunnen spelen bij beleidsbeslissingen, of worden ze expliciet geweigerd in lokale adviesraden. Toegang krijgen tot een adviesraad kon jaren in beslag nemen, of draaide uit op een 'nee'.

2. POLITIEKE PARTICIPATIE VAN MENSEN MET EEN VERSTANDELIJKE BEPERKING – EEN KWALITATIEF ONDERZOEKSPROJECT

Abstract

Although over the last few decades there has been growing attention for the situation and human rights of persons with an intellectual disability in society, there is still hesitation on many fronts. This research takes up the challenge of political rights and explores the political and civil participation of persons with an intellectual disability with regard to their involvement in political discussions in Flanders, the Dutch speaking part of Belgium.

Based on this participatory research, it can be concluded that the political participation of persons with an intellectual disability in Flanders is nowhere yet. Suggestions are made to consider political participation as a rhizomatic conception where difference is an integral part of relationships and it is with and by these relations that participation can be achieved (relational citizenship).

2.1 Introduction

Throughout history people with an (intellectual) disability have been discriminated against, mistreated, neglected, abused and institutionalised (Stiker, 1997). Even though we shouldn't assume that recent trends, such as deinstitutionalising and inclusion (Bjarnason 2011; Chenoweth and Stehlik 2004; Edgerton 1993), have solved all the problems, it is true that during the last 40 years there has been growing attention for the situation and human rights of persons with an intellectual disability in society (Bérubé 1996; Landsman 1999; Taylor and Bogdan 1989; Wolfensberger 1972).

For instance, at the international political forum we recently saw the United Nations Convention on the Rights of Persons with Disabilities (go to: http://www.un.org/disabilities/) put to the vote. Quite a few countries have signed and ratified this Convention. (By now – mid August 2013 – 156 countries have signed the Convention and 133 countries have already ratified the Convention). In 50 articles, the Convention aims to support a paradigm shift from charity to rights, to describe these rights and their wide area of application as clearly as possible and to establish a link with rights as anchor points that can be incorporated into projects concerning development cooperation. As regards the right to

political participation, art. 29, "Participation in political and public life", is particularly relevant for the work reported in this article.

In the theoretical sphere there has been quite a shift too, as illustrated by Martha Nussbaum (2006, 2009, 2010) who modifies the social contract theory of Rawls. Based on the work of Amartya Sen, Nussbaum develops a "capabilities theory" that 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 that enter in such a contract with the state are expected to have a set of skills considered necessary for participation in the political life of the community (Stark 2007). Tisdall (1994) points out, however, that assumptions about the fundamental competence and skills required for participation in political life are "arguably based on exclusion as well as inclusion" (3) and some groups are inevitably left out. To counter exclusion, Nussbaum develops an alternative that uses ten central capabilities, or substantial freedoms, that all governments should guarantee to their citizens.

According to Nussbaum the capabilities that should be supported by all democracies are (for our subject we pay special attention to the last capability): (1) being able to live of the normal length of a human life; (2) being able to have good bodily health; (3) protection of bodily integrity; (4) being able to imagine, to think, and to reason (senses, imagination and thought); (5) being able to have attachments to things and persons outside ourselves (emotions); (6) being able to form a conception of the good and to engage in critical reflection about the planning of one's own life (practical reason); (7) being able to live for and in relation to others (affiliation); (8) being able to live with concern for and in relation to animals, plants, and the world of nature (other species); (9) being able to laugh, to play, to enjoy recreational activities (play); (10) 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 capabilities approach uses the idea of a threshold (Nussbaum 2010, 78): 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.

2.2 And now we must go for the most controversial step: one of the motives for our research project.

When Nussbaum evaluates the situation of people with a disability 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 mainstream education – and while many specific support services for people with a disability are up and running), we still see hesitation on many fronts (partly for budgetary reasons, partly because persons with an intellectual disability are often still regarded as charitable 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 (Nussabaum 2009, 350; 2010, 94). She tries to illustrate this herself by considering the right of people with an intellectual disability to vote, or the right to serve on a jury.

In this article we take up the challenge as formulated by Nussbaum and we explore the political and civil participation of persons with an intellectual disability with regard to their involvement in political discussions. In this study we mean by political participation that they participate in municipal, provincial and national policy bodies and politics. We don't refer participation in councils for service providers or in specific ngo's for persons with an intellectual disability.

2.3 Research context

Flanders, the Dutch speaking part of Belgium, ratified the UN Convention on the Rights of Persons with Disabilities in July 2009. Ratification as such means that a country is obliged to follow the convention articles and report regularly on the country's progress regarding citizens with a disability. The reports are coordinated by the administration of Equal Opportunities Flanders, together with the Flemish Minister of Equal Opportunities.

In 2010 the Minister initiated a study on "participation in political decision-making by persons with an intellectual disability in Flanders". During one year a part-time researcher (second author) conducted this research project, under the supervision of the first author and in very close collaboration with Our New Future, the Flemish self-advocacy movement of people with intellectual disabilities, and in the spirit of "Nothing about us without us" (Charlton 1998).

2.4 Problem definition and research questions

A recent report by the EU Fundamental Rights Agency (FRA 2010) compared member states on the subject of the political rights of persons with an intellectual disability. In this report, Belgium is classified in the category of countries where there is exclusion from the right of political participation in decision-making by persons with an intellectual disability. This shows that persons with an intellectual disability in Belgium, and Flanders as a part of Belgium, clearly have to be considered as a minority group – a minority group whose political rights are in jeopardy.

Proceeding from this conclusion and the introduction of this article, the following research questions were included for our study:

- What is understood by participation in political decision-making?
- How many persons with an intellectual disability were participating in the political decision-making process in Flanders at the start of the research trajectory (baseline measurement)? Where are they participating?
- Who are the various persons involved in the participation in political decision-making by persons with an intellectual disability? What are their experiences, views and needs?
- What resources are currently made available by the administration to make it possible for persons with an intellectual disability to participate? How are these existing opportunities for participation functioning?
- How can participation in political decision-making be inclusive and meaningful for persons with an intellectual disability? How does that translate into practice?

2.5 Research methods

In this research project various methods and were used, which we will briefly discuss below.

2.5.1 Participatory research (Garbutt, 2009; Gilbert, 2004)

The entire study was developed in close collaboration with the Our New Future (ONF). This happened in various ways. Members of ONF - persons with the label of intellectual disability– were part of the steering committee of the study. They were involved in drafting questions for the interviews, they took part in conducting the interviews, they were actively involved in passing on the feedback from the first results of the study to the key members of ONF, they participated in interviews and focus groups and they were involved in converting the research report into accessible language for persons with an intellectual disability.

2.5.2 Baseline measurement

In the first phase of the study a baseline measurement was carried out. This was to determine how many people with an intellectual disability in Flanders participate in political decision-making. Using purposive sampling (Bernard, 1995, p. 95), an email was sent to fifteen organisations, selected by the researchers because they were sure that if people were participating politically they would know about it in these organisations. The two umbrella organisations of all Flemish provinces and municipalities were also contacted, since they have the most extensive knowledge of the local political decision-making processes in Flanders. Finally a letter was sent to all Flemish political parties. To gain an insight into the situation in the French speaking part of Belgium, the Walloon provinces, the Walloon self-advocacy movement "Vous et Moi" was contacted, as was the Walloon colleagues of "Inclusion Flanders" (AFrAHM). This was an attempt to introduce the other part of the country in a 'negative case analysis' (Mertens 1998, 182). The following questions were given to these organisations:

- What do you understand about participating in political decision-making and at what level do you think this participation is?

- How many persons with an intellectual disability that currently participate in the political decision-making process do you know and to what extent do they participate?
- Do you know of any colleagues we could write to and ask this question? In this way a snowball sampling process was generated (Bernard 1995, 97).

2.5.3 In-depth interviews

In the second phase of the research, several in-depth interviews were conducted with those involved with participation in political decision-making. In the first instance these were persons with an intellectual disability that participate in political decision-making or are interested in participating in the future. In addition to these persons seven staff members of organisations for persons with a disability that are involved as professionals in political decision-making and six persons from another minority group who are involved in political decision-making (e.g., hands-on experts on poverty and social exclusion within federal public services) and ten coaches of persons with an intellectual disability were interviewed. Coaches are what ONF members call volunteers who provide support to ONF members who are involved in community activities. These activities may include social or political events. Coaching has to be considered as the necessary support persons with intellectual disabilities need to show and realise their potential. Examples of coaching activities are: translation of inaccessible language; making sure that persons with intellectual disabilities get enough time to think and making up their mind; making sure that they get accessible information and enough time to prepare meetings; offering emotional support when painful topics are discussed; ... During the interviews the focus was on what kind of support is seen as being beneficial to make participation in political decision-making more effective.

2.5.4 Focus groups

In addition to the interviews three separate focus groups were set up for persons with an intellectual disability, coaches and policy makers (Adler and Ziglio 1996). Five persons with an intellectual disability, four coaches and five policy makers attended the focus groups. The focus groups with coaches and officials were primarily conducted online. Participants were

given the opportunity to comment on propositions and questions that were put forward, with topics such as support needs, structural coaching solutions, representation and the preservation of self-advocacy movement agenda within political decision-making.

2.5.5 Analysis of research material

The research material is analysed using the thematic analysis method. For the thematic analysis process we followed the model as developed by Braun and Clarke (2006). They propose to work in following steps: data familiarization – initial coding generation – search for themes – theme definition and labelling – report writing. In the following part of the article the results are grouped in five robust themes.

2.6 Results

(1) Where it concerns defining political participation it is noticeable that the organisations that were consulted gave very different answers. Most organisations state clearly that they position the participation in political decision-making on different levels. Some organisations indicate explicitly that participation in decision-making is also positioned at the level of services (residents' associations and consumers' associations). One of the organisations even talks only about this level and not about the broader political level. Some organisations see participation in decision-making also at the organisational level, e.g. taking part in working groups in an organisation for persons with a disability. No organisation gave us a clear description of participation in decision-making as defined in this study.

(2) Regarding the baseline measurement, only 3 persons with an intellectual disability were found who participate in politics in the Flemish speaking part of Belgium. One person is involved in the Consumers' Council of the Flemish Community, one takes part in an advisory body for persons with a disability at the level of a city, and one is a committee member in a policy-making organisation for persons with a disability. In

2010, Flanders had 6,161,600 inhabitants. The World Health Organization (WHO) estimates that 1% to 3% of the population has an intellectual disability – so the potential number of persons who could participate in politics lies between 61,616 and 184,848.

(3) From the experiences of persons with an intellectual disability and their coaches it is obvious that conditions for participation can easily be made clear. They are considered to be minimal structural preconditions and they are listed below:

- Persons with an intellectual disability would like to have equal influence on topics that will be discussed in the political arena. In order to have real participation it is essential that they also can determine points on the agenda for meetings.
- It must be possible to get to the location where the meeting takes place, either by public transport or other means (ideally the meeting place should be near an accessible railway station).
- The stress for persons with an intellectual disability will be reduced if clear and easy to understand symbols are used at the location where the meeting is held. (e.g., lift, signposts, information boards, emergency exits, etc.)
- Attending the meetings is much easier if accessible publications are made available. The invitation, preparation, report, additional documents and PowerPoint presentations can be made available on request. Each document could have a brief summary as introduction. By adjusting the typeface, using plain and simple language, introducing pictograms and photographic material, offering a digital version, avoiding unnecessary embellishments, etc. many things can be made easier to understand without affecting the actual contents.
- Participation actually starts with the invitation which could include a clear indication of the time and place, attaching a route description and map in simple language, a clear list of points on the agenda, full details of the contact person, asking what kind of support will be needed, and identifying the points on the agenda that indicate the points where the input of the persons with an intellectual disability would be

appreciated, etc. These are important signals for persons with an intellectual disability to tell whether or not they are taken seriously as active participants.

- Essential documents for the meeting (limited in number and pages) should preferably be sent 10 days before the day of meeting. It must be taken into account that not everyone has access to a computer and internet and persons with intellectual disability may need support in reading and understanding the documents prior to coming to the meeting.

- Participation is made easier for people with an intellectual disability if the language used during the discussions is calm and easy to understand, without complicated words and jargon.

- Time is an extremely important aspect for effective participation by people with intellectual disabilities. Much can be said about time: time is needed for planning, thinking, talking things through, consulting with others, developing principles, and achieving, in this way, full participation in the decision-making processes. Time is needed to learn to develop points of view, formulate advice and attend meetings. If participation is to be taken seriously, a different timetable is needed.

- It is best to avoid scheduling meetings in the morning, evening or at weekends. Many persons with an intellectual disability are dependent on the availability of professional staff members of the organisations who are giving them support. Travelling to meetings, nearly always by public transport, can take quite a long time.

- The meetings should not last too long and there should be a few breaks in the meetings for the persons with an intellectual disability and their coaches. There should also be an option to take a "time-out" in a meeting, so that persons with an intellectual disability can briefly consult their coach.

- It is best if the meeting has a limited number of points on the agenda and if the discussions have a clear structure.

- It is very important to announce fairly in advance if the meeting date is changed. In this way respect is shown for the fact that persons with an intellectual disability participate voluntarily and need plenty of time for preparation and planning.

- It is easier to secure political participation on a structural basis if some kind of remuneration is made available for the persons with an intellectual disability and

their coaches. This remuneration can be used to meet the expenses incurred and provide some compensation for their time if working as volunteers. Costs incurred can include transportation to/from the meeting site, copying, and meals (when traveling long distances). Working as a volunteer requires enormous dedication and remuneration encourages a full and lasting commitment. This remuneration sometimes clashes with existing regulations regarding disability grants and consequently it is not always possible for persons with an intellectual disability to commit themselves to political projects. However, it motivates people to participate if expenses can be claimed and if it is easy to do so.

- The meetings will become safe environments if there are no major unexpected changes in the length of the meeting, the persons sitting around the table, the points on the agenda, etc.
- It is easier to keep the concentration going in a meeting by avoiding distractions, such as requesting that mobile phones be turned off during the discussions.
- Active participation is only possible with tailor-made and continuous coaching (see 5).

"It is important that people with an intellectual disability and their coaches always remind people of their preconditions, ask explicit questions about certain matters, or confirm their agreement with affairs in hand. We have to keep hammering away at these things" (coach in an interview).

(4) The interviews and the focus groups also revealed the sticking points and pitfalls of political participation. These sticking points show that to participate or not is not just a matter of structural (technical) adjustments, but what is also (and perhaps mainly) needed is a shift in attitudes and foundations. Many participants in our study remain unconvinced that persons with an intellectual disability are "allowed" to participate "for the right reasons". They believe that participation is in name only. We will let them speak for themselves:

"Sometimes organisations do it to make them look good. We have to watch out for this." (person with an intellectual disability)

"I have the feeling that they are using people, just as a front. To engage people with an intellectual disability, seems to "be cool." (coach)

"Perhaps they want us to join so they can get more subsidies." (person with an intellectual disability)

In spite of all the progress made in international principles and declarations, there are still many persons with an intellectual disability in our study who point out that the danger of people "speaking for them" (see Alcoff, 1996) still exists.

"That is why I don't want to join an organisation I don't know anything about, because you could end up being one of their numbers that they show off about or use, and they may not consult you at all. I'm not saying it's everywhere like that, but in some organisations it is true that they don't consult you but they do use you, you see." (person with a disability)

During the entire study the question kept cropping up at what level people "should be allowed" to participate. To be present and receive information are seen as being the first, but inadequate, steps on the participation ladder.

"We know from experience that we are misled sometimes. We are invited to attend a meeting. But we just sit there and are not allowed to say anything. This may suit the organisation, but not us." (person with an intellectual disability)

"It should be more than just being there. Did he really have a say? Did they really listen to him?" (coach)

Many of the participants have given examples of the fact that persons with a disability are often seen as "a homogeneous group". That there can be diverse experiences and opinions around the table is obviously not apparent to everyone.

"Sometimes they say that "the consumers" have been consulted, but then you find that you sit there only with people who have a physical disability. Because

the building is accessible. So, those are then almost the only ones that take part, because the others need an interpreter or a coach. This means you have such a limited representation and then they say the consumers have been consulted."
(a policy maker)

A striking fact emerging from the research data is that persons with an intellectual disability often have to "fit in" with the structures and objectives that have been decided from above. People have the feeling that they are being "held hostage" in the system and don't have a channel to make their voice heard. They are only given the chance to participate within a given system and they hardly ever are involved in setting the agenda.

"We don't set the agenda. The agenda is set from above. If we ask for something to be put on the agenda, they don't pass it on. It is only one subject. I want to discuss various subjects. Inclusion, for example." (person with an intellectual disability)

The dubious title of "consumer" given to persons with an intellectual disability raises quite a few questions among our research participants. A "consumer" has the role of "using the system", not the role of (contributing to) decision-making. This name already raises suspicions that persons with a disability are forced into an inferior position.

They also draw attention to the danger of wrongly redefining the philosophy of "self-advocacy". In that way very few opportunities are created for the self-advocacy movement to develop and for people with an intellectual disability to actually be involved and heard.

Some interviewees (without intellectual disabilities) would like to see restrictions in the subjects and decision-making levels that people with an intellectual disability are allowed to participate in. They argue that persons with an intellectual disability cannot share in political decision-making when it concerns complex questions and would therefore opt for the alternative of involving them in matters that are "less complicated".

(5) From all the findings it emerged that coaching is the central, vital link in the chain if political participation is to be successful. There is not only a need for more

opportunities for people to participate but careful consideration should be given to ways of supporting them in this.

Coaching has to be flexible and on request. Not every person with an intellectual disability needs the same level of support and in the same areas. We have to stop thinking in "groups" and provide the level of support suiting the individual needs of each person. Individual coaching needs can also differ from time to time. In view of the fact that there is no such thing as a standard programme for coaching, it is imperative that there is open communication as regards the need for support. "What do you need?" is a simple but crucial question.

> "I think that the only rule that works is to agree on things together. It is important to reach an agreement on certain matters, on what you like and what you don't like. It may be that a person hates it when he sits in a meeting and has to whisper something in my ear, making it obvious that he doesn't understand. What do you do then? What the person wants is always the most important thing." (coach)

Coaching people with an intellectual disability is a relational matter where reciprocity, mutual respect and trust are key.

> "With coaching... There must be a connection. It must click." (person with an intellectual disability)

> "It is difficult to say how much input, percentage-wise, should come from the coach and how much from the person he coaches. This will also change, all the time. And it also depends on the subject matter. If the subject matter is something you have talked about a few times already, than you should not do too much anymore as a coach. You should take a backseat. If it is something completely new, you should definitely be on the ball." (coach)

Coaching a person with an intellectual disability is different from assisting persons with a physical disability: it is about thinking and deciding together. Coaching is not in the first instance about support for Activities in the Daily Life.

"Support is not just about hands and feet. People with a serious physical impairment, who say something like 'I get it, all you do is writing things down'. If that is your approach to coaching people with an intellectual disability, you'd better not bother at all." (coach)

A coach should be alert all the time and must be encouraged to look further than his own perspectives. If the perspective of the coach dominates, the support that is given will not be helpful. A simple example of this is that coaches can give "reminders" to persons with an intellectual disability if the subject matter being discussed is too complicated or concluded too quickly, but is important enough to dwell on. A coach could ask "did you hear that?" or "do you know what that means?" or "do you remember from last time?", ... However, this is about as far as a coach can go. Here too the coach must always remain "in function of" and he should never take over.

"Sometimes you hear things in a meeting that are not right. The person you support sometimes doesn't understand. That's why it is important that as a coach you know the person very well, so that you have a good idea of what the person would or wouldn't agree with, without making assumptions because that could be tricky, of course. But there are moments when I will say: 'you will have something to say about that, don't you remember, in that meeting last time you told them what you thought?' This is more like jogging their memory. Instead of saying 'this is what you think about that'. It would also not be a real participation if I did not intervene on these occasions". (coach)

The aim of coaching is to create the space and opportunities for persons with an intellectual disability to develop (more) self-determination. This support must always be in the control of the person himself, and the coach should not take over but facilitate and make possible. The coach must always question his "raison d'être".

"A good coach sits next to the person. And if there is a difficult word the coach must explain what that word means, if we ask him. A coach should not take things out of your hands. They should not always be the first to speak. Coaches

have to make time too. Time to properly prepare for meetings, for example."
(person with an intellectual disability)

"It is quite difficult for me to hold back sometimes. Because I have opinions too
and occasionally I would like to say something too. But I am there for him."
(coach)

During the discussions the coaches have to ring the alarm bell sometimes if someone with an intellectual disability is not being taken seriously or if they cannot make a meaningful contribution. However, it is again very important that this is done in dialogue. Participation in political decision-making doesn't mean that persons with a disability *have* to participate in everything. It means that they *can* participate in everything.

Sometimes the pitfall of "taking over" looms large, because others will often address the coach instead of the person with an intellectual disability. Therefore it is crucial that a coach always stays in the supporting role.

"As a coach you find that people often address you and ignore the person you
are supporting. You should put a stop to this pretty quickly. If they start talking
to me I'll say: 'it's those five there that you want to speak to.' (...) To know when
to keep your mouth shut, to know when to create an opening for people so they
can take the initiative, or to know that you can ask certain questions to facilitate
discussions or certain matters... These are the things I find very important."
(coach)

Because coaching means striking a balance all the time, it is extremely important that you assess one another and that you are honest with each other. One of the basic principles of coaching must be to know each other's thoughts and to make sure that you both have a say about the support being offered.

"And I always ask afterwards: 'how do you think the meeting went? And how did
I do? Did I explain everything ok? Did I talk too much? Did you understand
everything? Did you say what you wanted to say?' Later on I will informally

evaluate everything once more. And we have a few laughs too sometimes."
(coach)

Furthermore, as a coach you need quite a bit of time to familiarize yourself with the subject matter, concepts and structures and with the other – more implicit – rules that apply to every (policy-making) meeting, but you have to know these rules in order to give proper support. Just think about matters such as: who is who, who is from which group or organisation, who has what interests where, who is an ally of whom, what strategy will be used, what kind of power structures are there, etc.

> "The preparation with those coaches, that was not so good. We could not follow the meetings. From the summary you could not figure out what it was about. Because they didn't get it themselves, they could not coach us. So we sort of sat there, looking like dummies." (person with an intellectual disability)

The interviewees advocate a coach who is not dependent on a policy-making organisation, but on the person himself. This would mean mixed interests are avoided, the person would have more autonomy within the organisation, and it would be possible to use the coach for other activities and meetings. Some are in favour of external coaches who are trained in supporting the person, but also in supporting the policy-making organisation. Most think that a considerable expansion of the system of Personal Budgets seems a good solution. Some would like to see an independent agency for coaches where persons can choose their supporters from a "pool of coaches".

> "I cannot ask my coach to go to a meeting of another organisation, that's a shame. I was not allowed to use her either to translate a policy paper from the minister. I cannot use her for other things to do with politics. The organisation decides what she can and cannot do." (person with an intellectual disability)

All the tendencies detected in the study indicate that coaching is a relational matter rather than a technical one.

2.7 Discussion

From this study we can conclude that the political participation of persons with an intellectual disability in Flanders is nowhere yet. This conclusion runs parallel with the fact that we have learned through history that individuals who are located at the intersections of race, class, gender and disability were and are constituted as non-citizens and (no)bodies (Gabel et al. 2012) by the society and its institutions that are designed to protect, nurture and empower them (Erevelles and Minear 2010, 127). From a historical perspective, people with a disability are perceived as clearly different from the 'storybook ideal citizens' (Carey 2009). These latter are seen as citizens that are gifted with trumps like: to be able to take rational dicisions, to deal with complex information, to participate based on distinct communication, to be independently responsible for own basic needs, to be independent on a financial and social level.

How can this not (yet) participating of persons with an intellectual disability be understood and approached?

First of all, we cannot deny the strong binary thoughts in Belgium about citizenship and the associated political participation. However, more and more people with an intellectual disability question this division and accompanying exclusion and consequently the representation of the ideal citizen.

We have chosen to consider political participation for persons with an intellectual disability as a part of being on the way to the implementation of the UN Convention of the Rights for Persons with Disabilities. Whereas intellectual disability as a phenomenon is increaslingly described as a social construction more than a biological fact (Finkelstein 2009; Goodley and Rapley 2001), we have the moral duty to take the question of political participation seriously.

There are different ways in which citizenship and political participation is being translated.

Sometimes we see that traditional power relations are not altered but there are only certain linguistic shifts. Goodley (2011) points out the danger that under the banner of

political participation self-advocacy as a minority movement is confronted with re-colonization through a government/majority agenda.

Besides, Biesta (2011) warns us for a possible second pitfall: the solution cannot simply be found by preparing persons with an intellectual disability, via training or schooling programs, in the hope that they once "will be allowed" to participate.

In a third possible solution we follow Bérubé (2003) suggesting that it would be the better option if persons with an intellectual disability participate, if they want to, while we change the system. While they participate they are entitled to receive coaching, structural preconditions are being met and everyone involved is having a positive attitude which is needed to achieve real and proper participation. So, nothing is preordained, everything is flexible and negotiable. Through this last option we consider political participation as a rhizomatic conception where opportunities are being opened based on a non-standardized (not similar for everyone) coaching.

With this latter option we make a connection with the Deleuzian approach where thinking about difference makes room for the perspective of differenciation (Davies 2009). Whereas the approaches where Biesta and Goodley are cautious about are linked with the view where difference is a dimension of separation, we chose for an approach where difference can be considered as a continuum, a multiplicity of fusion (17). This results in a fluidity of categories (19) and an escape to some degree from the limits of the individual and new ways of becoming a subject (20). Hence, individuals don't have to 'fit in' (Pols 2004), citizenship and political participation imposes the responsibility not only by the person with an intellectual disability. This process of becoming is located within an understanding of citizenship as a relational concept, where interaction can lead to a political opening and gives people the chance to consider the collective (Winance 2007). Difference is an integral part of relationships and it is with and by these relations that participation can be achieved.

"We want to participate but not only to sit there and to vote "yes" on an agenda of others…" can be considered as a good closing quote (as stated by one of our interviewees) for this article.

2.8 References

Adler, Michael, and Erio Ziglio. 1996. *Gazing into the oracle: The Delphi Method and Its Application to Social Policy and Public Health.* Bristol: Jessica Kingsley Publishers.

Bjarnason, Dóra, S. 2011. *Social Policy and Social Capital: Parents and Exceptionality 1974-2007.* New York: Nova Science Publishers.

Bernard, H.Russel. 1995. *Research Methods in Anthropology: Qualitative and Quantitative Approaches.* Walnut Creek: Altamira Press.

Bérubé, Michael. 1996. *Life as we know it: A father, a family, and an exceptional child.* New York: Pantheon.

Bérubé, Michael. 2003. "Citizenship and Disability." *Dissent*, spring: 52-57.

Biesta, Gert. 2011. "The Ignorant Citizen: Mouffe, Rancière and the Subject of Democratic Education." *Studies in Philosophy and Education*, 30(2): 141-153.

Braun, Virginia, and Victoria Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative research in Psychology* 3: 77-101.

Carey, Allison. C. 2009. *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America.* Philadelphia: Temple University.

Charlton, James, I. 1998. *Nothing about us, without us: Disability, Oppression and Empowerment.* Berkeley: University of California Press.

Chenoweth, Lesley, and Daniela Stehlik. 2004. "Implications of social capital for the inclusion of people with disabilities and families in community life." *International Journal on Inclusive Education* 8(1): 59-72.

Davies, Bronwyn. 2009. "Difference and differenciation." In *Pedagogical Encounters*, edited by Bronwyn Davies and Susanne Gannon, 17-30. New York : Peter Lang.

Edgerton, Robert. B. 1993. *The Cloak of Competence*. Berkeley: University of California Press.

Erevelles, Nirmala, and Andrea Minear. 2010. "Unspeakable offences: Untangling Race and Disability in Discourses of Intersectionality." *Journal of Literary and Cultural Disability Studies* 4(2): 127-146.

Finkelstein, Vic. 2009. "The 'social model of disability' and the disability movement." In *Understanding Disability, from theory to practice*, edited by Michael Oliver, 142-152. Basingstoke: Palgrave Macmillan.

FRA 2010. *The right to political participation of persons with mental health problems and persons with intellectual disabilities.* Vienna: European Union Agency for Fundamental Rights.

Fraser, N. (2003). "Social Justice in the Knowledge Society. Redistribution, Recognition and Participation." Heinrich Boll Stiftung, http://www.wissensgesellschaft.org

Gabel, Susan, L., Carie J. Cohen, Kathleen Kotel, and Holly Pearson. 2012. "Intellectual disability and space: Critical narratives of exclusion." *Intellectual and Developmental Disability* 51(1): 74-80.

Garbutt, Ruth. 2009. "Is there a place within academic journals for articles presented in an accessible format?" *Disability and Society* 24(3): 357-371.

Gilbert, Tony. 2004. "Involving people with learning disabilities in research: issues and possibilities" *Health and social care in the Community* 12(4): 298-308.

Goodley, Dan. 2011. *Disability Studies. An Interdisciplinary Introduction.* London: Sage.

Goodley, Dan, and Mark Rapley. 2001. "How Do You Understand 'Learning Difficulties'?: Towards a Social Theory of Impairment." *Mental Retardation* 39(3): 229-232.

Landsman, Gail. 1999. "Does God Give Special Kids to Special Parents?: Personhood and the Child with Disability as Gift and as Giver." In *Transformative Mothering: On Giving and Getting in a Consumer Culture,* edited by Linda Payne, 133-165. New York: New York University Press.

Mertens, Donna. M. 1998. *Research Methods in Education and Psychology*. Thousand Oaks: Sage.

Nussbaum, Martha. 2006. *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge: Harvard University Press.

Nussbaum, Martha. 2009. "The Capabilities of People with Cognitive Disabilities." *Metaphilosophy* 40(3-4): 331-351.

Nussbaum, Martha. 2010. "The Capabilities of People with Cognitive Disabilities." In *Cognitive Disability and its Challenge to Moral Philosophy,* edited by Eva Federer Kittay and Licia Carlson, 75-95. West-Sussex: Wiley-Blackwell.

Pols, Jeanne. 2004. "Good care. Enacting a complex ideal in long-term psychiatry." PhD diss., Utrecht: Trimbos-reeks.

Stark, Cynthia. A. 2007. "How to Include the Severely Disabled in a Contractarian Theory of Justice?" *The Journal of Political Philosophy* 15(2), 127-145.

Stiker, Henri-Jacques. 1997. *A History of Disability.* Ann Arbor: The University of Michigan
   Press.

Taylor, Steven, and Robert Bogdan. 1989. "On accepting relationships between people with
   mental retardation and non-disabled people: towards an understanding of
   acceptance." *Disability, Handicap and Society* 4(1): 21-37.

Tisdall, Kay. 1994. "Why not consider citizenship?: a critique of post-school transitional
   models for young disabled people." *Disability & Society* 9(1): 3-17.

Winance, Myriam. 2007. "Being normally different? Changes to normalization processes:
   from alignment to work on the norm." *Disability and Society* 22(6): 25-38.

Wolfensberger, Wolf. 1972. *Normalization: the Principle of Normalization in Human*

3. SAMEN ONDERZOEKEN: 'VOICE' ALS GIDS IN ONDERZOEK

Gebaseerd op: Goethals, T., Van Hove, G., Van Breda, L., & De Schauwer, E. (2016). Researching Together: Voice as a Guide in Research. In T. Buchner, O. Koenig, & S. Schuppener (Eds.), *Inklusive Forschung. Gemeinsam mit Menschen mit Lernschwierigkeiten forschen.* Bad Heilbrunn: Klinkhardt.

Abstract

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.

3.1 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 getting 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.

3.2 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." (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.

3.3 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.

3.4 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" (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.

3.5 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." (1997, 93f.) This component of voice is "more than interpretive description". (1997, 93f.) It is the theoretical framework underlying the work that defines "what she [the portraitist] sees and how she interprets it". (1997, 93f.)

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..." (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".

3.6 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" (1997, 105f.) from his activist and constructivist position, but he needs to works "very hard not to simply produce a self-portrait" (1997, 105f). 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.

3.7 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.

3.8 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" (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" (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.

3.9 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 and 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.

3.10 References

Ashby, C.E. (2011): Whose ''voice'' is it anyway? Giving voice and qualitative research involving individuals that type to communicate. In: *Disability Studies Quarterly, 31(4),* 1723–1771.

Atkinson, D. (2002): Self-advocacy and research. In: Gray, B. & Jackson, R. (Hrsg.): *Advocacy and Learning Disability.* London, UK: Jessica Kingsley Publishers, 120–136.

Atkinson, D. (2005): Research as Social Work: Participatory Research in Learning Disability. In: *British Journal of Social Work, 35,* 425-434.

Atkinson, D. & Walmsley, J. (1999): Using Autobiographical Approaches with People with Learning Difficulties. In: *Disability & Society, 14(2),* 203-216.

Barton, L. (2005): Emancipatory Research and Disabled People: Some Observations and Questions. In: *Educational Review, 57(3),* 317-327.

Booth, T. & Booth, W. (1996): Sounds of Silence : narrative research with inarticulate subjects. In: *Disability & Society, 11(1),* 55-69.

Braidotti, R. (1994): *Nomadic Subjects.* New York: Colombia University Press.

Chapman, T.K. (2005): Expressions of ''Voice'' in Portraiture. In: *Qualitative Inquiry 11(27),* 26-51.

Dahlberg, G. & Moss, P. (2005): *Ethics and Politics in Early Childhood Education.* London: RoutledgeFalmer.

Davies, B. (2014): *Listening to Children. Being and Becoming.* Abingdon, Oxon : Routledge.

de Lauretis, T. (1987): The Technology of Gender. In: de Lauretis, T. (Hrsg.): *Technologies of Gender.* Bloomington/Indianapolis: University Press.

De Schauwer, E. & Van Hove, G. (2011): Swimming is never without risk. Opening up on learning through activism and research. In: *Qualitative Inquiry, 17(2),* 224-232.

De Waele, I., Van Loon, J. & Van Hove, G. (2005): Quality of Life Versus Quality of Care: Implications for People and Programs. In: Journal of Policy and Practice in Intellectual Disabilities, 2(3-4), 229-239.

English, F. W. (2003): *The postmodern challenge to the theory and practice of educational administration.* Springfield, IL: Charles C. Thomas.

Freire, P. (1972): *Pedagogy of the Oppressed.* Anthos: Baarn.

Freire, P. (2004): *Pedagogy of Hope.* London/New York: Continuum.

Garland-Thomson, R. (2005): Feminist disability studies. In: *Signs: Journal of Women in Culture and Society, 30(2),* 1557-1587.

Gibbs, M. (2001): Toward a strategy for undertaking cross-cultural collaborative research. In: *Society and Natural resources, 14*, 673-687.

Goethals, T. & Van Hove, G. (2011): Politieke participatie van personen met een verstandelijke beperking. Onderzoeksrapport voor de Cel Gelijke Kansen, Vlaamse Regering.

Goodley, D. (1996): Tales of Hidden Lives: a critical examination of life history research with people who have learning difficulties. In: *Disability & Society, 11(3),* 333-348.

Goodley, D. (1998): Supporting people with learning difficulties in self-advocacy groups and models of disability. In: *Health & Social Care in the Community, 6(6),* 438-446.

Goodley, D. (2000): *Self-advocacy in the Lives of People with 'Learning Difficulties'.* Buckingham: Open University Press.

Goodley, D. (2007): Becoming rshizomatic parents: Deleuze, Guattari and disabled babies. In: *Disability & Society, 22(2),* 145-160.

Goodley, D. & Van Hove, G. (2005): *Another Disability Studies Reader? People with Learning Difficulties and a Disabling World.* Leuven/Apeldoorn: Garant.

Lawrence-Lightfoot, S. (2009): *The third chapter: Passion, risk, and adventure in the 25 Years after 50.* New York: Sarah Crichton Books.

Lawrence-Lightfoot, S. & Davis, J. H. (1997): *The art and science of portraiture.* San Francisco: Jossey-Bass.

Nind, M. (2013): Understanding quality in inclusive research: a process of dialogue. In: *Nordic Network on Disability Research Conference, Turku, FI, 30 - 31 May 2013.*

Nussbaum, M. (2006): *Frontiers of Justice: Disability, Nationality, Species Membership.* Cambridge, MA: Harvard University Press, Belknap Press.

Nussbaum, M. (2009): The capabilities of people with cognitive disabilities. In: *Metaphilosophy, 40(3–4)*, 331–351.

Nussbaum, M. (2010): The Capabilities of People with Cognitive Disabilities. In: Kittay, E.F. & and Carlson, L. (Hrsg.): *Cognitive Disability and its Challenge to Moral Philosophy*. West-Sussex: Wiley-Blackwell, 75-95.

Rinaldi, C. (2006): *In Dialogue with Reggio Emilia. Listening, researching and learning.* London: RoutledgeFalmer.

Stark, C. A. (2007): How to Include the Severely Disabled in a Contractarian Theory of Justice. In: *Journal of Political Philosophy, 15*, 127–145.

Tregaskis, C. & Goodley, D. (2005): Disability Research by Disabled and Non-Disabled People: Towards a Relational Methodology of Research Production. *International Journal of Social Research Methodology, 8(5),* 363-374.

Van Hove, G., Roets, G., Mortier, K., De Schauwer, E., Leroy, M. & Broekaert, E. (2008): Research in Inclusive Education as a Possible Opening to Disability Studies in Education. In: Gabel, S. & Danforth, S.: *Disability & the Politics of Education. An International Reader.* New York: Peter Lang, 121-140.

Walmsley, J. & Johnson, K. (2003): *Inclusive research with people with learning disabilities: past, present and futures.* London/New York: Jessica Kingsley Publishers.

Ware, L.P. (2002): A moral conversation on disability: risking the personal in educational contexts. *Hypatia, 17,* 143–172.

Wilkinson, S. & Kitzinger, C. (1996): *Representing The Other: A Feminism and Psychology Reader.* London: Sage Publications.