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Having Your Say: Perceptions of Self Advocates on the Involvement of People with an Intellectual Disability in Decisions about their Lives

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Sixteen people with an intellectual disability volunteered for this study in which their opinions were gained by group discussion and individual interviews. Initially the participants gave their views on the following question: What are your views and priorities on the issue of ways of promoting choice and decision-making by people with very high support needs? The people were given the opportunity to correct and refine the summary made by the researchers. The results indicate that people with an intellectual disability put high value on interdependence and being an accepted member of their community. The participants showed considerable insight into a number of areas including the politics of service delivery, eg the way in which services can become self-serving. The implications for theory, research, policy and practice are examined.

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This study forms part of a larger research project, *Advancing Choice*, which is examining ways in which people with severe intellectual disability can be more involved in having choices and making decisions about their lives. There is evidence that people with disabilities are taking increased opportunities for autonomy afforded by changes in societal values, public policy and their own realisation about their rights (Bannerman, Sheldon, Sherman, and Harchik, 1990; Dattilo and Rusch, 1985; Mithaug and Mar, 1980; Parsons, and Reid, 1990; Realon, Favell, and Lowerre, 1990; West and Parent 1992). However, it is difficult for people with high support needs, particularly those with a severe intellectual disability, to become more autonomous and involved without considerable support.

The Advancing Choice Project has pursued a number of lines of enquiry including descriptive studies of choice in a variety of work settings (Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne, 1993; Shaddock, Zilber, Guggenheimer, Dowse, Rawlings and Nye, in preparation); ethnographic and participant observation studies in homes (Shaddock, Rawlings and Guggenheimer, in preparation; Dowse, Rawlings, Guggenheimer and Shaddock, in preparation); and studies which seek to develop more appropriate ways of communicating with people with severe intellectual disability (Shaddock, Dowse, Zilber and Rawlings, 1993). The intent of the current study was to add to the knowledge base on choice by seeking the views of 'self advocates' on ways in which people with high support needs can be more involved in making decisions about their lives.

The Self Advocacy movement is a good example of the ability of people with a disability, particularly those with an intellectual disability, to become more self-directing. Although many now question the need for yet another label (why should people with a disability have to be called 'something' in order to speak up for

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themselves?) there is no doubt that Self Advocacy and similar organisations have assisted many people to be aware of their rights, to speak up for themselves and to improve their quality of life. The ability of people with an intellectual disability for self determination has been seriously underestimated and their potential is still largely untapped.

The current study is an important one in the *Advancing Choice* Project because it canvasses the views of people with an intellectual disability in a systematic way. The purpose of the current study was to gain the perspectives of self advocates on the following issue: How can people with an intellectual disability, particularly those with high support needs, have more choice and a 'say' in their lives?

Although it is essential that the views of people with an intellectual disability be sought, it should be noted that self advocates do not claim to have special insight as the following extract from an Advocacy newsletter illustrates:

*My disability is different to yours – how do you know what I need?
That's easy – we'll ask you – and we'll listen to what you tell us. As
people with a disability ourselves we have all experienced the well
meaning people who tell us what we need – and who tell us what is good
for us. You tell us what you want – we'll do our best to help (Disability
Advocacy Network Inc).*

Method

Participants

Six self-advocates in one state participated in a pilot study designed to gain preliminary responses to the above question and to test the proposed methodology. In the second stage of the research, eight self advocates from another three eastern states were interviewed at a major self-advocacy conference. In stage three, these people (or alternates where necessary) were interviewed in depth. Overall, seven men and nine women participated in the study.

Procedure

The initial aim was for the researchers to attend the national conference and to commence a Delphi study (Cary and Salmon, 1976; Delbecq, Van de Ven and Gustafson, 1975; Linstone and Turoff, 1975; Sackman, 1975; Shaddock, Hattie, Edwards, Bramston and Brummell, 1986) based on responses to the question: How can people with intellectual disabilities, particularly those with high support needs, have more choices and a 'say' in their lives? However, after trialling the procedure in stage one, it was decided to abandon the delphi method. The participants in the trial found the stimulus question quite difficult and needed the additional support that could be offered by an interviewer. They had particular difficulty in discussing issues in relation to others (ie people with high support needs) and most of their responses were self referenced. As it was unlikely that the delphi method would have adequately addressed the second part of the stimulus question, it was replaced with focussed interviewing (Cohen and Manion, 1980; Keats, 1988; Minichiello, Aroni, Timewell and Alexander, 1990).

The trial clarified the issues in which self advocates were interested and highlighted concerns about which the researchers needed to be aware, eg how upsetting it can be for some people to talk about their own lack of choice in the past, or the sense of loss for missed opportunities in their lives or in the lives of people close to them. The trial also enabled the researchers to anticipate reactions that some people might have to participating in a study like this, eg uncertainty and lack of confidence.

A one hour discussion with the participants centered on the stimulus question and many issues were raised and explored. These issues were summarised and mailed to each participant. A convenient time was negotiated to contact each self advocate and to conduct a phone interview.

Each phone interview took about half an hour, and with the participants' permission, was audio recorded and subsequently transcribed. Each author independently analysed the transcripts and formulated a 'concept map' by the open coding method. This involved identifying and naming ideas which were then grouped into like phenomena to form categories (Strauss and Corbin, 1990). Team members met and compared their concept maps, and clarified, summarised and verified their findings.

A summary was then mailed to each participant. The written summary was supplemented by a more detailed version on audio cassette. Participants were invited to offer further comments or make changes by writing, phoning or sending a return message on the cassette.

Results and Discussion

This section is a compilation of the consultative process between participants and the authors. The results are presented under a number of broad themes that were identified during the data analysis process. The themes are interrelated and prominence is given in this section to those issues that were frequently raised by the interviewees. Selected quotations are provided to illustrate and exemplify the data.

Theme One: People with disabilities are people first

Over half of the participants commented strongly on wanting to be viewed as people rather than as *disabled* people, or as a *disability*. The following quotations illustrate their impressions of the way in which the label guides perceptions and the subsequent behaviour of the community.

A lot of the time they don't even think of you as a disabled person: they think of you as a disability!

The assumptions that people without a disability make about people with disabilities ... is that we're not human ... we don't have the same sorts of feelings ... we don't have the same sorts of aspirations or the same needs to learn the same skills anyone else learns in their life. People think we don't have to do any of that because ... that's not going to make a difference.

If you believed that someone's not human then you don't actually think it's important to treat them that way.

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The other thing to think about when you think about treating someone as a human, because you see yourself as human as well, you think how would I like it if I got, you know, if someone did this to me or did that to me?

If you don't want to be treated like that, why treat someone else like that?

Theme Two: Independence should not be made the most important goal for people with intellectual disabilities – Relationships are more important

Historically policy-makers and service providers have stressed independence as a goal for people with an intellectual disability. However, the consumers in this study stressed the importance of interdependence. Several pointed out that interdependence enabled choice and decision-making with support when necessary.

Well at the moment people who have more support needs ... in the beginning ... they might need more (staff) so they can get that support and when the support got less and less, it could go down a bit more.

I don't really want to increase (independence) ... I've come to the realisation that interdependence is what I'm on about ... I think the key to it is friendship.

If we were (dependent), there'd be no um need for things like friendship.

The other thing that disturbs me about self advocacy is the fact that there is this misguided conception that if you're a self advocate it means that you're actually supposed to stand on your own and do things all by yourself and get help from nobody else.

Beyond wanting to be interdependent, participants stressed the importance of having reciprocal relationships with persons other than relatives and those paid to be in their lives. Examples of these relationships included such activities as having tea with neighbours or being involved with local community groups. This was in contrast to the view that a person must consistently function without any support at all.

It's a matter of not just service worker relationships with people but real people who could be in people's lives, who are there because they are a meaningful person for them. It is essential that people with disabilities have opportunities to have natural relationships ... not just paid relationships.

The unfortunate thing is that the relationships she has which are paid ones, more often than not she sees as what we call real relationships.

I think to get to know people without disabilities is important so that people actually have a wide range of relationships ... so it's not just people with disabilities they have relationships with.

Not that I'd agree with a group home because a group home is just another, it's a smaller institution basically, but what I would see the

staff job as doing is developing, helping people develop, their relationships with people in the community that they live in.

Theme Three: Good services and staff are those oriented towards the best interests of clients

Several participants pointed out that services must be sensitive to people's needs and this involves a deeper appreciation of need than simply asserting people's rights.

(It's) not so much what someone has a right to but what would be in someone's best welfare.

It's not just a matter of ... we'll get this person out of the institution and put him into the community ... it's not that simple. ... What people neglect to say is ... you've got the right to go and get a job and you've got the right to to get the right services to get a job and no one actually sits down with this person and says, well if you're going to have a meeting with someone perhaps it would be a good idea if you looked your best ... and you did things like you had a shower ... but you actually wore something that was neat and tidy and, you know, you actually worked out some things you wanted to go to the meeting with so you were really clear and stuff like that.

Components of best interests from the participants' point of view, included simple but crucial involvement between the service provider and the participant. Participants emphasised listening to all forms of communicative behaviour, such as taking time to read communication boards, or interpret a person's gestures or facial expressions. One participant noted that challenging behaviour was a form of communication and should be responded to as such. Another suggested that service providers should value and encourage consumers' contributions to tasks in different contexts.

While stressing the importance of typical relationships that are unpaid, participants also stated how important it was for staff to display appropriate attitudes and behaviour in their interactions.

A good staff is a person who really cares about the person ... really takes an interest in the person ... really wants to talk and get to know that person as a person not as a lump, as a statistic or something like that.

In particular reference to making choices, participants frequently mentioned wanting and needing support with particular skills in preparation for, and integration into, the community. Those who had experienced support in this skill building process felt empowered and more able to be more independent choice-makers and therefore live more successfully in the community.

The participants expressed clear views about how services should be provided and were well aware that some so-called services can actually be a disservice.

And most of the time the treatment people get isn't so people stop doing something in an inappropriate way. It's actually to remove the staff member's guilt, and the well, I've got to do something here cause if I

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don't do something here I'm going to get into trouble sort of thing, and usually when they do whatever it is they do, they never do the right thing so, or they hardly ever do the right thing because they don't actually consider someone's humanness.

I was told that if I didn't get a job in a sheltered workshop that I would be long term unemployed, so um not knowing anything about sheltered workshops and knowing what long term unemployment meant, I thought, well I'll try this sheltered workshop business; so I went in and what I discovered at the end of six months ... was that I actually came out a lot more disabled than I'd gone in, um, to the point where other people were making my decisions for me.

Theme Four: Individual Program Plans can be good or bad

Contrasting views were given about Individual Program Plans (IPPs) and the extent to which they offered opportunities for people to become more autonomous. Some participants viewed IPPs as unnatural. They wondered why people with disabilities should have them when no one else does.

I don't think I have to have a piece of paper and a box to tick off (to say) this is what I want to achieve in six months.

If someone really cares about another person they'll do it (teach them). They won't sit down and write a plan about how they are going to encourage this person to do whatever they need to develop. I mean I think a lot of time and energy is wasted in writing things down on paper and not enough time and energy is used on doing anything.

Others thought IPPs were a means for propping up professionals and service providers in their roles, allowing them to feel they were doing something.

What tends to happen is that the person ends up being a tool of the service system to justify itself. (The service system) sits there and says, we're doing all of these things because we've got all these IPPs and these people are doing this and are doing that, and in actual fact people's lives aren't really changed.

The IPP process was also seen as putting too much pressure on people.

It hurts because you're seen as a person with a disability. You're seeing that you're always kind of show people that I can do it. I need support. Um, and it might take me a bit longer for me to learn. It might take time but I'll get there eventually. It hurts in that way.

It was also apparent that some participants were not present at meetings to discuss their own IPP.

It was very much imposed but I was theoretically free to debate what was put in it ... um, I didn't really feel confident to communicate my disgust with it. What I did was wag.

I was at work when that (IPP meeting) was on.

On the other hand, some participants felt that having an IPP was useful.

I think they're good because they show you where you're heading. And what your goals are and if you need to improve on your job they can help you with that.

(The benefits were) I wanted to learn to read; I wanted to travel and do things ... and I wanted to work with old people and that's something that I did.

When IPPs were developed collaboratively and implemented sensitively, encompassing people's best interests, needs and opinions, some participants perceived the IPP to be a positive contribution to their development. However, others felt that just having an IPP reinforced perceptions of devalued status.

Implications

Research

Future studies that monitor and evaluate processes that facilitate choice and decision-making need to include consumer input. Research must address ways this can be achieved in a meaningful way. Issues associated with the consequences of a person's choices and the duty of care of staff also need to be resolved.

Specific research could be directed towards short term and long term studies on the consumers' role in the IPP process. What happens when consumers choose not to have an IPP? How can consumers become full participants in the process rather than just recipients of the program? How can the unintended negative effects of the IPP process be avoided?

Practice

If increased choice is to become a reality, consumers and service providers need to be involved in a collaborative educational process which is accompanied by organisational change based on a rethink of the role of service organisations and providers. Ongoing education and support will be needed for both consumers and service providers. Opportunities must be identified for consumers to experience choice and decision-making in all areas of their lives.

Policy

Policy makers need to be aware of the implications of promoting interdependence in decision-making. When such policies are created consumer input should be mandatory to reflect a genuine sharing of power between consumers and policy makers.

Theory

Each participant in this study has been classified as 'intellectually disabled' and has occupied the role of a person with an intellectual disability for a significant period of time. Although definitions of intellectual disability have been widened to include attention to criteria other than a score on an intelligence test, they are still couched in

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terms of deficits. Erroneous and damaging assumptions and over-generalisations are still being made about people with an intellectual disability.

The reality is that a person's performances on an intelligence test and a measure of adaptive behaviour tell us very little about a person's **capacities** in a number of important areas ... having personal insights; making sense of one's experience; and 'problem solving' about one's own situation. In these areas, this sample of people with intellectual disabilities showed a depth of understanding that does not sit comfortably with conventional conceptualisations of intellectual disability. Until theories of intellectual disability acknowledge these strengths, societal responses and services are likely to remain poorly directed, heavy-handed and disempowering.

Summary

This sample of Self-Advocates valued choice and decision-making in the context of interdependent relationships. The current research highlighted issues such as the way in which choice and decision-making relate to relationships, to staff attitudes and behaviour, and to individual program plans. Emphasis was placed on the need for an interdependent relationship between service providers and consumers for choice and decision-making to occur. However, the major goal of consumers is to experience interdependence as accepted members of the community, a goal that Corsini (1987) suggests is "emerging as a preferred form of social interaction in the Western world since the Renaissance". Thus, as well as gaining the perceptions of Self Advocates, this study also reinforces the view that people with an intellectual disability are more 'like other people' than they are different.

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