Deinstitutionalisation: The educative implications

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Introduction

The purpose of this paper was to examine the educational implications of a study that focused upon community integration experienced by a group of 54 people with intellectual disability that moved from a long stay psychiatric hospital to live in community based settings in the North Island of New Zealand in 1988-1990. The educational implications will drawn for training of human service workers.

The study

In 1988 the New Zealand Society for the Intellectually Handicapped (now know as IHC, Inc.) the largest voluntary agency providing both residential and vocational services for people with intellectual disability in New Zealand, signed a contract with the Auckland Hospital Board to move 61 people with intellectual disability into IHC group homes throughout the North Island (Obrien & Parkrs, 1990). Eight years on from the date of the move of people into the community the Health Research Council of New Zealand funded a study to:

1. collect demographic information on the residential and work history of the people throughout the eight years since leaving the hospital

2. explore the perceptions of the people who had been deinstitutionalized, their family members, and caregivers about the effects of the move into the community

3. examine the extent to which the people had become involved with the community.

Design of the study

In order to meet the above aims the study combined both quantitative and qualitative methods across a cluster of three groups of participants: the person with an intellectual disability; an individual staff member with a long history of association with the person within the community service, and a family member and or advocate. A semi-structured interview survey was individually designed for the three groups of participants which covered the areas of transition into the community; health status; residential living; day and work activities; community integration; outcomes for the focus person and the future. The interview schedule was individually administered taking between one to one and a half hours to complete. The responses were content and, where appropriate, statistically analysed. A description of the interview schedules as well as the interviewing, reliability and analysis techniques can be found in O'Brien, Thesing and Capie, 1999).

In order to access a richer descriptive analysis of the community living experience of the people who had lived in the hospital a series of case studies were undertaken in an attempt

"to gain more information about the structure, process and complexity" of the experience. (Sarantokos, 1993, p.260). Each of the case studies was developed by a comparative analysis of interview data of the person, their associated staff member and their family member or advocate. The same interview schedules that were administered for the survey were used but the analysis combined a comparative thematic approach across the three interviews to construct how the experience of community living had been for the person.

Focus people of the study who had lived in Kingseat Hospital

The investigators worked with the management of IHC, Inc. to locate the addresses of people who had left Kingseat Psychiatric Hospital to live in IHC services as part of the joint Auckland Health Board (now restructured as a Crown Health Enterprise) and the IHC initiative in 1988. Of the 61 people who were funded under the original deinstitutionalisation initiative six people (five males and one female) were deceased by the commencement of the research project. A seventh person was unable to be located. The overall number of people who became the focus of the study was therefore 54 with 31 being female and 23 male. Their overall age range was from 36 to 65 years with the mean age of 48. In terms of the length of stay of the focus people within Kingseat hospital it ranged from two to 42 years with a mean number of 22 years.

On leaving Kingseat the people were relocated throughout the North Island within IHC branch geographic areas. At the time of the present study 34 people lived in greater Auckland and 20 in provincial areas. Two of the Auckland based people no longer lived in IHC services but were gaining support from another residential and work support agency for people with intellectual disability. Of the 54 people that the study concentrated upon 41 were considered to have high support needs, 3 medium and 10 low. Needs ratings were determined through a support needs check list that the IHC used at the time of the Kingseat Project to apply to the government for funding (IHC, n.d.).

Interview participants

Fifty four staff each considered to be the longest serving staff member associated with the focus person agreed to be interviewed. Two staff were interviewed for two of the 54 people and one staff member acted for three of the focus people. In all 54 staff interviews were conducted.

Twenty two family members agreed to be interviewed and nine of the focus people participated in the process. Nine of the 22 family members were mothers, three fathers, three brothers and three sisters and for one person an advocate participated.

The criterion for the focus people to participate in the interviews was that they could hold a conversation. This was established through their support needs rating. For 10 of the focus people they had a rating of low or medium which indicated that they had conversational skills. For 44 of the focus people they had a high support needs rating which indicated that they were non-verbal. At the time of the study nine of the other 10 focus people who were able to converse agreed to be interviewed. The tenth person was uable to be interviewed owing to illness.

Case study participants

Participants

As a means of gaining a deeper insight into the experience of the people who had lived in Kingseat, it was decided to seek the permission of the nine focus people who were able to be interviewed to tape record their responses and those of their respective staff and family members. Within this interview situation the person was asked if they would like to have a support person present. Three of the people chose a staff member to support them. For seven of the case studies the material analysed came from a full cluster of three participants and for two it consisted of only the focus person and the staff member as family chose not to participate in the overall study.

Findings

As a means of gaining insight into how people have experienced the community two aspects of O'Brien & Lyle's (1991) framework for community integration specifically the accomplishments of community presence and community participation will be focused upon. O'Brien & Lyle see these accomplishments along with those of respect, choice and competence as underpinning the development of effective community living. Their framework has been used extensively in community based service planning and delivery for people who were once institutionalised (Astbury, 1997; Cambridge, 1994; Hayes, Knapp, Gould & Feno; Cocks, 1997; Emerson & Hatton, 1996,a,b; Knapp et al., 1992).

O'Brien and Lyle (1997) defined community presence as "sharing of the ordinary places that define community" (p.177). The findings of this study gave insight into how the 54 people experienced the community as a "place to live"; a "place to work" and a "place to network". Similarly in relation to community participation which O'Brien and Lyle have defined as "the experience of being part of a growing network of personal relationships that included close friends"(p.178) the study gave insights into the extent of the focus person's social networks. According to Walker (1995) if community was to be experienced it was "not just about place but about social and emotional attachments and connections to and within a place" (p. 190). Findings as they relate to community presence and participation will now be presented.

Community as a place to live

When the type of accommodation was compared across the person's first and last placement the majority of people lived in group home settings (first: 48, 89 %; present: 51, 94%). In terms of numbers of people that lived in these settings at the time of interview one person lived alone; three people lived in settings with two other flatmates; two with three other people; eight with four others; 27 with five others and 10 with six other flatmates. For other types of accommodation that people lived in see Table 1.

Table 1

Type of setting compared across the first and present placement (N=54)

Setting	First		Present	
	N	%	N	%

Hostel 6 11 0 0

Group home 48 89 51 94

Attached flat - - 2 4

Board - - 1 2

Moves within accommodation settings

Over the eight years that had elapsed between the focus people leaving the hospital and the start of the follow up study the majority of the 54 people according to staff had moved twice(26, 51%) and three times for 14 (27%) of the focus people. Only one person(2%) had stayed in the same location with six (12%) people moving four times and four had had five moves (6%).

Community as a place to work

A range of day options that the focus people were attending at the time of the interview were identified by the staff. Thirty eight (70%) of the people attended day programmes while 12 (22%) were engaged in work type activities. The day programmes were equally divided between those activities organised within the person's home (19, 35%) and out of the home at another house or centre based venue (19, 35%), whereas for work the major areas were workshop attendance (5, 9%) and work groups in the community such as, a gardening group (6, 11%). Only one (2%) person was in supported employment (see Table 2) while for another person the support was individualised within an activity programme that was both home and community based.

Table 2

Day placement type indicated by staff (N=54)

Type N %

In home 19 35

Out of the house 19 35

Work groups 6 11

Workshop 5 9

Retirement programmes 3 6

Supported employment 1 2

One to one support 1 2

Moves within day placements

Staff were asked to comment on the number of day placement moves that the focus people had made since leaving Kingseat. Due to being only more recently associated with the focus person ,only 48 of the staff were able to comment. For families only 6 of the 22 family members believed that they had a reliable history which was considered too small a sample to report, whereas all nine of the focus people commented (see Table 3.).

According to staff, 20 (42%) of the focus people have remained in the same day placement, with 17 (35%) changing once. In comparison, 6 (66%) of the focus people indicated that they had moved once which may reflect a greater ability to initiate change. (see Table 3). More than one change in day placement was identified by a minority of both groups. (Staff:11, 23%; Person:1, 11%).

Table 3

No of moves within day placement programmes

Moves	Staff (N=48)		Person(N=9)	
	N	%	N	%
Stayed in same placement	20	42	2	22
Changed once	17	35	6	66
Changed more than once	11	23	1	11
Don't know	6	13	-	-

Community as a place to networkPlaces visited

As a means of examining how the participants viewed the integration of people into the community the staff, family and person were invited to describe the places visited while the interviewer drew a community map of these locations illustrating their geographic connection. For both the staff and the person, the mapping began around the community home, while for the family member it started at their home if the person visited. In the course of mapping the places that the person went to, the interviewer would try and ascertain the type of activity, how often the person went and who with, as well as if the activity was in an integrated or segregated setting. Table 4 outlines the experiences indicated by staff, the family and the focus person.

As can be seen from Table 4 the community experiences have been broken into the sub categories of: shopping; sports; culture; eating out; visiting; travel and rides and holidays; clubs and crafts; and nature outings. Across the three groups there was an agreement of over 60% for the following experiences: van rides (Staff 49, 91%; Family 15, 68%; Person 8, 89%); shopping as a form of entertainment (Staff 47, 87%; Family 15, 68%; Person 9,

100%); snacks & coffee (Staff 47, 87%; Family 13, 59%; Person 9, 100%); going to the beach (Staff 43, 80%; Family 14, 63%; Person 8, 89%); and walking (Staff 40, 74%; Family 13, 59%; Person 9, 100%). Visiting for the staff and the person were also high, with visiting people at other agency homes being 36(67%) for staff and 7(78%) for the person. Similarly, visiting other friends and family outside of the agency settings was the same frequency for the staff 67% (54) and 100% (9) for the person. These two groups also placed a high frequency on going for trips to the gardens, bush, parks and zoo (Staff 44, 82%; Person 8, 89%).

Table 4

Description of community experiences for the focus people.

Experiences Staff (N=54)Family(N=22)Person(N=9)

Shopping

N % N % N %

Shopping/provisions 30**a**. 56 11**b**. 50 9**c**. 100

Shop/clothes 25 46 11 50 9 100

Shop/entertainment 47 87 15 68 9 100

*Shop/beauty 32 59 3 14 6 67

Sports

*Swimming 40 74 9 41 4 44

*Gym 32 59 2 9 1 11

*Walking 40 74 13 59 9 100

Bikeride 1 2 3 14 2 22

Culture

Movies 18 33 11 50 8 89

Library/music 19 35 2 9 6 67

*Music/drama 44 82 10 45 6 67

*Concerts/theatre 17 32 5 23 4 44

Church 14 26 4 18 4 44

*Marae visits 5 9 - - - -

Eating out

Snacks/coffee 47 87 13 59 9 100

Restaurants 22 41 5 23 7 78

Pubs/RSA 9 17 3 14 1 11

Visiting

*Visiting agency homes 36 67 10 45 7 78

Visiting 36 67 12 55 9 100

Travel, rides & holidays

Bus/train 25 46 4 18 4 44

Plane 3 6 3 14 2 22

Ferry 14 26 - - 2 22

Van rides 49 91 15 68 8 89

*Holiday/NZ 27 50 1 5 8 89

Holiday/International 1 2 2 9 2 22

Clubs & craft activities

*Clubs 22 41 4 18 4 44

*Pottery/craft 22 41 4 18 7 78

Nature outings

Gardens, bush, zoo, park 44 82 10 45 8 89

Beach 43 80 14 64 8 89

* = activities that were done in both segregated, integrated or combined settings.

Note:

a. Thirty (56%) of the people with disability were involved in shopping for provisions according to staff.

b. Eleven (50%) of the people with disability were involved in shopping for provisions according to the family.

c. Nine (100%) of the people with disability identified their own involvement in shopping for provisions.

Neighbour contact

As part of the mapping process, staff and the person were asked to indicate how much contact the person had with the neighbours. As can be seen from Table 5, for the nine people interviewed, only one indicated that they had no neighbour contact, whereas for the staff they indicated that 22 (41%) of the focus people had no contact. Reciprocal visits were limited being indicated by 12 (22%) of staff and 3 (33%) of the people interviewed .

Table 5

Neighbour contact

Staff (N=54) Person (N=9)

Type of contact N % N %

No contact 22 41 1 11

Reciprocal visits 12 22 3 33

Friendly greetings 10 19 1 11

Emergency contact 7 13 2 22

Passive withdrawal from contact 1 2 - -

Who the focus people shared ordinary places with in the community

Both the staff and the person in the course of mapping community activities were asked to indicate who the experience was undertaken with. Table 6 indicates the perception from 100% of both the staff (54) and the persons interviewed (9) that the people experienced the community most frequently as a group of disabled people with staff. The second highest way in which activities were accessed was with one to one staff (Staff 52, 96%; Person 9, 100%). In terms of accessing the community with a group of disabled (Staff 10, 19%; person 5, 56%) and/or non-disabled friends (Staff 14, 26%; Person 8, 89%), the percentage ratings of the person were always much higher than that of the staff. This may reflect that the nine people who had lived in the hospital, who were able to be interviewed, were all people with low support needs, and had an increased likelihood to develop a network of friends whereas the staff perception related to 54 people with a greater range of support needs.

Table 5

Accessing the community

Staff (N=54) Person(N=9)

Ways N % N %

With a group of disabled people

and staff 54 100 9 100

With one to one staff 52 96 9 100

With two to one staff 18 33 8 89

With a group of non-disabled friends 14 26 8 89

Alone 14 26 5 56

One to one disabled friends 13 24 8 89

Within a group of disabled people 10 19 5 56

One to one with a disabled friend 8 15 5 56

Mix of disabled and non-disabled friends 7 13 4 44

Friendship and support networks

Close friendships were identified by asking the staff, family member and the focus person to indicate who the people were in the focus persons' close circle of friendship and support (Forest & Pearpoint, 1997). In coding the types of friends and supporters it was not the number that was coded but the number of people that had one or more supporters in that category, for example, where sister is mentioned it is not the overall number of sisters that the participants had but the number of participants who had one or more supporters in the sister category. In relation to close friends in the life of the focus person as distinct from intimates also reported in the larger study (O'Brien et al, 1999) (see Table 7) the highest categories for staff were staff in the person's house (18, 33%) followed by clients that lived and were supported in other IHC services (20, 37%) as well as the person's own home (16,30%). For the family, it was clients that lived in the person's home (5, 23%) as well as siblings (sister 4, 18% and brother 3, 14%). The focus person identified clients supported by the IHC (6, 67%) outside of the person’s residential address as well as clients in the same home (5, 55%).

On average when the overall number of supporters in each category was considered, staff said that the focus person had 5.5 close friends whereas the family reported the average as 2.0 close friends and for the focus person 6.7.

Table 7

Close friends categories

Categories Staff (N-54) Family (N=22) Person (N=9)

N % N % N %

Mother 4 7 1 5 0 0

Father 1 2 0 0 1 11

Brother 8 15 3 14 3 33

Sister 9 17 4 18 3 33

Cousin 1 2 1 5 1 11

Grandparents 0 0 0 0 0 0

Uncles & aunts 1 2 0 0 0 0

Nieces & nephews 3 6 2 9 1 11

Advocate 0 0 0 0 1 11

Friend 11 20 0 0 3 33

Staff in the home 18 33 0 0 1 11

Client in the home 16 30 5 23 5 55

Staff other 12 22 1 5 0 0

Client other 20 37 2 9 6 67

Close boy/girlfriend 0 0 0 0 0 0

Partner 0 0 0 0 0 0

Ex staff 5 9 2 9 0 0

Typology of community integration

In reflecting upon how people experienced the community it was apparent from the data presented in Tables 1 and 4 that the focus people were involved both in living in ordinary settings such as houses in suburban streets as well as the sharing of ordinary places. The data, however, which indicated ordinary places were shared with (see Table 6) combined with the extent of friendship (see Table 67, did not as strongly support O'Brien' and Lyle's (1997) concept of community participation. In the main, people did not appear to be developing a growing network of close friends and acquaintances upon which personal relationships could be built. This in turn led the investigators to reflect upon and discuss the level of networking found in the schedules, their own experience of interviewing across the three groups of participants as well as anecdotal evidence collected throughout their time on the project. From these discussions it appeared that there were three ways in which people gained a presence and participated in the community.

The first way was one where people frequently visited ordinary places in the community with other disabled people being supervised and supported by staff. They returned to the group home setting having made few, if any, transactions with the members of the public for goods and services or few, if any, social connections with members of the community that could lead to the development of personal relationships. These people were seen as ***venturing*** into the community.

The second way was where people frequently visited ordinary places with other disabled people being supervised and supported by staff, but were beginning to make connections with the public through being prompted by staff to acquire goods and services. Similarly people were encouraged by staff and chose to visit places, join groups, clubs and associations where there was opportunity to make social connections. Networking was developing through their own and staff re-instigation of the people revisiting the same ordinary places. These people were seen as ***participating*** in the community.

The third way was where people frequently visited ordinary places with a range of both disabled and non-disabled people supervised and supported by staff where and if required. Transactions, often with the same members of the public for goods and services were routine and purposeful as was membership of clubs and associations and sharing time in places where social links were retained and built up further. These people were seen as ***networking*** in the community.

Using the former three descriptions 54 of the staff schedules and the answers that related to community activities; changes in the life of the person; residential placements; day placements, family interaction and pleasure and satisfaction in the life of the person as well as circles of support were read and then the focus person was allocated into one of the following three categories: people who ventured into the community (35, 65%); people who were networked into the community (13, 24%); and people who participated in the community(6, 11%) (see Table 8).

Table 8

Types of participation in the community by focus people (N=54)

Types	N	%
Venturers	35	65
Networkers	13	24
Participants	6	11

Discussion

In overviewing the findings there is a sense in which people are in the community but not necessarily part of it. They continued after eight years of community living to be still living in the same type of accommodation, that is the group home model. Although such housing is found in ordinary places such as suburban streets and typically reflects the layout of large family homes it suggests that the people have not been extended in their experience of options that comprise residential living. This is not only a criticism of the lack of opportunity evidenced within this study but internationally the group home model continues to be the most popular for people who come into the community after years of institutional care (Conroy & Bradley, 1985; Knapp, et al 1992; St. Nicholas Deinstitutionalisation Project Evaluation Committee, 1988). Similarly the lack of accommodation options identified in the study was reflected in that the majority of people had been maintained within day programmes over the past eight years that were either home or centre based. The dependence upon group based activities as opposed to individualised activities and work options is not uncommon in other deinstitutionlisation studies (Stancliffe & Hayden, 1999). .

In that the majority of peoples' living situations and day activites have not been expanded into less restrictive models a note of caution is sounded. Safeguards need to be put into place to ensure that the hope for the community living movement does not descend into the same demise as that of institutional care where the needs of the individual became subsumed by those of the group and the institution. The parental hopes for training and rehabilitation as expressed by several families in the case studies associated with the study were not forthcoming instead people left the hospital, according to the images of staff, as a vulnerable group of people with lost potential arising from years of institutionalisation. If

safeguards (O'Brien, 1997) are not put into place community living runs the risk of becoming the new form of institutionalisation where the individual needs of people to grow and develop are replaced by people fittiing into the established structures of human service settings, such as, group home and day programme settings.

In order to safeguard the community living movement from becoming the new form of institutionalisation the training of human service workers needs to capture the need for supported living which according to Taylor (1991)

> is deceptively simple ..... find a home, whether a house, apartment or other dwelling, and build in the staff supports necessary for the person to live successfully in the community. Inherent in the concept is flexibility. Some people may need only part-time supports or merely someone to drop by to make sure they are okay. Others with severe disabilities and challenging needs may require full-time staff support. There isn't anything in the concept that precludes small groups of people from living together ... this, however, should be because they choose to live together and are compatible.
>
> (p.108)

Although the concept of supported living may be presented as a theoretical base within tertiary based programmes a limitation within New Zealand is availability of sites for practicuum opportunities that promote the concept. There appears to be resistance on the part of human services to embrace the concept of supported living which in turn may reflect that the government funding agencies do not see the concept as economically viable. Whose role is it then to educate funding agencies as to the viability of the model? Parental leadership in both Australia and the United States (Astbury, 1997, O'Brien, 1998) has shown that people with high support needs, given the right level of individualised fundng, can live in a place of their own with the required supports being funded to suit the person's preferences as different to the person having to adapt their needs to what is already offered within the structure of a human service agency.

Another concern associated with tertiary training is that in New Zealand human service agencies are becoming accredited as training providers with work place assessment which means that students will only be exposed to the models working within the specific agency. How then do human service workers gain exposure to what may be pockets of innovation outside their own service agency. This is an issue that needs to be considered by the New Zealand Qualifications Authority (NZQA) that accredits human services to become training providers. It also has further implications for the course content of nationally approved Certificates and Diplomas which the Community Services Industrial Training Organisation (ITO) approves. In order to safeguard that its membership which is constituted only by human service personnel does not reinforce the status quo there needs to be a balanced number of members representing a wider viewpoint

From the findings of the study staff training appears to have succeeded in imparting to staff an understanding of what constitutued community presence. People had and continued to experience a full range of activities that were community based, however the challenge for training is to assist staff to understand that moving around the community as a group does not enhance participation and networking. Where people were networked into the community they had usually been assisted to return to the same settings and experience the same routines on a regular basis. Such routines were usually facilitated through one to one or one to two staffing support. For the group of people who had been identified as networkers they routinely visited places such as the local pub, bowling clubs, particular

shops, the same restaurants, and coffee houses. To suggest that staff training whether it be either in tertiary settings or within house would not emphasise the need for one to one support would be naive,so the need for education goes beyond that of staff to management and funding agencies to make provision for one to one support. Without the staffing resource the extent to which staff can support people on a one to one basis is limited. The concept of routine however, that is, returning to the same places, meeting the same people, becoming known by people who notice if the person is not there, could be strengthened within staff training programmes.

As a means of bridging the gap between the need for one to one support and its accessibility within the resources available to human service agencies, management could enter into partnership with tertiary providers as already referred to with respect to the concept of the focus people acting as associates. Put in a more traditional framework within the training course, students could set an ongoing practicum in which over, for example, a one year Diploma course, they were required to implement a programme to assist the person to become networked through the development of significant relationships and connections. with other people in the community. Often a criticism of practicums is that students will begin a project with a person with a disability and then disconnect with the person when the academic requirements are met. If the aim of the suggested practicum was to network the person through the development of significant relationships then this concern would be lessened.

From the study it has been learned that for close friends the focus people were dependent upon staff and other clients. As a means of broadening these categories to include more natural supports, such as extended family members and neighbours, the setting up of specific programmes to strengthen these relationships is in keeping with the work of Felce (1999). He has emphasised that if people are going to successfully network in the community then it may involve staff in moving "away from the traditional laissez faire attitude to what activities residents may or may not do and creating an alternative which gives positive motivation to achieving that level of functional activity which everyone else needs to achieve to live an ordinary life" (Felce, 1996, p.133). What therefore are the functional activities that underpin the ability to make community connections that will led to networking. If the same question was asked in relation to daily living skills staff would easily give evidence of how they have taught the person to dress, to make a cup of tea, and to do bedmaking. In relation to becoming socially connected however, the question may be asked is enough emphasis in training placed upon how to teach skills .in developing reciprocal social relationships particulary when the people attempting to make connections are non-verbal.

From the research findings it appears that much energy is being expended in taking groups of people into the community; facilitating discretionary activities within the group home and planning activities within day programmes. but there was little evidence of focused programming to assist people to develop significant connections and friendships. Instead as previously indicated the majority of people were venturing around the community rather than participating in it. Lack of such programming may be related to a belief that if people are simply exposed to a great range of community settings connections will emerge. This has not happened for many of the focus people suggesting, that without targetted programming visiting places does not in and of itself led to the making of connections and the building up of networks.

If connections are to be strengthened with people already known such as family and neighbours, as well as new ones formed the role that human service worker needs to move into is that of social connection as opposed to what may have previously been seen as role that focused on an emphasis in social, self help and daily living skills training. In effect these

are the areas that have been reported in the larger study (O'Brien, Thesing & Capie, 1999) as having made the difference in terms of change for the person since living in the community. Being more connected with the community was not identified as a change for the person.

If the role of the human service worker was seen as a social connector, course content in human service training would need to target the much needed competencies that will enable staff to lead people beyond venturing around the perimeters of the community to becoming fully connected with it. The human service worker will not be able to work in isolation from the local community. Their training requires a greater awareness of what constitutes participation in the community and how to access community resources to assist people with disability to share their gifts and capacities with its members (Kretzmann& Knight, 1993). The concept of community participation requires an understanding that it is more than just transporting people to places and assumes a knowledge of how social development proceeds, with issues relating to how connections are made and friendships grow. At the same time it dictates choices with regard to which community settings will have the greatest potential for transaction with people. Some settings invite connections, such as, shopping venues, sports, cafes, whilst parks and beach venues do not. This is not to suggest that the latter should be avoided! At the same time staff need to recognise cues where attraction or connections are still fragile and need support to develop and survive.

In reflecting upon the findings of this study if staff are to be more successful at socially connecting people to their community, training needs to ensure that emphasis is placed upon:

recognising that the person who has been institutionalised has social needs beyond the membership of the group that they live and work with

strengthening connections that the person leaves the institution with, such as, family as well as friends made within the institution

recognising that often where institutionalisation has been over decades family members are aging and will need staff support to keep the connect going through such avenues as: receiving notes and letters from their sons and daughters as well as regular phone calls and having scheduled visits by their family member to the family home with support of staff

specifically encouraging families to informally come to their family member's residence apart from lifestyle planning meetings even to the point of participating in the domesticity of the house and in particular the decor and presentation of their family member's room.

teaching social skills that will assist people to connect such as greetings, making eye contact, turn taking in conversation, use of communication boards or note books and computer assisted communication devices

assessing the social geography of the community to find places where individual or small groups of people can return to enjoy the social scene such as a family restaurant, pub, music clubs and dance groups.

being innovative in terms of using public transport instead of residential vans with a view to connecting the people with members of the general public who routinely use the same transport routes.

working with local communities to recruit people who would be prepared to introduce people into their social communities through taking them along to events within, for example, local church groups, sports clubs etc.,

within the human service agency connecting people that live and work at different addresses but share a common interest

inviting members of the community particularly where a one to one connection is made to the ordinary events that occur within the house such as an evening meal or to a special events, such as, a house party.

creatively working staffing rosters and ratios to promote more one to one experiences between staff and the people they support

becoming more aware of how people who are non-verbal wish to spend their days through interpreting and responding to their non-verbal cues.

interfacing with the staff of community facilities where people spend time, such as the library, swimming pool, to discuss the potential of the site for making connections for the people when undertaking community based activities.

In reflecting upon the above points it would not be unexpected if the reaction of personnel involved in staff training as well as the management of human services was one of "so what is new"!. Nevertheless these issues arise from a systematic follow up investigation of how life was for people eight years after moving from an institutional setting into the community. If these findings are not common knowledge why then were the majority of people seen as venturing around the community rather than being party to the building of networks within it. Could it be that until people are able to live in the community with natural supports, service systems will continually be placed in a situation of compromise arising from funding restrictions, lack of trained staff, turn over of staff and structures that reinforce a group mentality such as group homes and group day programmes. In effect until people can move from being seen as part of a group venturing will continue. Supporting people on an individual basis, in the community as opposed to servicing them as part of a group holds the key to their becoming connected and as participators networked. Alongside the training of staff must be the opportunity for members of the community to respond and become involved also. If the community is to be open to the people that this study focused upon the commnity needs to be sensitised to their needs Maybe both tertiary and community based adult education has a role to play here. Is it too much to expect that regardless of what discipline people are studying a disability awareness training course is incorporated within the foundations of its content? Why wait until people are involved in tertiary and community education ventures? Disability awareness is needed acrosss the age span if people who were once institutionalised are to be recognised as individuals who have the capacity to enrich the lives of those that they meet in their journey to find a place in the community.

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