Collaborative user involvement in health research agenda setting

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DEVELOPING VOICE AND EMPOWERMENT: THE FIRST STEP TOWARDS A BROAD CONSULTATION IN RESEARCH AGENDA SETTING.

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ABSTRACT

Background Although people with intellectual disabilities (ID) are increasingly consulted in research, participation in research agenda setting processes is limited. This is not surprising as their voice can easily be dominated in consultations with researchers. The aim of this article is to explore the potentials of enclave deliberation as a first step towards broad consultation in research agenda setting.

Method The research agenda setting process followed a responsive methodology, which is characterized by a cyclical and emergent design. Two persons with ID and one parent participated in the research team. Seven persons with ID and six parents were interviewed individually. Subsequently, 10 focus groups were organised with people with ID and four focus groups with parents. Also, a questionnaire was sent to parents.

Results The process towards involvement of people with ID was characterised by several steps that guided enclave deliberation. First, stories of people were collected that reflected their intimate voice. Then, a political voice was further developed through dialogue and interaction in focus groups. This process resulted in a prioritised list of nine potential topics for research.

Conclusion The process of developing intimate voice and political voice can be regarded as a concretization of enclave deliberation among disempowered groups. These steps are necessary to initiate a process towards establishing a broad consultation between different stakeholders about research on ID.

4.1   INTRODUCTION

"The selection of research topics should therefore emerge through partnerships with all key players – people with intellectual disabilities, and their families and carers, those representing different groups …, clinicians and social care providers …, and those with research expertise …. … In the absence of broad consultation involving all relevant parties the research agenda will not be fully and properly informed" (Holland, 2007)*.*

Some years ago, Tony Holland, the editor of this journal, explained the need for broad consultation in research agenda setting to enhance the breadth and quality of these processes. Participation of people with intellectual disabilities (ID) in research agenda setting also has an intrinsic value, i.e. the democratic right to speak up in a process that ultimately aims at influencing their lives and serving their needs (Abma, 2006; Caron-Flinterman, 2005; Greene, 2006).

Ever more participatory studies are being published that take account of the perspectives of people with ID (Knox, Mok, & Parmenter, 2000; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Richardson, 2000). Participation in research agenda setting processes is, however, often restricted to consulting people with ID in response to research topics predefined by researchers (Ramcharan, Grant, & Flynn, 2004). Collaboration between various groups of stakeholders, as Holland suggests, is still exceptional (Holland, 2007). Even more infrequent is the actual involvement of people with ID in the research process itself. The study by Williams, Marriott, & Townsley (2008) is an exceptional example. In this research agenda setting process, the views of people with ID were contrasted with those of family members and professionals. Self advocates were involved in the research team. The agenda setting process presented here resembles Williams' project, and is very much in line with the tradition of inclusive research.

Inclusive research is an emerging approach where people with ID are supported by and collaborate with academic researchers to conduct their own research project (Bigby & Frawley, 2010; Walmsley & Johnson, 2003; Williams, 1999, 2005; Williams & Simons, 2005). It is considered crucial that people set their own agenda and participate fully in the design, data collection and analysis, as this will give them the opportunity to exert real control over the research process. Inclusive research follows a team approach as people with ID collaborate

with academic researchers. Roles and responsibilities change as people with ID learn and develop during the process relationships. This dynamic requires open discussion and reflection so that mutual expectations correspond (Abma, Nierse, & Widdershoven, 2009; Cook & Inglis, 2009; Williams & Simons, 2005). In general one can say that the academic researcher will, where possible, take a back seat, while still providing support and assistance where needed. Inclusive research is emancipatory in its normative orientation as it deliberately strives towards more equality in the social relations between researcher and the researched. As these relations change from hierarchic to more horizontal interactions, the distinction between researcher and researched begins to blur (Abma & Widdershoven, 2008; Oliver, 1992; Schipper et al., 2010).

The literature raises tensions and critiques of inclusive research, as well as practical descriptions of the process. For instance, points can be made about power imbalance, the question of the role of non-disabled supporters, and possible charges of tokenism (Bigby & Frawley, 2010). Participatory studies do not necessarily lead to participants exerting control over the findings and may result in pseudo participation or tokenism, if participants have no influence on the decision-making (Garcia-Iriarte, Kramer, Kramer, & Hammel, 2009). When including people with ID in broad consultations, one should be alert to the fact that their voice can easily be dominated, simply because they are not usual partners in research (Nolan, Hanson, Grant, & Keady, 2007). There may also be insufficient time to define their viewpoints. A marginalized position in society, stigmatization and self-censorship complicate the process of generating authentic experiences among people with ID. Furthermore, given the asymmetry between lay knowledge and scientific knowledge, one needs to consider how to go about empowering people with ID to participate in negotiations with professionals. One way of doing this is by helping them to first gain a voice as individuals and subsequently developing a shared, political voice based on collective experiences. In political science literature this is referred to as 'enclave deliberation' among disempowered (Karpowitz, Raphael, & Hammond, 2009).

This article discusses a Dutch project in which a research agenda was developed *together with* people with ID. In this project people with ID and parents actively took part in the research agenda setting process from the outset. Three of them (a mother and two people with minor ID) participated as partners in the research team (Abma et al., 2009). The aim of this article is to explore the potential of enclave deliberation as a first step towards broad consultation in

research agenda setting. Details about the dynamics in the mixed research team have been dealt with elsewhere (Abma et al., 2009).

4.2 METHOD

4.2.1 SETTING

In 2005 the Dutch Advisory Council on Health Research concluded that current scientific research did not incorporate the needs of people with ID and their parents (Raad voor Gezondheidsonderzoek, 2005). As William Westveer, the former president of the Dutch Association of Self Advocates aptly described it: *For us research is something others have come up with to find out something about us* (Jerphanion, 2005). In response, the Netherlands Organisation for Health Research and Development (ZonMw) invited two academic centres to embark on a research agenda setting process with people with ID. The project was a collaboration between two universities, the Dutch Association of Self Advocates ('Landelijke Federatie Belangenverenigingen Onderling Sterk') and the Dutch Federation for Parent Organizations of People with ID (currently named 'Platform VG', the Dutch ID Platform), hereafter referred to as advocacy associations. The project was conducted between December 2005 and September 2006 and was funded by ZonMw. Although the initial project proposal was developed by two academics in response to a call by the granting organization, with a deadline that left no room for consultation with the main stakeholders, this proposal did leave sufficient room for negotiations about the project design. Immediately following approval from the granting organization, the advocacy associations were contacted for their commitment and for further deliberations about the proposal.

One element in the discussion was whether or not to include research partners in the project team. Research partners are clients who join the research team on an equal footing with academic researchers. They share decision-making power with researchers and their degree of involvement is closer to the patient as an advisor or research principal than to the patient as an object of research (Abma et al., 2009). Forming a transdisciplinary project team was considered an important route towards emancipation, and equal social relations and shared control among researched and researchers (Oliver, 1992; Walmsley & Johnson, 2003; Williams, 1999; Williams & Simons, 2005). Moreover, it was decided that this kind of team structure was desirable in terms of bringing experiential knowledge, establishing trust, gaining

access and entrée, translating jargon, revealing prejudices and developing new perspectives. It meant that the academic researchers did not act as experts, but as supporters and assistants of the research partners. In order to stress the equality in the project team, the research partners received a financial contribution for their time and effort).

4.2.2 Theory

The research agenda setting process followed a responsive methodology, which has its origins in the field of educational evaluation (Abma & Stake, 2001; Guba & Lincoln, 1989; Stake, 1975, 2004). Responsive research acknowledges plurality and clarifies the issues of as many stakeholders as possible. Some later, interactive versions of responsive research aim more specifically at involving different stakeholders in exchanging their perspectives through dialogue and mutual learning (Abma, 2005b; Abma & Broerse, 2010; Abma & Widdershoven, 2005). Apart from exchanging perspectives in a dialogue, stakeholders can together develop new issues, insights, questions or recommendations (Abma & Widdershoven, 2005). This interactive methodology is suitable for involving people with ID in research agenda setting, since it pays specific attention to the inclusion of marginalized groups (Baur, Abma, & Widdershoven, 2010; Greene, 2001; Mertens, Farley, Madison, & Singleton, 1994) and aims to systematically establish partnerships between stakeholders (Abma, 2005a).

The methodology is characterized by a cyclical and emergent design (Abma, 2005b; Abma & Broerse, 2010) in which the specific research activities are not determined beforehand, but are developed during the process in consultation with the stakeholders. This allows researchers to adapt to the issues that emerge from the subjective experiences and stories of stakeholders (Abma & Widdershoven, 2005). In the present project, the design evolved during conversations with people with ID and their parents. Their concerns guided the research process.

Next to empower clients to become researchers themselves, academic researchers assist them to co-design and collaborate in the research (Abma et al., 2009; Schipper et al., 2010). Responsive methodology aims at participation by organizing dialogues within and between parties, a process that is fostered by the researcher as facilitator, educator, evaluator and Socratic guide (Abma & Widdershoven, 2005). Power imbalances are handled by a methodology in which those who are least heard are given the most attention; their voices are developed homogeneously and separately from other (established) stakeholders in order

to elicit their voices and emancipation. After having generated their agenda, heterogeneous meetings and dialogues follow to enhance mutual understanding. This methodology is a concretization of 'enclave deliberation' among disempowered (Karpowitz et al., 2009).

4.2.3   DESIGN AND PROCEDURES

This project used a combination of different data collection methods (Table 1). The initial exploratory phase resulted in the recruitment of the research partners. The advocacy associations approached three people who were willing to participate in the project as co-researchers: two people with mild ID and the mother of a son with severe ID. Instead of conducting a formal application procedure, they took part in a project team meeting and got acquainted with the researchers. They were asked at the end of the meeting whether they were interested in participating as research partners in the whole project. From then on they were actively involved in data collection, analysis and dissemination of the results (Abma et al., 2009). Over the course of the project meetings were held every two weeks with the project team at the office of the self advocate organization. As the team prepared and conducted all activities together they became a cohesive group. Support by the academic researchers entailed making time to have a coffee with the participants so they could listen to their concerns, provide reassurance, amend schedules and help the partners with difficult tasks. Creating a safe and respectful working environment was considered the responsibility of the whole team, and regular evaluations were held to reflect on the dynamics in the group.

The first stage involved interviews with key informants from professional organizations in the field (N=4) to gain a better understanding of the conditions for participatory research with this group. And a mixed advisory group with representatives of various organizations, including the self advocate organization, was established for feedback purposes.

During the consultation phase, people with ID, parents of young children with ID (N=7), and parents of children with severe ID (N=6) were interviewed until saturation was reached. They were recruited by both associations and selected by the researchers based on the criterion of maximum variation in terms of age, sex, daily activities and living conditions. Care settings for people with ID were also approached, and permission was sought for team members to observe and engage in daily activities (e.g. meals, a sheltered workplace, or a setting for decentralized living) and to interview people. Secondly, focus groups were organized with people with ID (9 groups, totalling 81 participants) and parents (separately) (4 groups, totalling

24 participants) with the aim of validating and deepening the themes that had emerged in the interviews. Focus group participants were recruited through local offices of the advocacy associations, through the personal networks of the research partners, and by contacting client councils of care organizations.

In the subsequent, prioritization, phase the research themes generated from the consultation phase were ranked. One focus group was held with twelve people with ID inviting them to decide on the three most important research by having them allocate three, two or one money bag(s) to their number one, two and three research topics respectively. Parents (N=34) completed a questionnaire based on the research themes that emerged from the consultation phase, and were asked to follow the same prioritization scheme as the people with ID (response rate: N=17).

All the interviews and focus groups were recorded, transcribed and inductively analysed following a structured approach, and the results were returned to respondents for validation (member check (Meadows & Morse, 2001)). Half way and at the end, a report was presented to an advisory group comprising representatives of professional organizations in the field and both advocacy associations for their feedback.

Informed consent of people with ID was corroborated by the caregivers or coaches from local offices, who first received informative texts about the project (one version for themselves, and one easy to read version), who then approach potential respondents.

If requested, a caregiver or coach accompanied a participant to the interview or focus group meeting. They generally stayed in the background but sometimes encouraged participants to say more. In two interviews a respondent requested the presence of a familiar caregiver, and a local coach was present in all the focus groups. The researchers saw this as beneficial rather than as disruptive, since it contributed to an open and friendly atmosphere for the participants.

The local university Research Ethics Committee decided that this project did not require ethical approval, since they did not see it as invasive medical scientific research.

Table 4.1   Data collection methods involving research partners.

Data collection method	Respondents / Participants	Involvement of research partners
In-depth interviews	People with ID: 7 interviews Parents: 6 interviews	Preparation (including topic list, recruitment), interviewer, analysis
Focus groups for validating and deepening issues (participants, total)	People with ID: 9 focus groups / totalling 81 participants Parents: 4 focus groups / totalling 24 participants	Preparation (including topic list, recruitment), moderator, analysis
Focus group for priority setting (participants, total)	People with ID: 1 focus group (10 participants)	Preparation (including protocol), co- moderator, analysis
Questionnaire for priority setting	Parents (17 respondents)	Construction of the questions and analysis

4.3   RESULTS

The results of the project can be described both in terms of process and of outcome. A process towards involvement was started: relationships were established with the group of people with ID, and people were guided along a process towards articulating topics they felt were important and recognizable. This resulted in people with ID feeling empowered to speak up and to exchange stories and experiences with each other. As a result, ownership of the research agenda was created with people with ID. However, this process towards developing voice and empowerment sometimes encountered obstacles. These moments and lessons will be described first, followed by a description of the outcome, the research agenda.

4.3.1 Stories illuminating intimate voice

Given that people with ID do not have a say in science, they first have to develop a voice as a valid source of knowledge. However, there were times during the data collection stage when the interviews did not result in a clear view of the experiences and life world of people with ID. The research partners and the academic researchers felt these interviews lacked credibility. Although the interview topic list served as guidance, it did, at times, actually inhibit some respondents from speaking openly about their difficulties or problems. Using a voice recorder made some respondents feel they were being interrogated. Breaking through this object-subject relationship and discussing a respondent's unease proved to be difficult. The project team eventually concluded that the interviews resulted in superficial, socially-desirable answers that only conveyed the idea that everything was perfect.

The more formal interview setting was eventually abandoned in favour of an initial tour of the respondents' home or workplace. The result was a more informal, open conversation (Abma, 2001) during which the respondents not only felt at ease, but also became more open and willing to share their stories. The researchers found it much easier to respond to what the respondents had to say, and the research partners eventually learned how to explore what the respondents wanted to tell them. As a result, the academic researchers could now take a back seat and say much less during the interviews (Williams, 1999; Williams & Simons, 2005). A particular strength among the research partners was that they were able to engage people in conversation and that they felt more empathy. One partner expressed it as 'putting out her antennae'. The responses were now much more authentic. For example, one respondent described how important friendship was for her:

"When I'm with friends, I have to feel I can trust someone and then I get tickles in my belly and tickles in my heart, because I'm a sensitive person. And then I get the feeling that I'm no longer being patronized. That is what friendship feels like to me."

In a similar vein, the parents of children with ID opened up when the team listened to their stories. Although the team were well aware of the fact that the parents' perspective as proxies was likely to be different from that of the child, they were not obliged to talk only about their child's experiences. Leaving parents room to express their own perspective helped the

researchers connect with them and get the whole story i.e. of the parent and the child, as the following quotation from a mother of an adolescent daughter with ID illustrates:

"Recently (my daughter) spent a weekend at a specialized guesthouse. There were only two caregivers for a group of seven children. When she came home she looked rather spiritless and unhappy. We got the impression she hadn't even got out of her wheelchair the entire weekend."

Life stories were a useful source of possible research themes, since people did not immediately come up with research topics when asked about them. Their specific subjective knowledge surfaced when stories were shared. Telling stories can also contribute towards the empowerment process. People with ID became aware of their experiential knowledge through their stories. Relating their stories gave them a voice, whereas simply discussing a list of potential research topics lacked both context and meaning that people with ID give to their story.

However, it was not self-evident for people with ID to automatically start sharing their stories with researchers. Involving research partners, abandoning the topic list, and foregoing a formal interview situation all helped to get people to share their intimate voice with the researchers. The context and meaning of the issues that mattered in the lives of people with ID became more prominent.

4.3.2   DIALOGUE TO DEVELOP POLITICAL VOICE

In the focus groups, the intimate voices were translated into shared, political voices. The interactions resulted in participants recognizing and reacting to each other's issues and experiences. This is illustrated by a sequence that started with a question posed by the research partner, referring to her own experiences. She asked the participants whether they ever felt they were taken seriously or not. This invoked considerable response from the group.

"In the village they didn't take me seriously. When I went to the hairdresser, he said afterwards that I had to pay. I said that I wouldn't do that, because everyone who had his hair cut, got coffee or tea. I hadn't been given one because I was from the institution. But

I'm also a human being, and I'm worth as people without a disability. … After I paid, I got a
coffee."

"You often hear this about people with ID. I get very angry. Sometimes I think that it's just
how it is. But it shouldn't be that way."

The interaction between focus group participants made them realize that it was not right for
one of them to be treated differently. Whereas the conversationalist interviews were
appropriate for people to develop their intimate voice by sharing their stories with the
researchers, the interaction in the focus groups helped people develop a political voice and
undergo an empowerment process. These focus groups were not too concentrated since
people with ID do not experience life as something where boundaries are drawn. There was
enough room for participants to discuss related themes in more detail (Balch & Mertens,
1999). As a result, participants reacted to each other's experiences by recalling experiences of
their own, and by pointing out problems they encountered in their own environment, thereby
creating joint experiences. Participants subsequently started to think aloud about possible
solutions and about how situations could be improved.

For instance, participants in one focus group talked at length about friendship, which is
particularly important for people with ID, especially for those who have lived in institutions
and then move to more independent accommodation. One participant explained how he saw
that people were very lonely:

"They now all live independently in the neighbourhood, but they often experience loneliness.
They never learned how to make contact with the neighbours, … they can't talk with other
people."

However, these dynamics were not automatic. When focus groups were held with people with
ID who did not know each other beforehand, the interaction tended to become somewhat
chaotic. The participants did not really listen to each other, some were very quiet, some had
a lot to say, and there was no exchange of experiences. Things improved when people were
not just randomly or reluctantly put together, but when existing groups were contacted.
People in these groups were used to talking to each other and, as a result, an atmosphere of

openness and inclusiveness contributed to an emerging dialogue within the group. Some of these groups were already engaged in a process of awareness raising, and were prepared to be more critical and assertive and not just accept everything.

Preparatory activities proved to be an important tool for fostering interaction and dialogue in a focus group. Getting acquainted with the group beforehand by calling in on a regular meeting helped familiarize the participants with the research project, the researchers themselves, and with what they wanted to know. As far as the researchers were concerned, getting to know the groups beforehand helped them to learn how to address the group in the most appropriate manner. For instance, after a focus group where there had been no prior personal contact, the participants expressed disappointment about the childish set-up and questions where key cards had been used, or people had been asked to raise a finger if they shared an experience with others. In response to this feedback, the researchers contacted the same group for a second time to involve them in the analysis by asking them to prioritize research topics. The participants later said they felt their abilities had been addressed much better.

Over time, the research partners would take the role of chair during the focus groups. The participants responded very well to their involvement, in the sense that they managed to encourage the quieter participants in the group to speak up.

4.3.3 RESEARCH AGENDA

The values (ownership, equality, openness) that proved important during the research process, resonated through the research agenda of people with ID and their parents. The research agenda contained a broad array of research areas (see Table 2). The highest priority was given to research on discrimination, followed by research on friendship and research on coaching and support. These three research areas are briefly described in order of priority below.

Table 4.2   Research priorities elicited from people with ID

Research areas	Definition	Subtopics
1. Discrimination	Create inclusive society	- Not treated equally
		- enabling/disenabling environments
		- Resilience and empowerment
2. Friendship	Improve social network	- Loneliness
		- Aggression
		- Own limitations
		- Social stability
3. Coaching and support	Improve support	- Time and attention
		- Shared decision-making
		- Person-centeredness
4. Work	Improve liveability	- Work pressure
		- Communication
		- Diplomas
		- Organization dynamics
5. Housing	Improve liveability	- Composition group
		- Institutional rules
6. School	Better tailored to person	- Lacking information
		- Didactic methods
		- Multi problem approach
		- Bureaucracy
7. The doctor	Improve communication	- Shared decision-making
		- Psychosomatic problems
		- Expertise

8. Hobbies	More leisure activities	- Assistance
		- Expertise
9. Travelling	More opportunities	- Public transport
		- Expenses
		- Assistance

People with ID gave numerous examples of situations in which they felt discriminated against. They believed they were not treated as equals, and that they were bullied, and asked for research to create a more inclusive society. Subtopics included research on disenabling and enabling environments, and research on the sources of resilience of people with ID and empowerment.

Research on friendship was given priority because many people with ID feel lonely and isolated. Research should hopefully lead to a larger social network. Parents also saw this as a very important topic. Subtopics included building and maintaining friendships.

Coaching and support was also identified as an important research area among parents and people with ID. Both parties pointed out that coaching and support could be problematic, but it could also make a difference. Participants talked, for instance, about supervisors who were never on time for an appointment, who never had enough time to talk, or supervisors who only followed rules and who do not listen properly to their clients wishing to talk about problems that are important to them. Other issues included not being able to choose a particular kind of supervision, or to speak up to supervisors.

Table 4.3   Quotations to illustrate the nine research areas identified

Research areas	Quotes
1. Discrimination	*In the village they didn't take me seriously (…). But I'm also a human being, and I'm worth as people without disabilities.*
2. Friendship	*I can't live without my animals. If they weren't there I would feel very lonely.*
3. Coaching and support	*Coaching is one of the foundations on which you have to rely. (…) If the coach doesn't function well, I don't function well.*
4. Work	*The regular group at work has fallen apart because of a merger. That was decided by the managers. We protested but we failed. I was very sad because of all the changes. I felt really bad that so many people were leaving.*
5. Housing	*They all now live independently in the neighbourhood, but they often experience loneliness.*
6. School	*And yet those who might want to learn the most, aren't allowed to educate themselves.*
7. The doctor	*When I leave the room, I feel that the doctor is laughing at me. And then I feel that I wanted to tell him more, but it doesn't come out of my mouth. If he tells me to 'take those medicines', it's okay for me. But when I get home, I think, why those medicines?*
8. Hobbies	*The other people in the fitness centre found me scary. They were afraid of me and didn't want to talk to me.*
9. Travelling	*I wanted a microcar from when I was twenty years old. But my mother wouldn't let me. She thought it was too dangerous. Now my mother has passed away, and I decided to buy one. Now I can travel anywhere.*

The research agenda was not intended to exclude issues as not appropriate research topics. It did provide an overview of areas that should be addressed in research.

4.4   DISCUSSION

In the agenda-setting project presented in this article, people with ID and parents were encouraged to talk about their lives and their daily experiences. Instead of asking people with ID to formulate a list of topics, the team started by getting people to talk about their general

experiences and insecurities, for example by showing the researchers and research partners around their home or work. This resulted in personal stories which were further developed and prioritized in focus groups leading to a research agenda covering nine research areas. This agenda now delivers input to a research programme of a major health research sponsor in the Netherlands (The Netherlands Organisation for Health Research and Development). The research priorities are very much in line with the agenda that Williams et al. (2008) came up with in the UK. Discrimination, and the need for friendship and respect from support staff are both prominent in our study and in their *Shaping our future* report (Williams et al., 2008).

The process of developing intimate voice and political voice can be regarded as a concretization of enclave deliberation among disempowered groups, and a first step towards establishing a broad consultation between different stakeholders about research into ID. Enclave deliberation helps to deal with power differences between groups and forestalls domination by established groups. It serves as an alternative to proportional deliberation, a process with equal numbers of participants with divergent interests. Enclave deliberation has been criticized for fuelling group think and polarization (Karpowitz et al., 2009). This dynamic was not observed among people with ID or their parents. There was considerable variation and internal critique. For example, at the start of the project the spokesperson from the federation of people with ID stated that getting children to participate was a hot topic among their members. They expected research on this theme to be highly prioritized. This topic was discussed during the process, but it did not receive much attention, which indicates that non-active members had their own priorities. Extreme or radical standpoints were not taken. This may also be related to the narrative approach that was adopted: stories are multi-layered and foster dialogue and mutual learning, rather than debate.

As pointed out, the active involvement of people with ID as research partners was important for the entire process. It resulted in co-ownership of the research agenda, and empowered both people with ID and the research partners, who reported benefits, such as improved knowledge and skills, self-esteem and meaningfulness. They became more ambitious and one of them started going to a regular school, got a diploma, and now works as a care assistant in a residential institution. It turned out that she is capable of much more than she ever expected. Yet her emancipation required a considerable amount of work from the whole team. It appeared extremely important to be very conscious and reflective of the team dynamics and needs of the research partners. For instance, during one focus group, the chair,

one of the research partners, did not have a lot to say. When commenting on this afterwards, it soon emerged that he had become tired of the travel involved, and had experienced trouble in focusing and asking questions during the meeting. This taught the team to take time to discuss not only the content, but also practical issues such as pace and the risk of research partners becoming overburdened. In another instance an academic researcher wondered openly what it meant for the research partners when she took over quite a lot of work in order to be able to complete research activities in the set timeframe. This confession created room to talk about the interests at stake. This disclosure did not solve the dilemma, but improved mutual understanding in the team, and encouraged members to think of ways to handle similar situations in the future (Williams & Simons, 2005). It helped avoid pseudo-participation, and it underscored the equality within the team as the academic researcher was willing to disclose her vulnerability and to learn from people with ID.

Some may still have doubts about the desirability of involving people with intellectual disability in research agenda setting. These doubts may, for instance, be related to perceived subjectivity, difficulty with thinking beyond one's own interests and cognitive impairments. Another fear might involve the idea that fundamental research may come under pressure if people with ID define research agendas. These are legitimate concerns, but the team noticed that people with ID are able to recognize the limitations of their own viewpoints if they are involved in an intersubjective process of awareness raising. The patient research partners were often the ones to point these notions out:

"People with ID should be made aware of their problems and abilities before they can decide for themselves or stand up for themselves."

The scope of people with ID is, of course, different from that of parents or professionals. For example, parents prioritized research on health conditions. People with ID did not consider this to be an important research theme, whereas going to the doctor was given as a research area, including subthemes such as communication, psychosomatic problems, and expertise on the specific problems surrounding certain syndromes. Consequently, their issues should not be the only ones on the agenda. They should become more influential; their control over research agenda setting should not be exaggerated, but should be seen as a welcome contribution given their added value.

As enclave deliberation among the disempowered has proven to be beneficial, a next step is to further explore the conditions for heterogeneous dialogue among stakeholders in a broad consultation. Ideally such a consultation would be more than a strategic negotiation and exchange of issues between parties, but rather a process of communicative action, mutual learning and relational empowerment (VanderPlaat, 1999). Both researchers and people with ID will have to learn to develop new relationships and to deal with their changing positions as the object and as the subject of power. This process will involve new activities, both for researchers and for people with ID. This will result in better research, and also help people with ID learn new roles and responsibilities.

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