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'You need to let your voice be heard': research participants' views on research

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Abstract

Background Persons with intellectual and developmental disabilities have had regrettably few opportunities to voice their opinions on aspects of research with which they have had direct experience. Understanding and responding to these views can contribute to policies and practices that increasingly treat people as they desire to be treated. Methods We conducted individual interviews and focus groups with 16 adults with intellectual and developmental disabilities to examine their perspectives on participating in research. Results Our analysis indicates that adults with intellectual and developmental disabilities want to engage in research to improve their quality of life and to have greater access to a worthwhile activity through more active participation. Our results also highlight trust as a critical ingredient in the success of research with this group.

Conclusions Our findings suggest that despite ethical challenges, researchers can and should pursue research that has the potential to improve the lives of persons with intellectual and develop-

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mental disabilities. Such research is more likely to be both ethical and successful if researchers pay attention to enhancing autonomy and personcentredness, while at the same time engendering participant trust.

Keywords intellectual disabilities, research ethics, research participation

Introduction

Addressing disparities in health outcomes experienced by persons with intellectual and developmental disabilities necessitates their engagement in research (Turnbull & Lakin 2005; Aman & Handen 2006). Researchers need to be mindful of the historical precedents of abuse, limited literacy and power imbalances. These dynamics test the boundaries of ethical research (Coleman et al. 2005). As we consider how to conduct safe and respectful research, we need to listen to the views of those most intimately affected by facets of research with which they have direct experience. Despite the importance of knowing stakeholders' views (Roberts et al. 2004; Iacono 2006), researchers have often paid insufficient attention to the perspectives of adults with intellectual and developmental disabilities. Understanding these views is critical to creating policies and practices that treat individuals as

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they wish to be treated (Alessandra, no date), and are thus instrumental in deciding what is 'right' and 'wrong' for the person taking part. This research paradigm reflects values similar to those embedded in participatory research approaches that promote the civil rights goal of 'Nothing About Us Without Us', and thus seeks to be inclusive of persons with intellectual and developmental disabilities in matters that affect them (Dybwad & Bersani 1996; Nicolaidis *et al.* 2011).

Persons with intellectual and developmental disabilities have an uneasy relationship with research. This history is marked by early exploitation which may have contributed to protective attitudes and decreased access to research participation (Aman & Handen 2006; Iacono 2006; Lai et al. 2006). Moreover, persons with intellectual and developmental disabilities are often excluded from research because recruitment strategies overlook them and accommodations to participate in the research (such as reading survey items aloud) are not provided (Aldridge 2007).

Scholarship in this area focuses largely on capacity to consent and has been approached from the perspective of researchers who had have to balance apparently competing ethical demands and tensions such as the right of a person to take risks (or their right to autonomy) while protecting them from harm (McDonald *et al.* 2009; McDonald & Kidney 2012). There has been a welcome shift in values towards a greater recognition of the risks of exclusion and paternalistic treatment (Lai *et al.* 2006; McDonald *et al.* 2008), as well as methodologies that equate respect for autonomy with the right to take risks.

In the field of intellectual and developmental disabilities, research needs to be viewed by those taking part in it as respectful, worthwhile, and of benefit to them (McCarthy 1998; Diesfeld 1999; Rodgers 1999; Dalton & McVilly 2004; Ellem *et al.* 2008). Participatory research may help proactively address ethical concerns (Ham *et al.* 2004; Nicolaidis *et al.* 2011) and researchers should live up to the trust placed in them by participants (Diesfeld 1999).

While we are learning about the perspectives of the scientific community, we know less about the views of adults with intellectual and developmental disabilities. Initial evidence suggests that many people with intellectual and developmental disabilities want to contribute to research, have their voices heard, and experience new settings, people and ideas (Heller et al. 1996; Ham et al. 2004). There is evidence that people with intellectual and developmental disabilities want researchers to focus on their abilities, value their contributions and time, demonstrate patience, provide accommodations, and conduct research which is relevant to them (Heller et al. 1996; Ham et al. 2004). Many adults with intellectual and developmental disabilities also prefer to make their own decisions, sometimes with input from others they trust (Becker et al. 2004; Iacono 2006; Woodring et al. 2006; Andre-Barron et al. 2008). Nonetheless, some people express difficulty understanding information about research, desire more time to consider participation, and have someone other than researchers, including peers, present information (Heller et al. 1996; Andre-Barron et al. 2008). Though informative, this knowledge derives from researcher accounts and small-scale research on collaborations for training and research (only some participants had research experience) and information for consent to biomedical research.

Examining the opinions of persons with intellectual and developmental disabilities on aspects of research with which they have had direct experience can foster inclusion of their voices in the values and practices that guide research and promote accountability to those most vulnerable (O'Neill 1989). In this preliminary effort, we use qualitative inquiry to examine the experiences and perspectives of adults with intellectual and developmental disabilities on participating in research, including motivations to participate along with preferences and values related to recruitment and decision-making.

Methods

We hired two advisors with intellectual and developmental disabilities whom we knew to ensure the appropriateness of all research strategies and materials (e.g. accommodation strategies and recruitment materials, consent forms, and interview and communication guides with sensitive and clear language and informative images). We also pilot tested all materials and worked with our university ethics committee.

Table I Participant characteristics

Variable	Number
Gender	
Female	11
Male	5
Age	
19–29	4
30–39	2
40-49	4
50–64	3
>65	3
Race	
White	8
Black	7
Asian/Pacific Islander	1
Latino	0
Education	
<high school<="" td=""><td>6</td></high>	6
Some high school	5
High school/GED	5
Work	
Part-time	13
Unemployed	3
Prior research experience	
Behavioural intervention	8
Individual interviews/surveys	4
Focus groups	4

We sent flyers in the post and via electronic mail to regional self-advocacy groups, non-profit and government service organisations, and researchers. We asked people to share the flyers with adults with intellectual and developmental disabilities who: (1) had participated in research; (2) were not under legal guardianship; and (3) were interested in and able to participate in interviews. Many people shared flyers with their peers, clients, or research participants in individual or group meetings or through the post. We also spoke directly to those who had questions about the research. We recruited 16 individuals through case workers (n = 9), disability researchers (n = 2), personal communications (n = 9), and participant recommendations (n = 3)(see Table 1 for more information on participants). We did not collect information on level of disability as our advisors indicated doing so could be unreliable and disrespectful.

When participants called us, we began the consent process by speaking to them about the

study and assessing their eligibility and interest. We decided when and where to meet to discuss the research further (offering travel support) and emphasised the voluntary nature of participation. We also let participants know they could bring a support person if desired; none did. With one exception, all individuals who contacted us participated.

We then scheduled individual interviews (in some cases, participants decided to do the interview right away) and planned to meet participants' needs and preferences, including meeting in convenient, comfortable and private locations (Heller et al. 1996). At all times, we read materials with participants. We again reviewed consent information and answered questions. To ensure that participants understood the research, we also asked questions about the purpose, risks, benefits and procedures of the study. Participants could elect to participate only in the individual interview. All participants evidenced an understanding of the research and agreed to participate and be audiorecorded. Using a semi-structured Individual Interview Guide, we asked participants to share a recent research experience. We followed up with questions about their experience and views on inclusion, recruitment, decision-making, safeguards, risks, and benefits. We also asked demographic questions. Interviews ranged from about 20-71 min, with an average duration close to 40 min.

A few months later, we conducted four focus groups in private rooms at our university. Twelve of the 16 participants were interested and available. We reviewed the research and ground rules and answered questions. All 12 participants agreed to participate and be audio-recorded. We developed the *Focus Group Guide* based on a thematic analysis of the individual interviews. We asked participants for reactions to findings, including their accuracy, relative importance, and completeness.

The first and second authors and a trained graduate research assistant (RA) conducted all interviews. We moderated interviews by following the natural progression of dialogue with appropriate follow-up questions and, for the focus groups, solicitation of different perspectives. We reimbursed participants for travel costs and provided a \$40 gift card after each interview. Focus groups also included a meal. After each interview, trained RAs

completed verbatim transcriptions which another RA reviewed.

We first created case summaries to examine individual perspectives (Miles & Huberman 1994). We then conducted a thematic analysis across cases to identify initial themes for the focus groups; this analysis indicated we had achieved data saturation. After the focus groups, we proceeded to a deeper inductive analysis (Lincoln & Guba 1985; Miles & Huberman 1994). We developed the coding framework by randomly selecting transcripts. We met to discuss emergent themes and their relationships until we came to agreement. We repeated this approach until we read all transcripts and agreed on a coding framework. Using Atlas.ti (Atlas.ti Scientific Software Development 2009), we discussed all coding discrepancies and modifications until we reached consensus.

Results

Improving quality of life

Participants spoke about wanting to engage in research to make a difference by helping researchers learn about their experiences and opinions. They wanted researchers to use this knowledge to improve the lives of persons with intellectual and developmental disabilities. Participants also reported wanting to benefit directly by learning new things related to achieving their goals or improving their lives, having new experiences, meeting new people, having something to do, and helping others learn about people like them.

It's important that [researchers] learn things from me. (Grace, 65, White)

I know that for things to change [researchers] need my input . . . I wanted to learn. I needed help with some things. (Felicia, 20, Black)

It help other disabled people out . . . in the long run. [And], I didn't have nothing to do with my extra time and I wanted to check it out. (Dennis, 41, Black)

[I wanted to participate] so I can learn more stuff, so I can be prepared for living by myself. I'm learning it might change my life . . . I had a chance to do something that I hadn't done before. (Claire, 19, White)

It helped me to see where . . . I could do better for myself. (Joan, 55, White)

I got to meet new people, I got a lot of knowledge . . . I've learned something. I'm helping people, I'm helping a good cause I suppose, and I'm helping myself. (Ashley, 22, Asian)

Participants added they did not want to participate in research with little social value: 'If it doesn't mean anything, what's the point of trying if it doesn't mean anything?' (Claire, 19, White).

Lastly, a few participants reported that compensation was important, either as a primary or as a secondary consideration. These participants felt being compensated signalled value for their contribution and that compensation is needed by people with low incomes: 'If I'm getting paid for it then I don't mind. Ya know, I'm just being honest. I won't mind doing research 'cause I need the help' (Lorraine, 49, Black).

Access to research participation

Participants also discussed the importance that all people with intellectual and developmental disabilities have the chance to learn about opportunities to participate in research and fully understand information about the study. Participants noted that many of them (and others like them) are socially isolated, are looking for things to do, and may not be able to read a flyer or go to agencies where announcements are posted. To address this, they felt researchers should send materials in the post, place ads in newspapers or television, call people, or have a website with information. Notably, participants had varied preferences for how they want to be contacted. In most cases, participants liked how they had been recruited in the past (e.g. through case managers, friends, mailing), although one participant noted no preference and another noted preferring to learn via the Internet.

Pretty much everybody's gonna check their mail. Everybody don't go in to an office . . . [but] some people don't know how to read. (Charissa, 32, Black)

I like the pamphlets, like you get in the mail, 'cause that's like tells you everything . . . [and]

when you're busy, you don't always have time to check your email. [And], if you're like me, you don't like talkin' on the phone. (Ashley, 22, Asian)

I prefer a phone call . . . it' better for me to communicate and understand it a little better. (Roselyn, 30, Black)

I don't read, but you know it'd be better if it was in a CD 'cause talking is the best thing to do . . . you understand more when a person talk. (Claire, 19, White)

[Online is better because] I still get a little fear [talking to people I don't know], sometimes it's scary. (Andre, 28, Black)

Participants added that materials should be brief, use visuals, provide demonstrations, and include feedback from those who have participated, and that the quality of these materials has consequences for their feelings and desire to participate. They also noted other supports that can promote their understanding including having researchers explain the study, read or review materials aloud, and answer questions. Some participants find it useful to hear other people's questions about the research whereas others prefer individual meetings with researchers. A few participants added that as they engaged in research, their understanding increased.

The person has to explain things clearly when they tell you about it . . . If you don't tell us what's going on then we won't feel safe. (Claire, 19, White)

I don't want to see no paperwork . . . It's just a hassle . . . Just tell me about it. If I don't understand that, I'll keep asking questions. (Charissa, 32, Black)

I feel like if there's no understanding, I'm not gonna participate. If a person can't explain to me and tell what I need to do or what's to be expected, I'm not doin' it. It makes you have a better understanding . . . and that makes . . . you be able to participate 'cause . . . then I know what I'm up against or what's gonna come toward me. (Roselyn, 30, Black)

If they would have explained it to me on paper, and showed me everything that they were gonna

be doing in a demonstration, that would have been helpful for me to understand. (Dennis, 41, Black)

Many participants reported being able to make a decision right away but that for some studies, especially those with greater commitments, they needed time to decide. When they were unsure of their final decision, a few participants shared that they decided to give the research a try, knowing they could terminate their participation at any time.

I decided right away because I know I'm depressed. I know my . . . input it can change somebody's life or it can change how you do the system different. (Charissa, 32, Black)

Sometimes I can decide right off the bat. Sometimes it takes time to think about it. (Rick, 48, White)

I kinda waited until after the . . . orientation to decide 'cause I . . . wanted to wait and see if it was something I could really get into. (Ashley, 22, Asian)

Trust

The role of trust permeated participants' views. First, several participants noted they prefer to learn about research from people they know and trust to help them assess the value or appropriateness of participation: 'I'd rather find that out from people I can trust . . . sometimes you don't know what you're getting in to. You need to be careful' (Alice, 61, White). These people include trusted service providers who can maintain individuals' privacy or friends and peers who have been in the study and are able to share their experience. Conversely, a few participants expressed openness to being contacted directly by researchers: 'It might not be too bad if they tell me how to do it and everything' (Charles, 61, White).

Trust also informed decisions about participation. Without exception, participants said that they should be in charge of their decision because they have confidence in their decisions, are adults, and are capable.

[Deciding on my own] puts me more in charge . . . I can make a decision . . . somebody don't have to make the decision for me. (Charissa, 32, Black)

When you get to a certain age you have to make your own choices, you can't let someone else do it for you . . . You need you let your voice be heard. (Claire, 19, White)

Trust also informs views on including others in decision-making. For some, they do not routinely seek advice although if it was offered they would consider it and expect to agree with it. Others noted that there can be benefits to hearing opinions, though most added that they only want them from those they trust and in particular situations (e.g. more substantial decisions). In such cases, participants reported preferring to discuss participation with trusted service providers, intimate partners or family members, or friends who have participated in the research. Participants reported that these individuals prevent them from engaging in harmful activities, make sure they can benefit, and provide support for decision-making, including helping them understand information. Participants noted that when they bring a supporter with them, researchers should directly address them, not the person providing support. At times, receiving encouragement from trusted family members and service providers helped participants address their hesitation to try new things and decide to participate, or at least find out more about the study. Participants' assessment of whether they trusted someone, especially service providers, appeared related in part to experiences of having felt listened to by the person.

Well... I think [asking other people's opinion is] a good thing because... you know other people have different opinions and ... it's good to go with other people's opinions sometimes, 'cause their opinion might be better than yours ... you never know. (Felicia, 20, Black)

Depends on who they is . . . depends on if you trust them or not. (Grace, 65, White)

I can make small decisions, but I can't make big ones (Alice, 61, White).

I call [case manager] up . . . I'd ask for his advice because I trust him a lot . . . I think it's good because [case manager] explained the whole thing to me and everything. (Charles, 61, White)

If somebody just called me up and asked me to go, I'll make sure somebody came with me . . . if I take somebody, they'll tell me it's not right. I usually agree with them. (Elizabeth, 46, Black)

Participants who receive support added that decisions about participation still had to be their own: 'It's not their decision to make. I always like . . . to hear their opinions, then check it out myself and have my own opinion. 'Cause we don't just want people to run our lives' (Claire, 19, White).

Participants also spoke about the importance of feeling they could trust researchers and the role of that judgment in their decisions to participate or not. Learning about the research, reviewing materials, and talking with the researcher helped them make these determinations; factors related to confidentiality were often important to these evaluations. A few participants added that a sense of trust allows them to contribute more to the research.

I watch and I observe. (Raymond, 67, White)

It's an aura when you talk to a person, you should be able to feel an aura from them. (Charissa, 32, Black)

How do you know to trust people? By talkin' to 'em, gettin' to know 'em . . . and do your best . . . by the information that they tell you . . . You'll feel calm . . . You won't feel, like, anxiety or antsy in your pants where . . . you [don't] want to jump up and get away. (Dennis, 41, Black)

I want to talk on the phone about it first, be able to get to know this person, who this person is, what this person's about . . . It matter how I feel . . . If I'm comfortable then I have no problem, but if I'm not, I'm not doin' it . . . [later] I was comfortable because after they explain to us that It wasn't gonna go no further, and our names wasn't gonna be used . . . I feel comfortable with that . . . [Trust] makes you feel comfortable. If you don't feel comfortable, you're not gonna really have much to say. (Roselyn, 30, Black)

[Talking on the phone first] you feel more comfortable coming so you know what to expect . . . I just follow my guts . . . If I did feel half nottrusted and half do, I might try it for one day,

but if I didn't like it, I wouldn't go to the other days. (Claire, 19, White)

If I don't feel good about it, I will say no and I will walk away. (Rick, 48, White)

Of note, participants largely felt that the decision to participate was up to them, and some have previously declined to participate in research. They also felt that they could end their participation at any time. Participants added that researchers should not push them nor use incentives to force participation or responses. Nonetheless, a few participants noted it can sometimes feel hard to say no, especially in the presence of a service provider.

I'm not gonna do something just because somebody want me to do or just because they got something to give you . . . it got's to be my own decision. (Roselyn, 30, Black)

[Being pushed] could be a reason, a reason not to want to participate, 'cause someone's making you do something. You know, like you have to do this or you have to do that. (Dennis, 41, Black)

When they say stuff like that, like I don't need the money that bad. I can get up and walk. (Clarissa, 32, Black)

Discussion

To pursue needed knowledge, we must engage adults with intellectual and developmental disabilities in research. As we seek to conduct this research ethically, we can learn from those most affected and consider their values on aspects of research that affect them. This study provides an initial effort to add to our knowledge base. Here, we learn how similar persons with intellectual and developmental disabilities are to others while also identifying ways they may be unique.

Before proceeding, it is critical to note limitations of this research. Although we recruited a diverse sample, this research is exploratory and participants may vary from others in meaningful ways. Our participants were US-based, not under legal guardianship, had prior research experience (largely with behavioural research), received information about our study, and were able to and interested in participating. It is unclear how these characteristics

may shape findings. It may be that participants are more pro-research, or have had more positive experiences with research, than others. And, concern for capacity to consent, coercion and strategies to mitigate it, and the importance and nature of support from trusted others may be altered for those living less independent lives, in different milieu, or who experience greater challenges communicating their experiences and views. Future research can illuminate these topics and provide further guidance.

Nonetheless, these findings are informative. Adults with intellectual and developmental disabilities value participating in research. Similar to perspectives illuminated elsewhere (Heller et al. 1996; Ham et al. 2004), they value research with personal and social benefit. And, consistent with their civil rights movement (Dybwad & Bersani 1996), they want researchers to use their experiences and perspectives to improve quality of life for people with intellectual and developmental disabilities. These findings suggest we should promote research participation, strive to infuse benefits of any size into each study, routinely articulate benefits to participants, and carry through on promises to promote long-term benefits of the research. And, researchers should share accessible research outcomes with participants (Dalton & McVilly 2004).

Also of note, adults with intellectual and developmental disabilities evidenced strengths germane to making decisions (Fisher et al. 2006) including confidence in their skills and resistance to relational and incentive-based coercion. Describing the information they evaluate (which mirrors information participants are encouraged to assess generally), they report declining to engage in research void of benefits. This finding reminds us of the value of transparency in research (Coleman et al. 2005; Aman & Handen 2006). Moreover, adults with intellectual and developmental disabilities discussed the importance of fully understanding research. Similar to others (Heller et al. 1996; Woodring et al. 2006; Andre-Barron et al. 2008), they shared strategies they employ (e.g. asking questions, taking time, involving a support provider) and approaches researchers can use (e.g. concrete descriptions or demonstrations, explanations, visuals, and having non-researchers explain the research) to bolster understanding. In other contexts, equal opportunity is an important dimension of justice

and accommodations serve as critical bridges to full participation (Dybwad & Bersani 1996; McDonald et al. 2008). We encourage researchers to anticipate, initiate conversations about, and provide flexibility and resources to meet participants' needs; achieving this promotes the quality of science and more widely distributes its benefits. Our findings also call into question avoiding monetary incentives (Becker et al. 2004; Dalton & McVilly 2004) and suggests that doing so may signal a lack of value for contributions, ignore financial need, and lead some to decline participation (thereby threatening the quality of the knowledge gained).

Also similar to prior research (Heller et al. 1996), adults with intellectual and developmental disabilities highlighted the importance of controlling decisions and the decision-making process, reflecting the importance of autonomy. These findings shed light on debates in scholarship, including ceding decisions to proxies, and lend support to contextual models of consent capacity which more explicitly consider the decision-making context (Dalton & McVilly 2004; Fisher et al. 2006; Cameron & Murphy 2007). Promoting self-determination throughout all phases of research participation should be prioritised.

Of equal significance, the importance of trust and intuition emerged. Participants want to learn about research from people they trust, select people they trust to provide input, and assess whether they can trust researchers. Participants also noted using intuition to inform their decision. Similar to Andre-Barron et al. (2008) findings, participants also talked about the value of discussing participation with peers. And, participants spoke about how they evaluate researchers' trustworthiness, as they do for other professionals (Clarkson et al. 2009). Part of the assessment of trustworthiness may include examining whether the researcher conveys an appreciation for the strengths of persons with disabilities (Heller et al. 1996) and evidence that the research is on a worthwhile topic and that researchers will keep their word. It is important to bear in mind that trust is earned after some initial testing of the individual or situation, and represents individuals' acceptance of taking a risk to believe that a positive outcome is likely (Sheppard & Sherman 1998). As such, trust may vary dependent on the research in question. This finding emphasises the importance

of researchers' interpersonal skills, honesty, and keeping their word (e.g. confidentiality, sharing findings; Becker et al. 2004; Cameron & Murphy 2007) and again furnishes evidence of the strengths of persons with intellectual and developmental disabilities. This finding also advocates for a decision-making process that affords individuals the opportunity to make a decision based in part on emotional factors, thereby challenging models that advocate for a rational weighing of risks and benefits (Fisher 2003; Coleman et al. 2005). However, we emphasise the need to attend to how judgments of trust are made, how to promote accurate judgments of trust, how researchers are professionally socialised to earn and merit trust, and the role of independent bodies to oversee facets of research that participants may not be exposed to and which are nonetheless critical to judgments of trustworthiness.

Of further note, literature debates *who* should recruit and be involved in decision-making (McCarthy 1998; Cameron & Murphy 2007) focusing on *categories* of people (e.g. researchers, service providers). Adults with intellectual and developmental disabilities provide a new framework centred on trust that suggests researchers need to privately ask who, if anyone, they would like to include. By providing time for decisions, researchers also allow participants to access preferred supports. As noted before, participants use their past experiences to inform their decisions about who they can trust.

It is also critical to emphasise the heterogeneity of views found herein. In some instances, adults with intellectual and developmental disabilities prefer different processes and accommodations. We thus suggest a flexible model for engaging this population in scientific inquiry and that researchers anticipate and plan for this diversity. Researchers should pursue varied recruitment strategies and means to present information and allow time for the planning and execution of these approaches; likewise funding needs to provide adequate resources.

In light of inadequate scientifically derived information, a history tainted by exclusion, and an eye on deficits, this research is important to adults with intellectual and developmental disabilities. We reiterate the importance of listening to and infusing our research policies and practices with the values

of those we engage in inquiry so that our research is carried out justly (O'Neill 1989). Collaborations with persons with intellectual and developmental disabilities on all aspects of research from what is funded to conceptualisation and dissemination may be especially useful in promoting this goal (Ham et al. 2004; Nicolaidis et al. 2011). Future research can also more thoroughly examine alignment of views between adults with intellectual and developmental disabilities and the research community, as well as aspects of research with which participants have less direct exposure including issues related to privacy and confidentiality (particularly for those who receive support or are interviewed with others nearby), the prevention of harm to participants, the role of gatekeepers in recruitment, and capacity to consent.

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References

- Aldridge J. (2007) Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability & Society* **22**, I–I7. doi: 10.1080/09687590601056006.
- Alessandra T. (no date) The Platinum Rule. Available at: http://www.squarewheels.com/articles2/platinum.html (retrieved 15 August 2011).

- Aman M. & Handen B. (2006) Reactions to 'ethical challenges and complexities of including people with intellectual disability as participants in research' by Dr. Teresa lacono. *Journal of Intellectual & Developmental Disability* 31, 180–2. doi: 10.1080/13668250600876400.
- Andre-Barron D., Strydom A. & Hassiotis A. (2008) What to tell and how to tell: a qualitative study of information sharing in research with adults with intellectual disability. *Journal of Medical Ethics* **34**, 501–6. doi: 10.1136/jme.2006.019521.
- Atlas.ti Scientific Software Development (2009) *Atlas.ti* (v.6.0). Atlas.ti Scientific Software Development, Berlin.
- Becker H., Roberts G., Morrison J. & Silver J. (2004)
 Recruiting people with disabilities as research participants: challenges and strategies to address them.

 Mental Retardation 42, 471–5. doi: 10.1352/0047-6765(2004)42<471:RPWDAR>2.0.CO;2.
- Cameron L. & Murphy J. (2007) Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities* **35**, 113–20. doi: 10.1111/j.1468-3156.2006.00404.x.
- Clarkson R., Murphy G., Coldwell J. & Dawson D. (2009) What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? *Journal of Intellectual & Developmental Disability* 34, 283–98. doi: 10.3109/13668250903285630.
- Coleman C., Menikoff J., Goldner J. & Dubler N. (2005)

 The Ethics and Regulations of Research with Human

 Subjects. LexisNexis, Newark, NJ.
- Dalton A. & McVilly K. (2004) Ethics guidelines for international multicenter research involving people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* **1**, 57–70. doi: 10.1111/j.1741-1130. 2004.04010.x.
- Diesfeld K. (1999) International and ethical safeguards: genetics and people with learning disabilities. *Disability & Society* 14, 21–36. doi: 10.1080/09687599926352.
- Dybwad G. & Bersani H. (1996) New Voices: Self-Advocacy by People with Disabilities. Brookline Books, Cambridge, MA
- Ellem K., Wilson J., Hong Chui W. & Knox M. (2008) Ethical challenges of life story research with ex-prisoners with intellectual disability. *Disability & Society* 23, 497–509. doi: 10.1080/09687590802177064.
- Fisher C. B. (2003) Goodness-of-fit ethic for informed consent to research involving adults with mental retardation and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 9, 27–31. doi: 10.1002/mrdd.10052.
- Fisher C. B., Cea C. D., Davidson P. W. & Fried A. L. (2006) Capacity of persons with mental retardation to consent to participate in randomized clinical trials. *American Journal of Psychiatry* **163**, 1813–20. doi: 10.1176/appi.ajp.163.10.1813.
- © 2012 The Authors. Journal of Intellectual Disability Research © 2012 Blackwell Publishing Ltd

- Ham M., Jones N., Mansell I., Northway R., Price L. & Walker G. (2004) 'I'm a researcher!' Working together to gain ethical approval for a participatory research study. *Journal of Learning Disabilities* 8, 397–407. doi: 10.1177/1469004704047507.
- Heller T., Pederson E. & Miller A. (1996) Guidelines from the consumer: improving consumer involvement in research and training for persons with mental retardation. *Mental Retardation* **34**, 141–8.
- Iacono T. (2006) Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual & Developmental Disability* 31, 173–9. doi: 10.1080/13668250600876392.
- Lai R., Elliott D. & Ouellette-Kuntz H. (2006) Attitudes of research ethics committee members towards individuals with intellectual disabilities: the need for more research. *Journal of Policy and Practice in Intellectual Disabilities* 3, 114–18. doi: 10.1111/j.1741-1130.2006. 00062.x.
- Lincoln Y. & Guba E. (1985) Naturalistic Inquiry. Sage Publications, Inc, Newbury Park, CA.
- McCarthy M. (1998) Interviewing people with learning disabilities about sensitive topics: a discussion of ethical issues. *British Journal of Learning Disabilities* **26**, 140–5. doi: 10.1111/j.1468-3156.1998.tb00070.x.
- McDonald K. & Kidney C. (2012) What's right? Ethics on intellectual disability research. *Journal of Policy and Practice in Intellectual Disabilities* **9** (in press).
- McDonald K., Keys C. & Henry D. (2008) The gate-keepers of science: attitudes toward the research participation of adults with intellectual disability. American Journal of Mental Retardation 113, 466–78.
- McDonald K., Kidney C., Nelms S., Parker M., Kimmel A. & Keys C. (2009) Including adults with intellectual disabilities in research: scientists' perceptions of risk and protections. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 244–52. doi: 10.1111/j.174-1130.2009. 00225.x.

- Miles M. B. & Huberman A. M. (1994) *Qualitative Data Analysis*. Sage, Thousand Oaks, CA.
- Nicolaidis C., Raymaker D., McDonald K., Dern S., Ashkenazy E., Boisclair C. *et al.* (2011) Collaboration strategies in nontraditional community-based participatory research partnerships: lessons from an academic-community partnership with autistic self-advocates. *Progress in Community Health Partnerships* 5, 143–50. doi: 10.1353/cpr.2011.0022.
- O'Neill P. T. (1989) Responsible to whom? Responsible to what? Some ethical issues in community intervention. *American Journal of Community Psychology* 17, 323–41. doi: 10.1007/BF00931040.
- Roberts L., Warner T., Anderson C., Smithpeter M. & Rogers M. (2004) Schizophrenia research participants' responses to protocol safeguards: recruitment, consent, and debriefing. *Schizophrenia Research* **67**, 283–91. doi: 10.1016/S0920-9964(03)00101-4.
- Rodgers J. (1999) Trying to get it right: undertaking research involving people with learning difficulties. *Disability & Society* 14, 421–33. doi: 10.1080/09687599926046.
- Sheppard B. & Sherman D. (1998) The grammars of research: a model and general implications. *The Academy of Management Review* 23, 422–37.
- Turnbull A. & Lakin C. (2005) National Research Goals for People with Intellectual and Developmental Disabilities. American Association on Intellectual and Developmental Disabilities, Washington, DC.
- Woodring J., Foley S., Santoro Rado G., Brown K. & Hamner D. (2006) Focus groups and methodological reflections: conscientious flexibility in the field. *Journal of Disability Policy Studies* **16**, 248–58. doi: 10.1177/10442073060160040601.

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