'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities

*Christine Bigby, *Tim Clement, #Jim Mansell and #Julie Beadle Brown

*School of Social Work and Social Policy, LaTrobe University, Melbourne Australia

#Tizard Centre, University of Kent, Canterbury UK.

Address for correspondence

Professor Christine Bigby

School of Social Work and Social Policy

LaTrobe University, Bundoora

Victoria, 3086

C.Bigby@latrobe.edu.au

**Abstract**

**Background.** The level of resident's adaptive behaviour and staff facilitative practices are key sources of variation in outcomes for residents in community based residential services. The higher the resident support needs the poorer their outcome. Though substantial investment has been made in values based training for staff, their attitudes and the impact of these on practice is largely unexplored. **Method and Findings**. The first study used ethnographic and action research methods to examine the daily lives of 25 residents with severe and profound intellectual disabilities, who lived in five small group homes, and the attitudes of the staff supporting them. Thematic analysis of the data led to a proposition that though staff accept principles of inclusion, choice and participation for people with intellectual disabilities in general, they do not consider it feasible to apply these to the people with severe and profound intellectual disabilities to whom they provide support. The findings from a second study that used a group comparison design and administered a short questionnaire about staff attitudes to 144 direct-care staff and first line managers working in disability services confirmed this hypothesis. **Conclusions**. The study suggests more focussed attention is needed to staff understanding the values embedded in current policies and their application to people with more severe disabilities.

'It's pretty hard with our ones, they can't talk, the more able bodied can participate':
Staff attitudes about the applicability of disability policies to people with severe and
profound intellectual disabilities

Although in general community-based residential services produce better outcomes
for people with intellectual disabilities than institutions (Kim, Larson, & Lakin, 2001;
Young et al., 1998), there is still much variation between services in the community
(Emerson & Hatton, 1994). The most important sources of this variation appear to be
the level of adaptive behaviour of the residents and the care practices adopted by staff.
The higher the support needs residents have (the greater their disability) the poorer are
their outcomes (Felce & Emerson, 2001; Mansell, 2006). In terms of staff care
practices, better outcomes are associated with higher levels of staff contact and
particularly of facilitative assistance (Felce et al., 2000; Jones et al., 1999; Mansell,
1995; Thompson et al., 1996).

There is as yet little clear evidence of what predicts the adoption and
maintenance of more facilitative care practices. Mansell et al., (2007), suggest care
practices are affected by four factors: service characteristics (type and size); staffing
(the ratio of staff to residents, staff qualifications, experience, training, knowledge,
attitudes and turnover); organisational hygiene (job satisfaction, stress role clarity and
conflict), and management (autonomy of mangers and systems for organising care).
They suggest these factors combine together rather than any one being predictive of
good practice.

Nevertheless, throughout the development of community-based services for
people with intellectual disabilities a very large investment of resources and effort has
been made in training staff to adopt certain values, particularly the principle of

normalisation (Flynn & Nitsch, 1980;  Wolfensberger, 1972), social role valorisation (Wolfensberger, 1983), the 'five accomplishments' (O'Brien, 1987), an 'ordinary life' (King's Fund Centre, 1980) and the social model of disability (Oliver & Zarb, 1989). Such efforts are based on assumptions that organisational values exert a powerful influence over service quality and in turn organisational performance can be improved through changing staff values expressed through their attitudes (Emerson, Hastings & McGill, 1994). Values, attitudes and ideology tend to be used interchangeably in the literature and some writers have little doubt about the importance of staff attitudes to practice. For example, Henry**,** Duvdevany, Keys and Balcazar (2004) state unequivocally, 'The attitudes of staff affect the extent to which the philosophy of inclusion of people with intellectual disabilities is implemented (p. 26). In an earlier paper Henry and his colleagues (2001) argue the importance of making explicit organisational values, as the fit between these and staff values is particularly critical in services for people with intellectual disabilities and the degree of fit is predictive of effective implementation.

Despite such assertions and the significant investment in training, there has been relatively little research about staff attitudes or their impact on care practices. In California, Lewis (2004) found that although staff in services for people with intellectual disability generally had very positive attitudes towards the inclusion and continued development of the people they supported, a substantial minority felt that what they provided in their services was inconsistent with what they were supposed to provide. Rather than education and promoting development, they thought services really provided 'care'.  Positive staff attitudes are found to affect the duration of staff-client interactions (Egli et al., 2000) and an attitude that values talking with clients is

associated with staff implementation of person centred active support (Mansell et al., 2007.

Research has shown that staff attitudes are usually very positive although some differences have been found between community and hospital staff, between staff with different levels of education and in different countries. For example, the work of the Jay Committee found that in the early phases of the development of community care, attitudes of community care staff were more positive about the application of community care to people with intellectual disability than hospital staff (Department of Health and Social Security, 1979). In contrast, Silver, Lubin and Silverman (1984) found that direct care staff in hospitals felt more affiliation with the facility where they worked and the people they worked with than community care staff. Henry et al., (2004) compared community agency staff in the USA and Israel using the Community Living Attitudes Scale and found that although in general attitudes were quite positive, staff who had higher levels of education were more positive in their views of community care. There was variability across the different agencies involved and there were differences between American and Israeli staff with the former having generally more positive attitudes towards empowerment and facilitation of people towards independence.

Much of the work on attitudes focuses on issues such as sexuality (e.g. Cuskally & Bryde, 2004; Bazzo et al., in press; Abbot et al, in press) or looks at how staff feel about challenging behaviour and how they attribute the causes of challenging behaviour (Hastings & Remington, 1995; Hastings, 1997). Only two studies have examined the effect of severity of disability on staff attitudes. Silver et al., (1984) found no difference between staff working with people who had very severe intellectual disabilities and those working with people with slightly less severe

disabilities. Henry et al., (1996) found that staff members in community living services working with less-disabled residents had more positive attitudes on the Community Living Attitudes Scale than those serving more-disabled residents. Since these studies, more people with severe disabilities have moved into community living settings in Australia, the USA and UK but there has been no further study of staff attitudes focusing on level of disability.

This paper brings together the findings of two linked studies that explored attitudes of staff in community based services towards the realisation of current policy visions for people with more severe intellectual disability. It exemplifies the complimentarity of qualitative and quantitative research methodologies (Cresswell & Clark, 2007. The first part reports some findings from a large ethnographic and action research study that examined life in the community for residents with intellectual disability who moved from an institution to small group homes as the institution closed during 2005-2007. A tentative proposition arising from this study was ' that though staff accept principles of inclusion, choice and participation for people with intellectual disabilities in general, they do not consider it feasible to apply these to the people with more severe intellectual disabilities to whom they provide support'. This proposition is tested in the second study, which compared staff attitudes to people with differing levels of impairment. Both projects received ethical approval from La Trobe University's Ethics Committee. Consent on behalf of each resident was given by their formal guardian or next of kin. Staff and family members gave their own written consent and were therefore aware of the overarching aims of the study. All names used in this paper are pseudonyms.

**Study 1.**

**Method**

This was an ethnographic study. The sample comprised 25 residents, who lived in five purpose built houses in the community, and some of their staff and family members. The houses were located in residential areas of Melbourne, and accommodated four, five or six residents. Houses were staffed 24 hours a day, and had been open for less than 12 months when the fieldwork commenced. Every house had access to a medium sized bus and all residents attended formal day programs on a part-time or full-time basis. These houses were built as part of the closure of the state's oldest institution, which was part of the implementation strategy of visionary rights based policy for people with disabilities in Victoria. For example, the State Disability Plan 2002- 2012 set out ambitious policy goals, of equal citizenship, participation, choice and inclusion for people with disabilities which were reinforced by a new Disability Act, 2006 (Department of Human Services, 2002). One of the Plan's goals for instance is to 'To strengthen the Victorian community so that it is more welcoming and accessible, so that people with a disability can fully and equally participate in the life of the Victorian community' (p. 11). The plan refers to all people with a disability and does not distinguish between people on the basis of the nature or severity of their impairment.

No formal testing of residents was conducted but updated assessments undertaken before they left the institution indicated they all had severe or profound intellectual disability. All the residents required assistance with personal care and most did not have expressive language or other formal systems of communication. The age of residents varied, as did the length of time they had spent in the institution. The youngest was in his 30s and the oldest in his 70s. Although many staff had previously worked in the institution, some had worked in the community sector as well and some had never worked in the institution. Staff received two weeks transition

training focussed on the goals of the State Disability Plan prior to taking up positions in these houses and in one region in particular additional resources in the form of a dedicated community inclusion officer were available to support their work.

*Data collection*

The overarching focus of the larger study was resident participation and inclusion in the community and in their daily lives. All the work on this study was undertaken by the first two authors, and for the first 12 months a third researcher. All brought considerable experience of working in and researching supported accommodation settings. They were also familiar with much of the relevant literature, which reveals group homes as complex settings, with the determinants of high quality services as yet undiscovered (see Felce, Lowe & Jones, 2002, for example). Although the researchers' experiences and ideas influenced the research, they did not enter the field with the intention of testing any *a priori* hypotheses, but with the aim of exploring phenomena as they emerged from the study (Taylor & Bogdan, 1998). Lecompte and Schensul (1999) point out that ethnographers begin analysing their data as soon as they begin fieldwork. Writing fieldnotes involves interpretation and sensemaking (Emerson, Fretz & Shaw, 1995) and the different researchers made varying use of asides, commentaries, and memos as they produced their full fieldnotes from their scratch notes and headnotes. A total of 159,196 words of fieldnotes were written. Speech extracts are presented in single quotation marks. This reflects their genesis in field notes, rather than verbatim quotations that typically come from an interview (see Emerson et al., 1995).

Data were collected primarily through participant observation by working shifts alongside staff. In addition the researchers attended some staff training sessions before the houses were opened and house staff meetings. In four of the five houses

staff also participated in a half-day sessions, where simple ethnographic descriptions of day-to-day life in the houses were discussed. These contained little of the researchers' interpretations as the aim was to facilitate discussion with the respective staff teams as a way into cycles of action research. Two hundred and sixteen hours of participant observation was undertaken by three researchers, ranging across the five houses from 36 to 59 hours. In addition eight interviews were conducted with staff and four with family members. The interviews were semi structured, using open ended questions to seek their views on goals of the service, nature of support provided by staff, and community participation of residents. These were recorded and transcribed, and are reported using the usual conventions for direct quotes.

*Analysis*

The researchers could not simply put their experiences to one side, but could, as Hammersley and Atkinson (1995) suggest, subject those experiences to analytic reflection. All field notes were shared and the research team met regularly to reflect on the data and discuss emerging propositions and interpretations. The staggered nature of the research meant that the researchers undertook fieldwork at different times. Early on in the process the researchers who were not engaged in fieldwork were more able to adopt the role of 'critical friend', giving feedback and probing for alternative interpretations (Winter & Munn-Giddings, 2001). During this early analysis discussion focussed on questions such as, how was it that the opportunities that existed for residents to enjoy a good lifestyle in small housing were not being fully exploited? How were the low levels of participation and choice to be accounted for? How could the negative attitudes towards the goal of building inclusive communities be explained? This led to further discussion about the attitudes held by staff that appeared to inform their practice and eventually to the proposition that staff

did not appear to believe it was feasible to implement the policy visions of choice, inclusion and participation for the people with whom they worked,

The data was further analysed with the above proposition in mind. A 'start-list' of codes was developed prior to systematically analysing the data (Miles & Huberman, 1994). McGuires' (1985) conceptualisation that attitudes comprise affective, behavioural and cognitive components was used to guide the code development and analysis. The language used by staff about residents and policy goals, their comments about residents and their work, and their behaviour towards residents were considered. The data was reread looking for all examples that illustrated both positive and negative staff attitudes towards goals of choice, inclusion, and participation, which were then grouped into sub-themes (Denzin & Lincoln, 2000). The coding, search and retrieval functions of NVivo (Qualitative Solutions and Research, 1999) were used to assist the analysis and manage the large volume of data.

**Findings**

Though not demonstrated by all staff at all times, a core theme in the affective, behaviour and cognitive outlooks (attitudes) of staff about choice, participation and inclusion, was 'Lets be realistic, it's not feasible with this group'. Three sub-themes were identified: 1) 'It won't make any difference' 2) 'Residents are too different' 3) 'It's too hard because….' The attitudes reflected in these themes challenged the relevance of current policy visions to the people with severe or profound intellectual disability with whom staff worked. Whilst within our data there were varying attitudes, and some examples of very positive attitudes towards policy visions, these were overshadowed by more doubtful perspectives.


'**It Won't Make Any Difference**'

Whilst some staff did not directly dismiss the relevance of choice and participation, they doubted that offering opportunities for these to be exercised would be appreciated or make any difference to the lives of residents. For example, the view was often expressed that residents always made the same choice regardless of what was offered and anyway staff knew the choices that residents were likely to make.

> Although there was something good about offering the choice, Laura [staff] also commented that she knew exactly what people were going to choose. (AS/081206)

> Mel [staff] commented that they only want to go out and eat. (BS/170106)

> Joan [staff] said that the person who comes shopping with her at the weekend chooses the cereal. I [researcher] suggested that what people choose was often constrained by what they know. One of the roles of the staff was to increase the amount of options that people could choose from. Staff thought that even if new things were available people might still choose what they usually choose. (BS/080206)

Some staff appeared to understand residents' expression of preferences within narrow boundaries, dismissing the relevance of 'choice', rather than exploring possibilities by offering new and unknown options or finding ways in which residents could be assisted to express a preference. For example, during a staff training session, the following exchange occurred.

> Sue (trainer) gave an example of going out to eat and residents looking at pictures on a menu. Jo started to say 'No, they couldn't do that', but got interrupted. (CS/141205)

Although it had been established some of the residents could not use symbolic communication neither the staff member nor the trainer pursued other possibilities to be considered. Talking about possibilities for participation some staff drew attention to the apparent disinterest of residents in efforts to involve them in daily activities. For example,

> 'When I [staff] am outside weeding I give Brian the weeds. He drops them on the floor'. (CS/270206)

> We need to make the home itself homely, clean and tidy, because the fellas haven't got the capability of doing that or in one case he [Milan] doesn't want to be involved in doing what we need to make sure that that's done. (DS/210906)

> 'Aphrodite would probably go to sleep if I took her out in the evening'. (MC/030806)

**'Residents Are Too Different'**

Staff language and behaviour consistently suggested that some staff held childlike images of the residents. Sexual behaviour was referred to in a way that indicated it was aberrant or childish rather than adult behaviour. For example, phrases such as 'that dirty thing' or 'inappropriate behaviour' were used rather than a term such as masturbation that conveys acceptable and adult behaviour. Although not necessarily a disparaging term both staff and supervisors collectively referred to male residents as 'the boys' and in one instance as 'kiddies'. Day programs were consistently referred to as 'school'.

> 'Usually everyone goes out. If we are going in the bus I take all the boys.

We went to Ocean Grove a good trip for the boys' (DS/030206)

In several instances a direct reference was made to the similarity between residents and children. Comments were often made that residents had to be amused or kept happy, analogous to the way children are referred to. For example when staff were reflecting on taking residents out into the local community;

> Cliff suggests that there are some problems. After Claudia has said, 'We don't get stared at' she adds, 'Little things happen. Wally may stop the traffic at Safeways. It's a bit like having a five-year old …residents do things that make people look'. [I [researcher] write on my notepad, 'Worlds apart'. Our thinking on these issues is on different planets.]. (DS/17706)

Some activities organised by staff such as birthday parties were particularly childlike, such as Aphrodite's 54th birthday celebration. Although, as this passage illustrates not all staff approved of the approach adopted.

> Sunny [staff] disappears for a minute. She comes back into the kitchen. She has her Swiss cow-bell tied around her neck. She has a mask on of some sort. She has her back to us all. Paul [staff] looks at me and pulls a face. There are comments from the relatives. She is lighting candles and sparklers in the cake. They are not birthday candles, but table candles. There are lighted candles on two of the tables. Sunny turns round. She is wearing what looks like a gorilla mask. She brings the cake over to Aphrodite, the cow-bell clunking, puts it in front of her, and then gives her a hug. She takes the mask off and then hangs the cow-bell around Aphrodite's neck. She rings it once and then takes it off. After 'Happy Birthday' is sung Aphrodite blows out some of the candles and then Alberto blows out the last one. Sunny serves everyone a piece of cake. (BS/300106)

Dismissive behaviour of some staff towards the purposeful choices and actions of residents, suggests also that residents are regarded as childlike, whose wishes are not of equal standing to those of adults. Most common was disregard for residents' choice of dress and presentation

> Wally is wearing shorts and a T-shirt. He has tucked the T-shirt into the shorts. Joan [staff] walks by and tells him in a loud voice to take the T-shirt out. (BS/251105).

> After Wally had dressed (T-shirt and shorts) he went and stood by the front door, with his Simpson's knapsack. He had tucked his T-shirt into his shorts. 'What would Joan say?' says Laura [staff]. Wally did not seem to want to change how he had dressed. 'Right I'm going to get Joan', she said. Laura opened the door and said, 'Joan'. Coming back into the room she half-pulled his shirt out so that it was folded over his waist band, but still tucked in. (BS/081205)

The fieldnotes from a reflective meeting with the staff team which discussed the notes above recorded:

> Joan [staff] said that Wally has learnt that when she is on it is not a good look to have pulled up socks and tucked in shirt. He is gradually learning this not a good look and when she is around he will not tuck his shirt in, but she has seen him tucking it in when he is outside away from her. …Pat [supervisor] said in an ideal situation Wally could do what he likes in the house and tuck the shirt in when he was out in the community …Tim [researcher] challenged the view and posed the question about the residents' right to look as they want to, and

wear socks pulled up. Joan replied 'I won't be caught dead in the community with him. I won't do it it's not a good look' and then talked about duty of care for clients to look respectable and some clients need staff to guide them still. (BS/170106)

Actions such as these by staff that over-rode or disregarded residents' choice, and gave preference to their own views were evident in various circumstances. This approach was compounded by the failure of these staff to explain or justify their actions to residents. For example,

Rose appeared in night clothes and a dressing gown. She drew the curtains and switched on the radio. Opening the curtains revealed a man looking over the top of the fence. A few minutes later Pat [supervisor] came and closed the curtains again, without giving any reason for doing so. Rose went to the curtains and started to open them again. I [researcher] started with an explanation, and tried to get Rose to look at the man. Pat took over and shut the curtains telling her to wait until after people had showered. Rose opened them again when Pat was out of eye-sight. (BS/081205)

Lily [staff] starts to prepare breakfast. She heats some spaghetti in the microwave and fries some eggs, which she puts on a plate and then puts them in the microwave. Brian has come to stand by the kitchen worktop looking at Lily cook. The doorbell rings, which I answer. Jo [staff] arrives at 08.00. She comes into the kitchen and tells Brian to sit down. (CS/180206)

The physical design of houses, that included separate staff toilet facilities created social distance between staff and residents. Some staff practices, including the

common use of separate crockery and cutlery, further reproduced a sense of 'them and us', valued – devalued, adult – child. For example,

> The fire 'backpack' (in bright yellow material) was discussed. As well as official content (tabard, torch, first aid kit, and clipboard/pen) there was some discussion about having 'incentives and pacifiers' in the bag. Incentives are for clients ('lollies') and pacifiers for staff (cigarettes). (DS/ 210705)

> I ate my fruit from a disposable dish. John and Jo [staff] would not let me take a plate from the cupboard as they said Shane sometimes got cold sores. (CS/230106)

> There is a staff toilet/shower en suite next to the office. I was directed to use this one. There are three toilets in the house, but when it was suggested that someone use one of the other toilets Cathy [staff] said, 'No, that's the clients'. (DS/200706)

An approach used by some staff, that avoided direct challenge was to mock or ridicule ideas about inclusion or participation, with the implicit suggestion "you must be joking". In this example one of the researchers is discussing some observations she had made at the day program about Shane who has no literacy skills and requires facilitive support to participate in activities.

> Jan [researcher]: 'When Shane gets to the day programme Vince [staff] is waiting for him in the kitchen with a drink. I watched Shane in a cooking programme. He was at the stove stirring things. He was in the kitchen for two hours. He didn't go seeking drinks'.

> Lydia [staff]: 'By himself? Maybe he can cook for you Lily'.

…..

Lily [staff]: 'It's about giving them the chance. You're not asking them to cook the whole meal. There's no way he can learn the whole skill'.

Albie [staff]: 'It's about involvement'.

Lydia: 'You should give him the recipe Lily'. (CS/270206)

There was some laughter and jokes about the possibility of setting up a yoga class at the house and asking the neighbours. Milan [who has very flexible joints] to lead it, someone else to open the door etc. (DS/030206)

**'It's Too Hard Because…'**

As staff talked about their daily work and its challenges, many reasons were put forward as to why residents did not exercise more choice or participate more often in the community or their own homes. These ranged from significant to trivial, and were associated with the negative attitudes of community members to residents, the characteristics of residents such as their age, degree of impairment or motivation , insufficient staff and resources, the risks to residents or staff, and the complexity and difficulty of the task that confronted staff. Such attitudes were exemplified by a staff member talking about the policy goals in the State plan:

Good idea but it won't work. You can only do so much with people who are more severely disabled; the people who write the cheques [senior bureaucrats] need to have a look. (CS/270206)

One staff member commented that really we cannot expect much from these men because of the time they have spent in institutions adding it would be easier to have inclusion with the next generation. (DS/030206)

There is a cooked breakfast at the weekend and this was thought to be more problematic for people to serve themselves. 'They might take too much scrambled egg'. (BS/080206)

Joan [staff] raised the issue of finance as being a barrier. 'The supervisor gets their butt kicked if they are over budget at the end of the period'. Thus you couldn't buy lots of different types of cereals. (BS/080206)

Lydia: 'I was coming to work one day and saw the guy next door and he gave me a dirty look'.

Albie: 'They're not ready to accept us'.

John: 'Parents don't tell their kids. It could easily be one of them. Their education must be lacking'.

Albie: 'We went to McDonalds and sat outside. Once other people saw us they avoided us'.

John: 'This is a job for teachers, we can't do that. We don't get the time'.

Jan [researcher] suggests that there are times when people can pursue these things.

John: 'We're not psychologists'.

Lily 'You need to start with people at a young age'.

John: 'It's society…'

Lydia: 'They need more information'. (CS/270206)

Pat [supervisor] said, 'If each resident has their own routine it would be chaos'. In his view the principle was that if you had something standardized everyone would get a fair go, and talked about how difficult it would be to have six people doing six different things at the same time. (BS/170106)

On several occasions supervisors talked explicitly about the attitude or comprehension of their staff as being problematic. The comments from one supervisor below also illustrate the variance of staff views.

I'm [supervisor] not going to be able to move him [staff member] on any further. He doesn't comprehend what I want to do. He doesn't comprehend to give the boys the opportunity, that dignity of risk. He doesn't comprehend that, because that's where he's come from. Apart from his cultural background one of the things that I taught him was to hang clothes on the line properly. (DS/210906)

**Strengths and Limitations**

Trustworthiness criteria, which include, credibility, transferability, dependability and confirmability are used to evaluate qualitative research of this kind (Cresswell, 1998). With regard to credibility there was extended engagement over a period of time with the houses in the study that spanned more than 12 months for 3 of the 5 houses. This allowed rapport to be built with participants and opportunities for field notes and data to be checked. In several houses direct member checking occurred as field notes were shared with participants, and in others summary papers prepared from the field notes were shared and used as the basis for reflective discussions with staff. Discussion of findings with a reference group and other staff within the organisation responsible for

managing the houses, demonstrated a resonance with their experiences which added to credibility. Transferability has been addressed by the rich thick description of the field notes and larger reports produced about the study (Clement, Bigby & Johnson, 2007; Clement & Bigby, 2008). As discussed earlier a process of peer debriefing has occurred on a frequent and regular basis within the research team. The second study described below was undertaken to test the confirmability of the findings.

**Study 2**

The qualitative data in Study One suggests that some staff do not see it as feasible to involve people with severe and profound intellectual disabilities in choice and participation in the community or their home. This group are 'excused' from the goals of an ordinary life by reason of their disability: that is, though staff accept the principle of an ordinary life for people with intellectual disabilities in general, they do see it as feasible to apply this principle to the people with serious disabilities to whom they provide support. The aim of the second study was to test this hypothesis, by asking staff to what extent they agree with various statements about people with intellectual disabilities, under two conditions – one in which people consider the statements as applying to people with intellectual disabilities in general, and one in which they consider them as applying to a person they know, especially to a person with severe disabilities.

If the hypothesis that staff who believe in the principle of an ordinary life for people with intellectual disabilities in general, do not apply this principle to people with serious disabilities to whom they provide support, is correct, then staff rating agreement with statements under the 'general' condition will have more positive views than those considering individuals with severe disabilities.

**Method**

Participants were 144 direct-care staff and first line managers supporting adults with intellectual disabilities in residential, in home support or day services in Victoria. Participants were an opportunity sample recruited at staff training workshops in country Victoria. People attending these workshops were invited to complete a short questionnaire about their attitudes towards people with intellectual disabilities. Questionnaires also asked for some demographic information (gender, age-group, length of service, training). Completion was entirely optional and anonymous.

Each participant was invited to complete a short questionnaire based on the Staff Experience and Satisfaction Questionnaire (Beadle-Brown, Gifford, & Mansell, 2003). The questionnaire was in one of two forms – a 'general' form and an 'individual' form. The two forms of the questionnaire were prepared in equal numbers and sorted randomly into one set. They were then distributed to potential participants in the order they were presented. After approximately ten minutes, they were collected in from the group.

The questionnaire comprised 20 statements about people with intellectual disabilities with which participants were invited to record their agreement on a 5-point scale. Items were counter-balanced by reversal. Part 1 of the questionnaire contained 16 items asked in different forms for two groups of participants. In the general form, participants were presented with statements of the form "people with intellectual disabilities…" For example, participants were asked to rate their agreement or disagreement with the statement, "People with intellectual disabilities do not have the ability to live supported in the community"

For the individual form, participants were asked to think of an individual with intellectual disabilities they knew; to say whether this person had mild or moderate

intellectual disabilities, severe and profound intellectual disabilities, challenging behaviour, physical impairments, sensory impairments, epilepsy or communication difficulties; and then to rate their agreement with statements prefaced "This person…".

Part 2 comprised four questions which were the same for both groups. These asked whether "Community care is better than institutional care for" carers/support workers, for the community, for all people with intellectual disabilities and for all people receiving services (elderly, mentally ill, children, people with disabilities, etc.). These questions were included to detect any difference between the groups answering 'general' and 'individual' forms of the questionnaire.

The questionnaire also included questions about the participants, such as gender, age, ethnicity, qualifications, length of work experience in intellectual disability services and in current service, job title, average hours work per week, number of people with intellectual disabilities supported and the characteristics of these.

Cronbach's alpha was 0.715 and 0.827 for the 16 questions (part 1) and 4 questions (part 2) respectively, with median item-total correlations of 0.356 and 0.664 Taking the two different forms of the questionnaire, the general form had Cronbach's alpha of 0.626 for part 1 and 0.884 for part 2, and the individual form had Cronbach's alpha of 0.746 for part 1 and 0.768 for part 2. These are conventionally acceptable levels of internal consistency. The questionnaire has some predictive validity, having been shown to discriminate between care staff trained in active support and those not trained (Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2007).

*Analysis*

The data were transcribed from the questionnaires to computer and analysed using SPSS. Two summary variables were computed for the 16 item and the 4 item parts of the questionnaire. Descriptive statistics were calculated for participant characteristics. Differences between the means for staff completing general vs. individual forms were tested using Mann-Whitney non-parametric tests of significance. A Kruskal-Wallis analysis of variance was used to compare the attitudes of staff focusing on persons with mild or severe intellectual disabilities with those completing the general form. Finally, Mann-Whitney tests were used to compare the attitudes of staff focusing on persons with challenging behaviour and other complex needs with those completing the general form.

**Results**

*Participant characteristics*

Eighty percent of participants were women, 61% were over 40 years of age , 73% had a professional, academic or TAFE qualification and 94% were born in Australia. Participants were experienced - 60% had worked for more than 5 years in intellectual disability services. Participants had worked in their current service for some time; 73% had worked in their current service for more than a year. There was a very wide range in the number of hours worked per week (mean 31, range 3-85) and number of clients supported (mean 17, range 1-350). The highest numbers of clients were reported by case managers or service managers. The only difference between participants who completed the general vs. individual forms was that there were slightly more women in the latter group ($\chi^2$=4.18, df=1, p<0.05).  There were no other statistically significant differences between these two groups. Nor were there any statistically significant differences between respondents completing the general form

and those selecting people with mild or moderate, or severe or profound, disabilities for the individual version of the questionnaire.

*Effect of respondent gender on attitudes*

Taking the whole sample, women had more positive attitudes on part 2 of the questionnaire (z=2.47, p<0.05, n=142). Selecting only those who had answered the general form of the questionnaire, women showed more positive attitudes than men of part 1 (z=2.24, p<0.05, n=69) and part 2 (z=2.07, p<0.05, n=69). Selecting those who had answered the individual form of the questionnaire there was no significant difference between men and women for either the group responding about people with mild or moderate intellectual disabilities nor the group responding about people with severe or profound intellectual disabilities.

*Effect of severity of disability on attitudes*

There was a small difference between the groups; participants responding to the general version of part 1 gave more positive responses than those responding to the individual version (z=2.647, p<0.01). There was no difference for part 2, which was the same for both groups (z=1.438, p>0.05). Therefore people rating an individual they know rather than people with intellectual disabilities in general expressed somewhat less positive attitudes.

Insert table 1 about here

In order to examine whether this was because people were selecting more disabled individuals when they thought about a particular person, three groups of responses were compared: those answering about people in general, those who had

chosen a person with mild or moderate intellectual disabilities and those who selected a person with severe or profound intellectual disabilities. Of the 73 questionnaires involved, only 60 had identified the level of intellectual disability and could be used.

There was a significant difference between these groups on part 1 of the questionnaire. Post-hoc analysis using Mann-Whitney tests showed that the significant difference lay between the general group and the severe or profound intellectual disability group, where attitudes were less positive ($z=2.46$, $p<0.05$). The same pattern was found in respect of staff focusing on those with challenging behaviour (n=51, mean=60.84, SD=6.86) compared to the general group ($z=2.73$, $p<0.01$). Of the 15 cases where staff had identified a person with severe or profound intellectual disabilities, 13 also recorded other impairments or problems. These 13 cases, when compared to the general group, also showed significantly less positive attitudes on part 1 (mean=60.46, SD=6.68; $z=2.011$, $p<0.05$). This implies that severity and complexity of disability is the factor producing the difference between the general and individual groups. There were no differences for any of these groups on part 2 of the questionnaire.

Although a group-comparison design cannot rule out the possibility of some pre-existing differences between the groups of staff involved in the study, their assignment to the two conditions (general and individual forms of the questionnaire) was random and the only significant difference found between the groups was that those in the individual group included slightly more women. Gender does not explain the difference between the respondents focused on people with severe disabilities and those completing the general form.

**Conclusions**

These studies suggest that though staff in services agree with the principles of choice, inclusion and participation for people with intellectual disabilities in general, some staff find it difficult to accept they can be applied to people with more severe intellectual disabilities. The second study drew on a larger group of staff working in a wider range of intellectual disability services than the first, indicating that it is not only ex-institutional staff working in newly established groups homes, who struggle with these ideas. The qualitative study suggests that rather than being actively opposed to ideas such as choice and inclusion, some staff just do not consider them as feasible or valuable to apply to the people with severe intellectual disabilities with whom they work. It is likely to be the case that any staff group will contain staff with a variety of different attitudes, some positive, others less so, similar to those described in study. It will be hard to move towards consensus in such groups, or for progressive staff to practice in settings where the attitudes described are evident. The incongruence between attitudes of some staff towards people with severe intellectual disabilities and the values that underpin policy and service delivery goals helps to explain why their practices may not support similar outcomes for this group compared to those for people with milder disabilities.

Concepts such as choice, inclusion and participation that figure prominently in goals of disability policy and the mission statements of both government and non government disability providers are seldom well defined or illustrated with examples of people with severe intellectual disability. One reason for this lack of specificity is the de-differentiated approach to disability policy in Australia that means policy must be applicable to a diverse population of people with disabilities. In the absence of clear explication in policy it is understandable that staff struggle to interpret the

meaning of these broad and ill defined concepts for people with severe intellectual disabilities. The possibilities and value of community participation and the subtle distinction, for example, between community presence and participation, for a person with a severe intellectual disability (O'Brien,1987), , are not self evident. The application of such goals to this group are certainly much less obvious than to an elite paraplegic athlete for example, or other goals such as excellent care routines and safety procedures. It is easy too for concepts such as independence and choice, to be misinterpreted and staff to assume that they are not applicable to a person who is never going to learn the necessary skills.

This study suggests that conscious attention must be paid to the staff understandings of policy principles and their application to people with more severe intellectual disabilities. A task for policy implementation and service delivery is the explicit interpretation and demonstration of policy goals for frontline staff, supervisors and practice leaders - seeing might mean believing for staff. Traditional methods for interpreting policy and reinforcing consistency between staff and service values are through pre- and in-service training, supervision and the formal operating procedures of organisations (Emerson et al., 1994). In the UK another mechanisms is detailed policy guidance (see for example, Routledge & Sanderson, 2001) that sets out expectations about policy implementation and outcomes. This type of guidance is not found in Australia, and could be a useful means of systematically conveying the meaning and application of policies to people with severe intellectual disabilities for frontline staff. The development and evaluation of demonstration programs may be another strategy to ensure staff have access to examples of excellent practice with people with severe intellectual disability. In a de-differentiated service system it is also important that both senior generalist managers and front line practice leaders

have an explicit understanding of what policy goals mean for people with more severe intellectual disabilities so that examples are diffused throughout organisations.

The study supports conclusions by Henry et al., 2001 about the fit between organizational and staff values, and thus the importance of attention paid to staff attitudes as well as skills in recruitment, training and organizational arrangements. Supervision and staff meetings for example can be designed to provide a safe space for staff to talk about their understanding of policy and misgivings they may have. Opportunities for debate about attitudes may not only help staff to rethink them but also to rehearse ways of dealing with the negative attitudes of community members they encounter in their daily work. Individualised and regular supervision may be pivotal in supporting staff to understand the potential for values to be translated into everyday practice, generate performance expectations and effective feedback. Emerson et al., (1994) suggest that staff training may be ineffectual in changing beliefs, but effectiveness may be enhanced if it is based upon an analysis of individuals' current beliefs and linked to practical experiences. Herein lies the value of ethnographic work that captures everyday experiences of staff and residents and can form the basis for training materials.

Parts of the qualitative study pointed towards the lasting impact on staff practices of values training based on normalization. This was most clearly illustrated by staff concern about community perceptions of a residents' appearance, which at times took precedence over resident choice. This suggests the importance of values training but also the need for continuous discussion, particularly with more experienced staff to reconcile values derived from normalization with a more recently adopted rights perspective.

Although the effects of staff beliefs can be overridden by the formal rules in a setting, Emerson et al., (1994) suggest such rules maybe ineffectual in determining staff performance, if expectations are unclear, monitoring unreliable and feedback ineffective. A challenge lies then in conveying a clarity of purpose to staff, through the careful use of language, and the formulation and consistent implementation of organisational procedures to monitor staff practices and call them to account when their practice does not reflect policy values. There is no inherent reason why mechanisms to monitor staff support for client participation and choice cannot be as effective and demanding of compliance as those that that monitor health and safety issues. The tasks of policy implementation are to create a climate where personal beliefs of staff are either consistent with policy or if they are in conflict ensure they can be identified and challenged by organizational rules and procedures (Emerson et al., 1994).

References

Abbott, D., & Howarth, J. (in press). Still off-limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships? *Journal of Applied Research in Intellectual Disabilities* (online early articles) Doi:10.1111/j.1468-3148.2006.00312.x

Bazzo, G., Nota, L., Soresi, S., Ferrari, L., and Minnes, P. (in press). Attitudes of social service providers towards the sexuality of individuals with intellectual disability. *Journal of Applied Research in Intellectual Disabilities.* Online Early doi:10.1111/j.1468-3148.2006.00308.x

Beadle-Brown, J., Gifford, J. and Mansell, J. (2003) *Staff Experience and Satisfaction Questionnaire (Learning Disability).* Canterbury: Tizard Centre.

Creswell, J. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks. Cal.: Sage.

Cresswell, J., & Clark, V. (2007). *Designing and conducting mixed methods research.* Thousand Oaks, CA: Sage Publications

Clement, T., Bigby, C., & Johnson, J. (2007). *Making life good in the community: The story so far.* Melbourne: Victorian Government Department of Human Services.

Clement, T., & Bigby, C. (2008). *Making life good in the community: As good as it gets.* Melbourne: Victorian Government Department of Human Services.

Cuskelly, M. & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. *Journal of intellectual & Developmental Disability*, 29, 3, 225-264

Department of Health and Social Security. (1979) *Report of the Committee of Enquiry into Mental Handicap Nursing and Care* (Chairman: Peggy Jay). London: Her Majesty's Stationery Office.

Department of Human Services. (2002). *Victorian State Disability Plan 2002-2012*. Melbourne: Disability Services Division.

Denzin, N., & Lincoln, Y. (2000). Introduction: The discipline and practice of qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 11-28). Thousand Oaks; CA: Sage

Egli, M., Feurer, I., Roper, T., & Thompson, T. (2002). The role of residential homelikeness in promoting community participation of adults with mental retardation. *Research in Developmental Disabilities, 23*, 179-190.

Emerson, M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes*. Chicago: The University of Chicago Press.

Emerson, E., Hastings, R., & McGill, P. (1994). Values, attitudes and service ideology. In E. Emerson, P. McGill & J. Mansell (Eds.), *Severe learning disabilities and challenging behaviours: Designing high quality services*. London: Chapman and Hall.

Emerson, E., & Hatton, C. (1994). *Moving out: Relocation from hospital to community*. London: Her Majesty's Stationery Office.

Felce, D., Lowe, K., & Jones, E. (2002). Staff activity in supported housing services *Journal of Applied Research in Intellectual Disabilities,* 15, 388-403.

Felce, D., Bowley, C., Baxter, H., Jones, E., Lowe, K., & Emerson, E. (2000). The effectiveness of staff support: evaluating Active Support training using a

conditional probability approach. *Research in Developmental Disabilities, 21*, 243-255.

Felce, D., & Emerson, E. (2001). Living vith support in a home in the community: Predictors of behavioural development and household and community activity. *Mental Retardation and Developmental Disabilities Research Reviews, 7*(2), 75-83.

Flynn, R. J., & Nitsch, K. E. (1980). *Normalization, social integration and community services*. Baltimore: University Park Press.

Hammersley, M., & Atkinson, P. (1995). *Ethnography* (2nd ed.). London: Routledge Hastings & Remington, 1995;

Hastings, R. P., & Remington, B. (1995). The emotional dimension of working with challenging behaviours. *Clinical Psychology Forum*, 79, 11-16.

Hastings, R. P. (1997) Measuring staff perceptions of challenging behaviour: The Challenging Behaviour Attributions Scale (CHABA). *Journal of Intellectual Disability Research,* 41(6), 495-501.

Henry, D., Duvdevany, I., Keys, C., and Balcazar, F. (2004). Attitudes of American and Israeli staff towards people with intellectual disabilities. *Mental Retardation, 42*(1), 26-36.

Henry, D., Keys, C., Balcazar, F. & Jopp, D. (1996) Attitudes of community-living staff members towards persons with mental retardation, mental illness, and dual diagnosis. *Mental Retardation, 34*(6), 367-379.

Henry, D., Keys, C., & Reese. (2001). Value based job analysis: an approach to human resource management in rehabilitation agencies serving people with developmental disabilities. *Journal of Rehabilitation Administration 25*, 1-17.

Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., et al. (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support. *Journal of Intellectual Disability Research, 43*(3), 164-178.

Kim, S., Larson, S. A., & Lakin, K. C. (2001). Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. *Journal of Intellectual & Developmental Disability, 26*(1), 35-50.

King's Fund Centre. (1980) *An ordinary life: Comprehensive locally-based residential services for mentally handicapped people*. London: King's Fund Centre.

LeCompte, M. D., & Schensul, J. J. (1999). *Analysing & interpreting ethnographic data* (Vol. 5). Walnut Creek, CA: AltaMira Press.

Lewis, J. L. (2004). Attitudes toward federal policy and organizational functioning among workers that serve adults with cognitive disabilities (California). *Dissertation Abstracts International Section A: Humanities and Social Sciences, 65*(4-A), 1318.

Mansell, J. (1995). Staffing and staff performance in services for people with severe or profound learning disability and serious challenging behaviour. *Journal of Intellectual Disability Research, 39*, 3-14.

Mansell, J. (2006). Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability, 31*(2), 65-76.

Mansell, J., Beadle-Brown, J., Whelton, R., Beckett, C. and Hutchinson, A. (in press) Effect of service structure and organisation on staff care practices in small

community homes for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*.

McGuire, W. J. (1985). Attitudes and attitude change. In G. Lindzey & E. Aronson (Eds.), *Handbook of social psychology* (3rd ed., Vol. 2, pp. 233-346). New York: Random House.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: A sourcebook of new methods.* (2nd ed.). London: Sage Publications.

O'Brien, J. (1987) A guide to life-style planning. In G. T. Bellamy & B. Wilcox (Eds.). *A comprehensive guide to the activities catalogue: An alternative curriculum for youths and adults with severe disabilities* (pp. 175-189). Baltimore: Paul H. Brookes.

Oliver, M., & Zarb, G. (1989). The politics of disability: a new approach. *Disability, Handicap and Society, 4*(3), 221-239.

Routledge, M., & Sanderson, H. (2001). *Planning with people: Towards person centred approaches; guidance for implementation groups.* Great Britain: Department of Health

Qualitative Solutions and Research Pty. Ltd. (1999). *Using N Vivo in qualitative research*. Melbourne: QSR N vivo.

Silver, E. J., Lublin, R. A. & Silverman, W. P. (1984) Serving profoundly mentally retarded persons: Staff attitudes and job satisfaction. *American Journal of Mental Deficiency*, 89(3), 297-301.

Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource* (3rd ed.). Chichester: John Wiley & Sons, Inc.

Thompson, T., Robinson, J., Dietrich, M., Farris, M., & Sinclair, V. (1996). Interdependence of architectural features and program variables in community

residences for people with mental retardation. *American Journal of Mental Retardation, 101*(3), 315-327.

Winter, R., & Munn-Giddings, C. (2001). *A handbook for action research in health and social care.* London: Routledge.

Wolfensberger, W. (1972). *Normalization: the principle of normalization in human services.* Toronto: National Institute on Mental Retardation/Leonardo Crainford.

Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation, 21*(6), 234-239.

Young, L., Sigafoos, J., Suttie, J., Ashman, A., & Grevell, P. (1998). Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual & Developmental Disability, 23*(2), 155-170.

Table 1 Attitude scores for the general group and for the individual group broken down by severity of disability of focal person

| | General version | | | Individual version – person with mild or moderate intellectual disabilities | | | Individual version – person with severe or profound intellectual disabilities | | | Kruskal-Wallis ANOVA |
|---|---|---|---|---|---|---|---|---|---|---|
| | Mean | N | SD | Mean | N | SD | Mean | N | SD | |
| Part 1 (max=80) | 64.21 | 72 | 6.27 | 62.82 | 45 | 6.48 | 58.93 | 15 | 8.47 | $\chi^2$=6.32, p<0.05 |
| Part 2 (max=25) | 18.16 | 70 | 2.38 | 17.78 | 45 | 2.54 | 17.67 | 15 | 2.06 | ns |