

ORIGINAL RESEARCH

Twenty-five years of Community Living: Changes in Support Staff Perceptions

Stuart Wark^{1*}, Kathleen Bleechmore²

1. School of Rural Medicine, University of New England, Armidale, Australia

2. The Ascent Group, Armidale, Australia

ABSTRACT

Purpose: *The attitudes of support staff towards people with intellectual disability can greatly impact upon an individual's quality of life and level of social inclusion. However, there are few studies that examine how perceptions and beliefs have changed within one organisation over the past few decades; a period during which there have been major social and government policy changes including deinstitutionalisation, inclusive education and the introduction of the United Nations Convention on the Rights of Persons with Disabilities. In conjunction with a 25th anniversary review of a community-living project in rural Australia, the current research replicated a study from 1987 that examined attitudes of staff with respect to people with intellectual disability, and thematically compared the findings of the two questionnaires.*

Method: *In 1987, a purpose-designed questionnaire was developed and completed by 15 direct care staff. This 10-item tool asked for basic demographic information and for the participants' perceptions of people with intellectual disability and their own work roles in the disability sector. This tool was replicated in 2013 and was again completed by 15 direct care staff from the same organisation.*

Results: *The thematic analysis indicated a number of differences between the 1987 and 2013 cohorts in regard to their attitudes. The wide acceptance of the rights of people with intellectual disability was one key change. There was an age separation found within the 2013 cohort, with older participants (> 50 years of age) more likely to display similar attitudes to the 1987 group than the younger participants (<30 years old). Dealing with the problem of ageing-related issues, something that was not obvious 25 years ago, was now considered of major importance. There was evidence that disability support was increasingly*

* **Corresponding Author:** Stuart Wark, School of Rural Medicine, University of New England, Armidale, Australia.
Email:swark5@une.edu.au

recognised as a valid career choice, with a substantial difference in motivation found between the two age groups. Across both cohorts, direct exposure to the realities of the job was seen to be the best training for new employees.

Conclusions: *The past 25 years have seen positive developments in both social acceptance and expectations for people with disabilities. Individuals are now viewed in a realistic but more positive light. As an exemplar of this change, concerns about individuals entering a consenting sexual relationship have changed dramatically, and what was once an issue of major concern is now no longer raised. While the training provided to staff has changed significantly over the past 25 years, on-the-job exposure to people with intellectual disability, combined with support from peers, is still perceived as vital for developing a quality support network.*

Key words: *Attitudes, intellectual disability, staff, training, quality of life, community living, deinstitutionalisation*

INTRODUCTION

The past three decades have seen fundamental shifts in how services are provided to people with disabilities. Major policy and practice reforms over this period have included widespread deinstitutionalisation (Mansell & Beadle-Brown, 2010), a movement towards inclusivity in education and community (Forlin, 2006), the Convention on the Rights of Persons with Disability (United Nations General Assembly, 2006), and a greater focus on person-centred and person-directed support (Ageing Disability and Home Care, 2013). These initiatives and changes were implemented with the goal of improving the lives of people with disability and to also foster greater community acceptance (Amado et al, 2013). Studies within Australia and elsewhere in the world have indicated that people with disabilities have been subject to many negative beliefs and attitudes (Commonwealth of Australia, 2009; Corr McEvoy & Keenan, 2014), and the attitude of both the general community and support staff is known to have a considerable impact upon the social inclusion and quality of life for people with an intellectual disability (Cummins & Lau, 2003; Patka et al, 2013). Much of the literature has focussed on the prevailing attitudes towards people with an intellectual disability at a particular point in time (e.g., Yazbeck et al, 2004; Golding & Rose, 2014; Horner-Johnson et al, 2015); however, there has been little comparative examination of how staff attitudes have changed over time. The current project replicated a study from 1987 and compared how the attitudes of

disability support staff within the same organisation had changed over these past 25 years of major policy and practice reform.

Deinstitutionalisation, Social Inclusion and Community Living

The 1983 report, *Inquiry into Health Services for the Psychiatrically Ill and the Developmentally Disabled* (Richmond, 1983), was a pivotal point in changing attitudes towards people with intellectual disability in Australia. Commonly known as the Richmond Report, it contained recommendations that added to momentum gained through the 1981 International Year of Disabled People to improve both the lives of individuals and the general community's understanding of disability issues (NSW Audit Office, 1997). The Richmond Report was a catalyst in achieving a major change in service delivery for people with disabilities through the subsequent introduction of the Commonwealth Disability Services Act in 1986 (Ashman, 1989).

The 1986 Act facilitated the development of clear policy directions that moved people away from institutionalised care and towards community-integrated support models. Demonstration projects were funded to show that such options were indeed viable within both metropolitan and rural Australia (Ward, 2006). The smaller hostel models that had been established during the 1960s and 70s, many of which still housed up to one hundred individuals, were broken down further into group home settings of just a handful of people, or even single individuals living separately in their own dwelling (Edmundson et al, 2005). Such community-based housing options have been found to result in increased quality of life, adaptive behaviours and decision-making opportunities when compared to the traditional institutional care model (Young, 2006). It is noted that deinstitutionalisation was possibly the biggest reform in government policy for disability service provision since World War II (Mansell & Beadle-Brown, 2010) and that this change is now well developed in Australia and other countries (Epstein-Frisch, 2007).

In New South Wales, the first rural demonstration project took place in 1986 when a group of twenty adult residents within a hostel in the city of Armidale were supported to relocate into individual flats and houses by The Ascent Group, which was then part of the statewide Challenge Foundation and known as Challenge Armidale (Bleechmore, 2010). This project was financed initially by the Government as a demonstration model using a 'block funding' grant and was similar to the process undertaken by the metropolitan-based Hornsby Challenge

(Van Dam & Cameron-McGill, 1995). This model involved the disability organisation receiving one set figure to cover service provision for a nominated group of clients, rather than a specified sum of money per individual. The project was reviewed over the first three years and it was deemed by the funding body to be a desirable model to replicate across the state (Edmundson et al, 2005).

Training of Disability Support Workers

Research has long shown that the actions and attitudes of staff are significantly related to the quality of life of the people with disabilities whom they support (Felce, 1996; Hatton et al, 1999). The widespread movement towards inclusive policies and the implementation of deinstitutionalisation in the past twenty-five years has resulted in a dramatic change in how disability services support people with intellectual disabilities (Bigby, 2006). Associated with this change is a substantial reform in the way disability staff are expected to support their client group (Felce, 2005). As noted by Hatton et al (2002), *“Staff provide the interface through which national, regional and organisational philosophies and policies are translated in practical action directly affecting the quality of life of people with learning disabilities.”* However, the disability sector faces significant challenges relating to how best to train its workforce in order to provide quality support that properly reflects wider changes in societal attitude (National Disability Services, 2009), with these issues potentially magnified in rural locations (Wark et al, 2013). Supporting people with intellectual disabilities, personal care needs and challenging behaviours has been linked with high staff turnover (Felce et al, 1993; Hatton et al, 2002), which can impact on the provision of relevant and timely attitudinal training.

During the early stages of The Ascent Group’s demonstration community accommodation project, a written questionnaire was developed in 1987 and distributed to support staff to assess their general attitudes towards people with an intellectual disability, and their perceptions of working with this cohort. Fifteen individuals were surveyed to gain an understanding of their attitudes, and how they viewed their job and the associated daily interactions with people with intellectual disability. The purpose of the original study was to provide *“insight on the basis of changes in perceptions and attitudes towards people with disabilities by residential care workers who facilitated community integration”* (Bleechmore, 1989). The results of this project were not published externally and were retained by the organisation.

Current Project

As part of a 25-year review of The Ascent Group's accommodation service, the original survey and its results were re-examined in 2013. In order to review whether staff attitudes had changed over this time period, and if any modifications to existing induction attitudinal training processes were required, it was determined that the 1987 questionnaire would be given to interested current employees. The purpose was to examine whether there were any identifiable changes in perceptions and attitudes of the staff over this time of considerable policy and practice change. There was one minor change made to the wording of the survey, with this alteration involving changing the terminology 'disabled person' to 'person with an intellectual disability'. Otherwise, the content of the original survey was unchanged to facilitate direct comparison between two cohorts of employees from the same organisation.

It is hypothesised that, as a consequence of the significant changes in policy and practice over the past 25 years, the 2013 cohort of staff would generally demonstrate more positive and inclusive attitudes towards people with intellectual disabilities when compared to their 1987 peers.

METHOD

Tools

The original 1987 survey tool established simple demographic information for participants including age, gender, education and experience (both work and social) with people with an intellectual disability. The questionnaire was divided into 3 sections and featured 10 open-ended questions. These questions, described in greater detail in the results section, asked participants to reflect upon their personal attitudes towards people with an intellectual disability and to also consider key areas of employment, including their motivation to work in the sector and the adequacy of training. A copy of this questionnaire can be obtained from the corresponding author.

Participants

The 1987 survey was completed by 15 participants who were working in the new accommodation service; however, all had been employed by the organisation in other sections for a minimum of 20 months. This cohort was composed of 12 females and 3 males, with an age range of 20 to 50 years, and a mean age of 28.6

years. 40% (6/15) of the respondents had a university qualification, 6 participants had a trade qualification, while 3 had no formal post-school qualifications.

In 2013, a request for participation was sent via both email and internal mail to all Ascent Group employees in the accommodation service. The survey was distributed to the first 15 staff members who indicated their willingness to complete the questionnaire and who, to mirror the 1987 study, had been employed for at least 20 months. This sample was composed of 10 females and 5 males, with an age range of 19 to 63 years, and a mean age of 41.3 years. 47% of participants had a university qualification, while the remaining 8 all had relevant post-school qualifications in disability work.

The gender imbalance evident in each of the surveys is representative of the demographics of both the disability and also wider community services sectors (Shaddock & Rose, 2009; Martin & Healy, 2010). One key difference between the two cohorts was the difference between their mean ages, with the 1987 group over a decade younger on average (28.6 years versus 41.3 years). There is a lack of reliable data regarding disability worker demographics in the 1980s which makes it impossible to determine if this difference is reflective of the disability sector at that time, or if it is an anomaly. However, it is worth noting that the average age of the 2013 group is similar to that of the national disability sector (Martin & Healy, 2010). None of the participants from the original 1987 project were still employed by the organisation in 2013, and therefore no individual completed both surveys.

Data Collection

Requests for participants in both the 1987 and 2013 surveys were distributed internally through line managers, and participation was entirely voluntary. There was no personally-identifying information collected, with the focus on general demographic data including age, sex, qualifications and years of experience in supporting people with intellectual disability. Participants were given the same information sheet in each project, with the only change being an updating of terminology to 'people with intellectual disability' rather than 'disabled persons'. All 1987 participants were interviewed by one researcher, with a second researcher completing the second round of interviews in 2013. Formal ethics approval for the current project was granted by the University of New England's Human Research Ethics Committee [Approval Number: HE13-290].

Analysis

The original 1987 study used a basic thematic analysis of the interview data, with consistent themes and ideas identified through a process of statement coding. In order to facilitate comparative data, a new thematic analysis was conducted. The work of Charmaz (1990, 2006) was utilised to establish guiding principles for the thematic analysis. This new analysis examined the data gained from the 2013 employees and compared it to the information obtained from the 1987 cohort to see if there was continuity in the thematic areas or if different issues had emerged over the past quarter of a century. The 6-stage framework of Boyatzis (1998) was used to create meaning units and overarching themes. Every response was not categorised, as some issues were not considered to fit into a larger theme. The purpose of the thematic analysis was not to specifically generate quantitative data with respect to presence, frequency or intensity. It was instead designed to assist to identify concepts that recurred, conflicted or emerged through the two surveys conducted approximately 25 years apart.

RESULTS and DISCUSSION

To facilitate continuity and ease of reading, the results and discussion sections have been combined. The findings from the 1987 study are presented first, and then results from the 2013 cohort follow, for each of the 3 sections of the questionnaire. Each section finishes with a discussion of the similarities and differences that have emerged through the thematic analysis. Pseudonyms have been ascribed to each quote throughout the text in order to preserve the anonymity of participants. Exemplar quotations that reflect some of the key themes are provided at the end of each section.

Section A

Section A asked participants to identify why they applied for the job to assist people with intellectual disabilities, and to reflect upon their attitudes towards people with disabilities prior to commencing work.

1987 Survey

The thematic analysis identified 2 distinct reasons that were nominated as the rationale for choosing to work with people with intellectual disabilities. The first answer was that it was purely because *"I needed a job"* (Fred, 36 years) at that

point in time, and individuals had replied to the advertisement in the process of seeking employment in any sector. The second reason identified was that the individual wished to *“have a change in direction”* (Pip, 26 years) and was looking to move into human services. There was no strong evidence that the majority of employees were specifically seeking to work with people with disabilities, with the timing of the advertisement a major factor in their applying for the job. Many of the participants (8/15) identified that they had no experience of working either generally in human services or specifically with people with disabilities.

The analysis indicated that staff members who had no previous direct experience with people with disabilities tended to report that their prior perceptions of people with disabilities were either negative or, at best, neutral. Dot (22 years) commented that people with disabilities *“were different and to keep away”*, while Min (43 years) noted her previous belief that they were *“bottom of the rung in the social order”*. In contrast, individuals who had either worked in the sector before, or who had a family member with a disability, displayed responses that were more positive and nurturing, with Sally (23 years) stating that people with intellectual disabilities were *“gentle, fun and happy”*.

It was noted that it can take a couple of years for new staff to realise that people with disabilities were inherently *“just like everyone else”* (Carla, 32 years), and *“just the same as everyone else”* (Holly, 31years) in the wider community. A general concept of homogeneity was evident among staff with no previous experience of people with disabilities. Many of these staff indicated that they had previously viewed this cohort as being very similar, and did not recognise the considerable differences that are evident in the personalities and characteristics of any group of individuals. This view included both a romanticising aspect, i.e., not realising that people with disabilities could or would intentionally *“lie, cheat, manipulate and deliberately deceive”* (Dit, 20 years), as well as negative stereotyping about *“helplessness”* and how they *“always showed their limitations”* (Greg, 42 years) based on a perceived lack of skills and ability.

1987 Exemplar Quote:

*“They can be nice or total ****s just like everyone else – they are more individual than other groups, for example, teenage girls at least have age, puberty and femaleness in common whereas our group have no common denominator except being retarded and even the degrees of that are different. I was expecting some sort of across the board general thing but there’s not – they’re all different – much more than any other group”* (Jess, 49 years).

2013 Survey

The main pre-employment theme that emerged was that the staff members considered this job would be an appropriate fit for them. There was a strong focus on staff having chosen to work in the disability field, and having very specifically targeted this sector of the human services workforce. No participants indicated that this was solely a *“job of convenience”* (Phil, 43 years); instead, the answers indicated a level of deliberate intent towards securing a job in this area: *“I really wanted to help support people with intellectual disability”* (Stan, 37 years). A second theme was that respondents had often been encouraged to apply for the position, by friends or family members who also worked for a disability organisation. The recommendation to apply was based upon a perception from existing staff members that the person would be *“suited for this type of work”* (Elyssa, 32 years).

The second question asked participants to recall how they viewed people with intellectual disabilities prior to commencing employment in the field. On the basis of age, there was a divergence in the responses to this question. The responses of participants over the age of 50 were generally aligned with negative concepts and were similar to those of the 1987 cohort who had no experience with people with disabilities. Words used to describe their initial beliefs regarding people with intellectual disabilities included *“useless”* (Kate, 53 years), *“silly”* (Roger, 58 years) and *“embarrassing”* (Annie, 63 years). However, the participants below the age of 30, irrespective of their prior home or work experiences with people with disabilities, were far more positive in their pre-employment perceptions, and used phrases such as *“no different to anyone else”* (John, 24 years), *“just someone with additional needs”* (Steph, 19 years), and, *“human beings who can care and love like anyone else”* (Cathy, 20 years). The responses of this 2013 ‘younger group’ were very similar to those of the 1987 participants of any age who had a family member with a disability (e.g., *“there is no real difference as people”* - Holly, 31 years).

2013 Exemplar Quotes:

“I had no experience in helping disabled people - didn’t know what to do or how to talk to them” (Roger, 58 years).

“While I hadn’t worked in this area before, I was used to seeing people with disabilities and thought I would be good at this type of stuff” (Cathy, 20 years).

Discussion on Section A

There were two major areas of difference between the 1987 and 2013 staff cohorts. Firstly, it appears that disability work has gained a level of recognition as a valid career within the wider community. Many of the 1987 participants had ended up employed in the disability sector primarily due to chance, while the 2013 workforce appeared to be far more deliberate in their choice of workplace. This difference is perhaps reflective of the movement away from the medicalised models premised on accredited nursing-care that predominated in the 1970s and 80s, towards the more community-based social-care systems that are evident today (Scullion, 2010).

Secondly, there was a separation within the 2013 staff in terms of pre-existing attitudes towards people with intellectual disability that was not as evident in the 1987 group. The first survey cohort did not show any identifiable differences in relation to education, gender or age with regard to pre-existing attitudes, with a negative viewpoint common among those employees with no previous home or work experience with people with disability. However, the 2013 group did reveal that while older individuals (over 50) still demonstrated this negative mindset prior to commencement, younger employees (under 30) had a generally more positive attitude. It is noted that three of the 2013 younger participants commented that they were *“used to people with disabilities due to school”* (Angela, 19 years), and that this generational shift in staffing attitude seems to coincide with the movement towards inclusive rather than segregated education practices within schools (Forlin, 2006).

It is subsequently speculated that the inclusive education system, whereby both mainstream students and children with disabilities attend the same campus and are often taught in the same classroom, provides a level of familiarity that has not been historically evident. This change removed some of the stigma that appears embedded within the older cohort that may not have had any significant exposure to people with intellectual disabilities. This assumption requires further testing as the small sample size in the current study is a limitation, but it is possibly indicative of a more positive future with subsequent generations of people with disabilities facing progressively less discrimination due to this increased familiarity.

Section B

Section B of the survey asked participants to reflect upon the relevance of the training they had received, to consider what aspects of their job were most

difficult, and to nominate options and suggestions which could either improve or mitigate these more difficult aspects of their job roles.

1987 Survey

In general, the training questions were answered positively. There were no specific areas of weakness identified in the internal training; however, a common theme was that no training could adequately prepare new staff for the reality of working with people with disabilities. It was repeatedly stated that *“learning on the job”* (Carla, 32 years; Dit, 20 years; Bev, 50 years; and Reg, 30 years) was the most effective training mechanism, with 13 of the 15 participants specifically mentioning on-the-job training as being a major influence on their having become competent support workers. Teamwork and support from more experienced staff was also greatly valued, as shown by Sally (23 years): *“I have learned heaps from other staff”*, and Kit (30 years): *“It was very valuable learning from others – particularly other staff”*.

The thematic analysis revealed 4 key themes in relation to dealing with the difficult aspects of their job:

- The environment - *“It was strange working in a house – staff don’t associate that with work because home is a place to relax”* (Pip, 26 years);
- Coping with the behaviour of the residents - *“The first time I had to meet a resident in town she was in a foul temper and nearly pushed me through a jewellery shop window”* (Kate, 26 years);
- Dealing with other staff members - *“You have to be a total bitch for some of the staff to listen”* (Jess, 49 years); and,
- Conflicts in their own personal values and ethics - *“At the time, all staff were affronted with decisions/values at times”* (Kate, 26 years).

Over half (9/15) of the participants noted that specific difficulties occurred in the process of supporting people with disabilities to integrate into the local community, and not knowing how to appropriately support an individual who may be displaying *“difficult behaviours”* (Fred, 36 years) when in public. It was identified that coping with the difficult aspects of work were addressed through mutual support, teamwork, and trial and error, with it being stated that *“you learn how to cope by doing it”* (Holly, 31 years).

1987 Exemplar Quote:

“So much happened and you had to deal with it there and then. I became more confident and believed that I could do it. I had one very difficult resident and that has made me a stronger person – you become sharper and have to be on the ball – you have so many things to do and you have to just get on with it – and I found that a few wrong decisions didn’t really matter” (Bev, 50 years).

2013 Survey

The respondents identified that their induction training had been very beneficial, and had established a good knowledge base for commencing employment. The main theme was that *“doing the job”* (Sarah, 44 years) was the best possible training, and was seen as the best way to prepare staff. Explaining exactly what the job entailed was not seen to be conveyed well (*“I didn’t understand what to do until I started actually doing it”* – Emmanuel, 44 years), and that *“experiencing the reality of personal care and challenging behaviours”* (John, 24 years) was the best method for teaching staff. The imparting of knowledge and support from experienced staff members was generally seen to be very important for newer workers (*“The older workers were great in sharing their knowledge”* – Kate, 53 years). However, there was a contrasting sub-theme that emerged, with 7 of the 15 participants noting the potentially negative influence of some experienced staff members, described as the deleterious impact of *“older burnt out”* (Kathryn, 57 years) employees.

There were 2 main themes regarding the most difficult aspects of their job. Both related to *“challenging behaviours”* (Nicole, 46 years); one, by people with intellectual disabilities, and the other, by fellow staff members. Of these 2 themes, the focus was far more on the difficulties in coping with fellow staff than with people with intellectual disabilities who may display behaviours of concern. Issues included *“other staff not working as a team”* (Kathryn, 46 years) and *“staff failing to support new workers”* (Steph, 19 years). People with intellectual disabilities who displayed behaviours of concern was an issue noted by 3 participants; however, this issue was seen to be at least partially mitigated as it was stated that there was *“good support through the internal behaviour support team”* (Phil, 43 years).

2013 Exemplar Quote:

“I was shocked that some support staff didn’t enjoy their jobs anymore and this impacted on me as a new employee. Their lack of passion meant that they were of no

use as a resource to me, but they frustratingly had so much knowledge to share that would have been fantastic to know” (Sarah, 44 years).

Discussion on Section B

The thematic analysis revealed similar beliefs and concerns for staff in both the 1987 and 2013 groups in relation to both their training and the more difficult aspects of their job. While behaviour of concern is still seen as being difficult for staff, it is recognised that positive changes have occurred in this area. Staff in the 2013 cohort indicated that the underlying support structures with a trained behaviour support team assisted them to more appropriately help individuals who may at times display behaviours of concern. This level of support was not present in the 1987 participant group, and it is therefore not surprising that more participants indicated concerns in this area.

Another distinguishing feature between the 1987 and 2013 groups related to the issue of peer support. Both cohorts identified learning on the job from fellow staff members as being one of the most important aspects of their induction. However, the 2013 participants clearly recognised that there were also negative aspects to having “*longstanding staff members*” (Sarah, 44 years) in the workplace. Specifically, the issues of burn-out and carer fatigue (as noted by Campbell, 2011) and how these problems manifested in poor team dynamics were reported. All staff in 1987 were relatively new to the community-based accommodation model, and as such, a lack of existing negativity is perhaps not surprising. Nonetheless, it reinforces the need to ensure that staff in potentially stressful roles are supported to avoid becoming “*burnt out*” (Kathryn, 57 years).

Section C

The third and final sector of the survey asked participants to nominate what training or support enabled them to feel competent as a direct care worker, and to then consider whether their attitudes towards people with disabilities had changed since commencing employment.

1987 Survey

Thematically, the main influences on competency that were identified were formal training, experience on the job, and development of personal responses. Four key desirable attributes in disability workers were identified. These were organisational and administrative skills, capacity to effectively teach and train,

knowledge of medical issues, and a reflective approach towards work. Participants also spoke of their frustration and disappointment at the gap between the idealism of government policy and the actual ability to meet these goals on a daily basis.

The clearest theme was that exposure to and experience with people with disabilities had the largest impact on attitudes becoming more positive, more individual and less stereotypical. It was noted that many staff struggled with the need to separate personal judgements, based upon their own predominantly religious beliefs, from professional ones. This seemed to be particularly relevant in relation to adults with intellectual disability having a sexual identity and the right to a consenting partner relationship. For example, Min (43 years) stated that individuals with an intellectual disability were “*not viewed as people with a purpose or as sexual beings*” by some other staff. On a positive note, participants reported significant personal growth and development through their exposure to people with disabilities, and an increased level of self-esteem from feeling like they were making a difference in people’s lives. Pip (26 years) noted: “*I gained personally too – and my home life improved*”.

1987 Exemplar Quote

“I realise how much I have learned. This job has made me more assertive but in a different sort of way – in personal life I’m still not – but I am at work. I am surprised at times by how much I know” (Sally, 23 years).

2013 Survey

Participants indicated that their competence as a worker had been greatly facilitated by support from experienced colleagues, guidance and advice from supervisors, and the organisation’s structured training programme. Three key features of a desirable workforce were the use of appropriate augmentative communication systems, collaborative planning and effective advocacy, all to “*support holistic lifestyles and resources to promote improvement*” (Kathryn, 57 years). Eight participants also noted that experience and knowledge of supporting people who were ageing was advantageous.

Comments about changing perceptions towards people with intellectual disability were primarily related to gaining a greater understanding of the “*myriad of health conditions*” (Nicole, 46 years) and the “*complexity and multiple needs of the disability sector*” (Kate, 53 years), while 10 of the 15 participants noted the emergence of ageing issues as a major area of concern. There was only one

response that specifically indicated a change in belief about the capacity of people with intellectual disability: *“They are in fact very clever”* (Michelle, 61 years). There were no responses that implied, either explicitly or implicitly, that people with an intellectual disability needed to be protected and did not have the same rights as any other member of the community in areas such as sexuality.

2013 Exemplar Quote:

“I have learnt collaborative planning, facilitating, advocacy and communications that changed many of my perceptions and attitudes to understand holistic lifestyles and resources to promote improvement. I have gained conceptual knowledge to the complexity and multiple needs of the disability sector” (Kathryn, 57 years).

Discussion on Section C

None of the key attributes for staff, identified in the 1987 survey, were consistently recognised by the 2013 group, although there were isolated references across the participants’ responses. This is in spite of recent research that has shown many of these characteristics are still valued by current workers (Wark et al, 2014a). The key attributes identified by the 2013 cohort all pertained to modern concepts that were not necessarily commonplace in 1987, and as such, there is little surprise that there is no retrospective overlap.

One of most obvious differences between the two cohorts related to the fact that specific knowledge of medical issues was not identified as an area of desired competence in 2013, even though emerging health problems were identified as a major concern. This is possibly indicative of the organisation’s current internal support whereby there is access to a part-time Registered Nurse, as well as a comprehensive medical review system. Specialist medical issues no longer need to be dealt with by individual staff members as they are immediately referred onto more appropriate external professionals.

The relatively recent emergence of issues associated with an ageing cohort was recognised in the 2013 survey. In 1987, all of the residents of the service were under the age of 40. Many of these same individuals were still within the service in 2013, but were therefore a quarter of a century older and some were starting to experience ageing-related issues. The service had also grown over these 25 years, with the addition of a number of newer residents who were presently aged in their 70s. The phenomenon of people ageing with an intellectual disability is now well identified (Bigby, 2008; Coppus, 2013), as are the many health and

wider community-access related disparities that this sub-group will face (Bowers et al, 2014; Wark et al, 2014b). This identification of ageing as a priority area is therefore to be expected.

Limitations

The authors acknowledge that many of the issues raised by the rurally-based staff in this project may be specific to the policy environment within New South Wales. It is recognised that there were a number of methodological limitations, including the lack of matching between the groups and the lack of some demographic area. Similarly, any generalisation of the results to other geographic locations, both within Australia or elsewhere around the world, would be limited by the small sample size. Also, while the comments of all participants were taken at face value, it is possible that some responses of the 2013 cohort may have been moderated to meet perceived 'political correctness' standards. This may have resulted in more extreme viewpoints not being as readily expressed as in 1987.

One of the other issues that is not necessarily a limitation, but certainly requires acknowledgment, is that the base for the current study is a small rural city with a population of around 25,000 people. Within smaller communities such as this, people with disabilities may be far more 'visually obvious' than in a metropolitan location, and therefore individuals may hold prior positive or negative expectations of people with disabilities, not similarly evident within larger areas where this cohort may still be largely 'invisible'.

CONCLUSION

This project replicated a questionnaire from 1987 to examine whether there have been changes in the attitudes of workers who support people with an intellectual disability. It would appear that the past 25 years have seen positive movement in both acceptance and expectations by support staff, and individuals with a disability are now seen in a realistic but more positive light. One of the best demonstrations of this change can be seen in the greater understanding and acceptance of people's right to a sexual identity. Concerns about adults with an intellectual disability entering a sexual relationship was not mentioned as an issue even once by the 2013 participants, but it was a very strong theme in 1987 and was clearly evident to the staff of the time.

It is positive to reflect on the changing perceptions of working in the disability sector as there has been a shift from taking a job merely as a matter of convenience,

to viewing disability support work as a legitimate and planned career choice. The training provided to staff has changed significantly over the past 25 years; however, on-the-job exposure to people with intellectual disability, combined with support from peers, is still perceived as the key element in developing appropriate attitudes among the workforce. At the same time, this approach does need to be considered carefully, as it was noted that older staff could also present a very negative perspective.

REFERENCES

- Ageing Disability and Home Care (2013). Personal centred approaches - living life my way. Available from: www.adhc.nsw.gov.au/pca. [Accessed on 15 April 2013].
- Amado AN, Stancliffe RJ, McCarron M, McCallion P (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*; 51(5): 360-375. <http://dx.doi.org/10.1352/1934-9556-51.5.360> PMID:24303823.
- Ashman A (1989). Change and disability services in Australia: A ten year retrospective. *Australian and New Zealand Journal of Developmental Disabilities*; 15(2): 73-80.
- Bigby C (2006). Shifting models of welfare: Issues in relocation from an institution and the organisation of community living. *Journal of Policy and Practice in Intellectual Disabilities*; 3(3): 147-154. <http://dx.doi.org/10.1111/j.1741-1130.2006.00074.x>
- Bigby C (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual and Developmental Disability*; 33(1): 76-86. <http://dx.doi.org/10.1080/13668250701852433> PMID:18300170.
- Bleechmore K (1989). Learning to be a residential care worker. University of New England, Armidale: 4. Unpublished Master's Thesis.
- Bleechmore K (2010). A history of challenges and achievements. Armidale: The Ascent Group.
- Bowers B, Webber R, Bigby C (2014). Health issues of older people with intellectual disability in group homes. *Journal of Intellectual and Developmental Disability*; 39(3): 261-269. <http://dx.doi.org/10.3109/13668250.2014.936083>. PMID:25750581.
- Campbell AK (2011). Nurses' experiences of working with adults who have an intellectual disability and challenging behaviour. *The British Journal of Development Disabilities*; 57(112): 41-51. <http://dx.doi.org/10.1179/096979511798967179>
- Commonwealth of Australia (2009). Shut out: The experience of people with disabilities and their families in Australia. Available from: https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf [Accessed on 15 May 2015]
- Coppus AM (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews*; 18: 6-16. <http://dx.doi.org/10.1002/ddrr.1123> PMID:23949824

- Corr McEvoy S, Keenan E (2014). Attitudes towards people with disabilities – what do people with intellectual disabilities have to say? *British Journal of Learning Disabilities*; 42(3): 221-227. <http://dx.doi.org/10.1111/bld.12032>
- Cummins RA, Lau ALD (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*; 16(2): 145-157. <http://dx.doi.org/10.1046/j.1468-3148.2003.00157.x>
- Edmundson S, Watson M, Kennedy M, Sevil A, Bleachmore K, Jordan M, Mead K (2005). *Keeping the doors open : A history of challenges and achievements* (2nd ed.). Armidale, NSW.: Challenge Armidale Ltd.
- Epstein-Frisch B (2007). Deinstitutionalisation: A review of literature. *Interaction*; 21(1): 7-16.
- Felce D (1996). Quality of support for ordinary living. In J Mansell & Ericsson K (Ed.), *Deinstitutionalisation and community living: Intellectual disability services in Britain, Scandinavia and the USA*. London: Chapman and Hall, 117-133. http://dx.doi.org/10.1007/978-1-4899-4517-4_8
- Felce D (2005). Support in the community: Staffing and staff support in relation to service user needs. *Intellectual Disability Australasia*; 26(2): 10-13.
- Felce D, Lowe K, Bestwick J (1993). Staff turnover in ordinary housing services for people with severe or profound mental handicaps. *Journal of Intellectual Disability Research*; 37(2): 143-152. <http://dx.doi.org/10.1111/j.1365-2788.1993.tb00581.x> PMID:8481612.
- Forlin C (2006). Inclusive education in Australia ten years after Salamanca. *European Journal of Psychology of Education*; 21(3): 265-277. <http://dx.doi.org/10.1007/BF03173415>
- Golding NS, Rose J (2014). Exploring the attitudes and knowledge of support workers towards individuals with intellectual disabilities. *Journal of Intellectual Disabilities*. <http://dx.doi.org/10.1177/1744629514563777> PMID:25542699.
- Hatton C, Emerson E, Rivers M, Mason L, Swarbrick R, Kiernan C, Reeves D, Alborz A (1999). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research*; 43(4): 206-218. <http://dx.doi.org/10.1046/j.1365-2788.1999.00208.x> <http://dx.doi.org/10.1046/j.1365-2788.1999.00190.x> PMID:10392607
- Hatton C, Rivers M, Mason H, Mason L, Kiernan C, Emerson E, Alborz A, Reeves D (2002). *Staff in services for people with learning disabilities*. Manchester: UK: University of Manchester, 1.
- Horner-Johnson W, Keys CB, Henry D, Yamaki K, Watanabe K, Oi F, Fujimura I, Graham BC, Shimada H (2015). Staff attitudes towards people with intellectual disabilities in Japan and the United States. *Journal of Intellectual Disability Research*; 12 January 2015, 0964-2633. <http://dx.doi.org/10.1111/jir.12179>
- Mansell J, Beadle-Brown J (2010). Deinstitutionalisation and community living: Position statement of the comparative policy and practice special interest research group of the international association for the scientific study of intellectual disabilities. *Journal of Intellectual Disability Research*; 52(2): 104-112. <http://dx.doi.org/10.1111/j.1365-2788.2009.01239.x> PMID:20070475

Martin B, Healy J (2010). Who works in community services? A profile of Australian workforces in child protection, juvenile justice, disability services and general community services. Adelaide: National Institute of Labour Studies, Flinders University.

Mental Health Council of Australia (2009). Home truths: Mental health, housing and homelessness in Australia. Available from: https://mhaustralia.org/sites/default/files/imported/component/rsfiles/publications/MHCA_Home_Truths_Layout_FINAL.pdf [Accessed on 15 May 2015]

National Disability Services (2009). Disability Safe. Available from: <http://www.disabilitysafe.org.au/about-us>. [Accessed on 15 May 2015]

NSW Audit Office (1997). Large residential centres for people with a disability in NSW. Available from: <http://www.audit.nsw.gov.au/publications/reports/performance/1997/rescar/disabili.htm> [Accessed on 1 May 2009]

Patka M, Keys CB, Henry DB, McDonald KE (2013). Attitudes of Pakistani community members and staff toward people with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*; 118(1): 32-43. <http://dx.doi.org/10.1352/1944-7558-118.1.32> PMID:23301901

Richmond DT (1983). Inquiry into health services for the psychiatrically ill and developmentally disabled (NSW). Sydney: Department of Health (NSW).

Robertson J, Hatton C, Felce D, Meek A, Carr D, Knapp M, Hallam A, Emerson E, Pinkey L, Caesar E, Lowe K (2005). Staff stress and morale in community based settings for people with intellectual disabilities and challenging behaviour: A brief report. *Journal of Applied Research in Intellectual Disabilities*; 18(3): 271-277. <http://dx.doi.org/10.1111/j.1468-3148.2005.00233.x>

Scullion PA (2010). Models of disability: their influence in nursing and potential role in challenging discrimination. *Journal of Advanced Nursing*; 66(3): 697-707. <http://dx.doi.org/10.1111/j.1365-2648.2009.05211.x> PMID:20423405

Shaddock A, Rose V (2009). National Disability Services: Direct support worker survey report. Brisbane: National Disability Services Queensland.

United Nations General Assembly (2006). Convention on the rights of persons with disabilities. Available from: <http://www.un.org/disabilities/convention/conventionfull.shtml>. [Accessed on 11 June 2009]

Van Dam T, Cameron-McGill F (1995). Beyond group homes. *Interaction*; 8(3): 7-13.

Ward M (2006). The vision of the Disability Service Act 1986: A never-ending struggle. *Journal of Intellectual & Developmental Disability*; 31(4): 253-254. <http://dx.doi.org/10.1080/13668250601006940> PMID:17178540.

Wark S, Hussain R, Edwards H (2013). Rural and remote area service provision for people ageing with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*; 10(1): 62-70. <http://dx.doi.org/10.1111/jppi.12017>

Wark S, Hussain R, Edwards H (2014a). Impediments to community-based care for people ageing with intellectual disability in rural New South Wales. *Health & Social Care in the Community*; 22(6): 623-633. <http://dx.doi.org/10.1111/hsc.12130> PMID:25252081

Wark S, Hussain R, Edwards H (2014b). The training needs of staff supporting individuals ageing with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*; 27(3): 273-288. <http://dx.doi.org/10.1111/jar.12087> PMID:24436133.

Yazbeck M, McVilly K, Parmenter TR (2004). Attitudes toward people with intellectual disabilities: An Australian perspective. *Journal of Disability Policy Studies*; 15(2): 97-111. <http://dx.doi.org/10.1177/10442073040150020401>

Young L (2006). Community and cluster centre residential services for adults with intellectual disability: Long term results from an Australian-matched sample. *Journal of Intellectual Disability Research*; 50(6): 419-431. <http://dx.doi.org/10.1111/j.1365-2788.2006.00788.x> PMID:16672036.