Pathways 6 Conference 2002
Taking their place: People with Intellectual Disability at University

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ABSTRACT

Despite many groups of people with a disability having increased access to the university system, people with an intellectual disability remain the forgotten group. This study examined the inclusion and integration of people with an intellectual disability in the university environment at Flinders University in Adelaide, Australia during the period January 2000 to December 2001. The research involved case studies of ten young adults with an intellectual disability who had been, or continue to be, part of Flinders University's Up the Hill project, an Inclusive Post Secondary Education (IPSE) program.

The aim of the research was to assess whether access to the University experience had an impact upon the self-esteem and self-concept of this group of participants. Data were collected over a two year-period, using participant observation and field notes, with the primary data collection period occurring between October and December 2001 using long, semi-structured interviews. These interviews were conducted with the Up the Hill participants, their families and a number of academic staff who each had participants in his or her class.

A number of common themes or perceptions emerged following analysis of the data using narrative analysis. These themes included; developing friendships through the inclusion of people with an intellectual disability in educational settings, benefits for both non-disabled students and those with an intellectual disability through involvement in an IPSE program, and perceptions by participants, parents and academic staff that increased maturity, self-confidence and self-esteem resulted from the opportunity to be part of the university environment.

1. INTRODUCTION

Australian universities have taken a more proactive approach to the issue of access and equity for people with a disability over the past twelve years since the release of the Commonwealth government's policy statement on equity and social justice in higher education for people with disabilities. 'A fair chance for all' (DEET, 1990) resulted in the appointment of Disability Liaison Officers and the development of Disability Action Plans at universities around Australia. Subsequently O' Connor and Watson (1996) reported that the profile of people with a disability in universities improved following these changes, however Andrews (1991) could not find any students with an intellectual disability among the students with disabilities accessing university education in Australia.

Sigafoos and Arthur (2002), highlight the increasing trend toward including students with an intellectual disability in a variety of mainstream preschool, primary and secondary education settings. Westwood (1987) argues that the gains made from inclusion in the early years should also be realised in the post-compulsory school period. Internationally the current focus of post-school options tends to be limited to the vocational needs of students with an intellectual disability (deFur, Getzel & Trossi, 1996; Wehman, 2001). Apart from the need for employment, Knox and Parmenter (1991) found that young people with an intellectual disability have needs in other areas of their lives including friendships, social activities, recreation and leisure, and community and home living skills. Brown and Hughson (1987) suggest an integrated 'quality of life' approach to meet the diverse range of needs of students with an intellectual disability who are leaving school and entering the community.

McElwaine (1993) identified over one thousand South Australian school leavers with intellectual disabilities who were not involved in employment, recreation and leisure pursuits or other forms of day option programs, having limited opportunities to socialise, make friends or participate in age appropriate activities. This finding supported research by Newton and Horner (1993) and Schleien and Ray (1997) who also found that young people with intellectual disabilities were often socially isolated after leaving school, with few friends and social activities, especially with their non-disabled peers.

University was chosen by Uditsky (1988) as a suitable community for young people with an intellectual disability to participate in a range of activities including education, leisure, recreation and socialisation. Universities are small communities, with shops, banks, food outlets, and entertainment venues where a wide range of people congregate. Universities comprise a wide range of age groups, cultural and ethnic backgrounds, and tend to be more accepting of a range of social deviance (Grantley, 2000) and, since many students with disabilities already attend university, students with an intellectual disability can also enjoy the valued social role of 'university student' that many other students enjoy (Wolfensberger, 1983). As a component of her Honours research, a pilot study was conducted by Gibson (1997) that trialed the integration of four students with an intellectual disability at Flinders University in Adelaide, South Australia. This study followed similar programs involving students with intellectual disabilities in Edmonton, Canada at the University of Alberta in 1987 (McDonald, MacPherson-Court, Frank, Uditsky, & Symmons, 1997; Uditsky, 1988; Uditsky, Frank, Hart, & Jeffrey, 1988; Weinkauf, 2000) and at the University of Jyväskylä, in Finland in 1995 (Saloviita, 2000). The success of the Gibson (1997) study resulted in the birth of the Up the Hill project at Flinders University in January 1999.

2. UP THE HILL PROJECT

The Up the Hill project is an Inclusive Post-Secondary Educational (IPSE) opportunity for adults with mild to severe intellectual disabilities located at Flinders University in Adelaide, South Australia. The Up the Hill project provides educational opportunities for up to twelve (12) participants by placing them as auditing students in mainstream topics throughout the University. The project is acknowledged and supported by the Department of Disability Studies, School of Medicine at Flinders University and the Intellectual Disability Services Council of South Australia (IDSC). The project is administered by a Steering Committee consisting of participants' family members, community members, the project manager, coordinator and participant mentors, as well as academic staff of Flinders University. The project has been operating successfully on campus since first semester, 1999. The Mission Statement of the Up the Hill project is:

Our mission is to provide a quality service at Flinders University, which enables people who have an intellectual disability to access the university environment, to develop social skills and social networks, and to experience a range of educational opportunities and activities.

The aims of the Up the Hill project are:

- To facilitate the educational development and functioning of people with intellectual disabilities in a positive and supportive environment.
- To provide opportunities for the development of social networks of people withintellectual disabilities.
- To provide opportunities to increase the range of interests and knowledge of people with intellectual disabilities.
- To enable people with intellectual disabilities to exercise their rights to continue formal education.
- To facilitate the development of self-esteem and self-confidence for people with intellectual disabilities.
- To enhance the vocational opportunities for people with intellectual disabilities.
- To provide opportunities for both academic staff and students to benefit from interaction with people with intellectual disabilities

Each Up the Hill project participant is matched with a mentor and this person is usually another Flinders University student who supports the participant, and provides the link between the participant and the University, facilitating the establishment of social networks. Up the Hill participants audit University topics of their own choice and are encouraged to participate in all aspects of University life with the intention of developing skills and improving their opportunities for future employment. With new opportunities and connections in the community it is hoped that participants will open new doors for their future. Up the Hill project participants are free to audit any number of topics each semester, and most participants opt to audit up to three topics, however participants new to the project usually audit a single topic at first. Topics audited so far include; Visual Arts, Sculpture, Drawing, Painting, Family Law, American Studies, Rediscovering Science, Women's Studies, Australian Studies, Counselling and Case Management, Augmentative Communications, Health Issues and Disability, Family and Professional Partnerships, Perspectives in Disability Studies, Sociology and Human Service Provision, Human Relationship Skills, Play and Recreation for People with a Disability, Human Growth and Development, Management of Groups and Organisations , Studies of Autism Spectrum Disorder, Learning Development and Support 1, and Practicum in Disability Studies.

Audit students generally are entitled only to attend lectures, however through care and goodwill the Up the Hill project has been able to negotiate attendance in tutorials, workshops, seminars and field trips, issue of a Flinders University Student Identity card with library borrowing and email facilities, and limited adaptation of assignments and examinations for non-award purposes. Lecturers have adapted topic material for participants and, although this is not a requirement of the project, the participants appreciate the value of this kind of support. This support is performed gratis, as the program relies on the goodwill of lecturing staff, given no funds are available for this kind of assistance. One of the most important aspects of the project is the natural support the participants receive in the classroom. At the beginning of each semester the mentor will seek volunteers who will sit with students during lectures and support them to participate to their level of comfort. This support is not disruptive but casual and from our experience has enhanced the participation and involvement in the classroom for everyone. The mentors and manager of the project constantly monitor the progress of the participants so that they can address any problem that may arise. The

mentors, manager and coordinator of the project oversee the whole process. They help develop study schedules, assist in identifying goals, gain lecturer support, promote inclusion, and work one to one with participants to ensure the study topics and other activities meet the needs of each individual. Grantley, (2000) reported that mentors in the Up the Hill Project have reported [about the participant]" an observed increase in self esteem and self confidence … and an expansion of social networks…"(p. 9). Flinders University offers a rich and supportive environment in which to develop the participants' independence, social involvement and active lifestyle. Another major goal of the project is the involvement of participants at Flinders University to help them meet the real challenges of being a young adult while furthering their educational opportunities.

3. RESEARCH METHOD

During 2001 a qualitative study by Lobban (2002), involving ten Up the Hill project participants, five current, and five who had been part of the project previously, was undertaken. The following research questions were posed:

- How do students with an intellectual disability perceive their experiences of attending University?
- How do parents of students with an intellectual disability perceive the experiences of their son or daughter when attending University?
- How do academic staff (who have had participants from the Up the Hill project in their classes) perceive the experiences of students with an intellectual disability attending university?
- How do the findings above impact upon self-esteem and the self-concept of young adults with an intellectual disability?
- Does a relationship exists between the university experience and the self-esteem and self-concept of the participants in the Up the Hill project?

Data were collected using participant observation and documentation. Long interviews were also conducted involving ten participants, eight sets of parents and ten academic staff who had experienced Up the Hill participants in their classes. The interviews were recorded, transcribed, coded and analysed using a technique known as narrative analysis. Considerable effort was taken to observe a range of ethical considerations and observe confidentiality at all times during the research process and afterwards. Interview questions were designed to allow for acquiescence and nay saying responses common with people with an intellectual disability.

4. RESULTS

One of major findings of the research was that the university experience contributed significantly to the self-esteem and self-concept of young people with an intellectual disability. A common response from participants highlighted the difference between attending TAFE and university. Many participants attended both TAFE and university and stated that TAFE colleges in South Australia did not offer the range and variety of courses for available at Flinders University, and the limited nature of courses offered at TAFE were aimed exclusively for people with an intellectual disability, providing a segregated rather than integrated classroom environment. People with an intellectual disability could not attend mainstream classes at TAFE whereas at Flinders University this could occur. These TAFE environments did not encourage people with an intellectual disability to be included with their

non-disabled peers. In regard to university Up the Hill participants and their families stated that "just being there" (Lobban, 2001, p. 170) was highly important in relation to social inclusion in the university setting.

The table below is one snapshot of responses received from Up the Hill participants and their families regarding their perception of the University experience.

Table 3-5: Perceptions of the university experience by Up the Hill participants and their parents (Lobban, 2002, p. 122)

	Name	Participant perceptions	Parent perceptions
A	Yvonne	*It's excellent…I get to do lots of work…really good…really grown up…I meet new people*	*She's happy there…Uni would be her number one activity…her most favorite*
B	Kathy	*Real good…Something I wanted to do …*	*Learning some academic things…and to meet people and be in the environment was good. She was happy to come to university… I think that she's very proud to show us the things she's done at university and talk about the people she met in class*
C	Hillary	*Something I wanted to do…I enjoy going to Uni and it makes me busier and that's how I like to be …I like getting out of the house…seeing people …making new friends*	*It [Uni] gave her another circle of people to meet…it just helped give her more independence…university's been one of the key components which has helped Hillary really show a real sense of s self management…increased level of independence*
D	Leanne	*Fantastic….you meet so many new people and your mentors are great …I really enjoy myself …The lectures are really good…they give me a lot of handouts which is good.and watch videos…I catch up with friends…go to the DeCafe…go to the library*	*She enjoys it very much and looks forward to coming…it has been a very good experience for her…she likes going to the library and getting out …books …its certainly been a benefit for her…she's definitely learning things she would never have been able to if she didn't come*
E	Candace	*When I saw my other friends I would talk to them about Uni…it was pretty important …going to the classes…it [Uni] built up my confidence, meeting new people and just going there is very good…I knew my way around, so it was pretty good by the end of the year.*	*I knew she's learn about the real world…she certainly opened up…her conversation improved…it gave her a taste of what she could do which she probably wasn't aware of and didn't have the confidence to do until then…at Uni the conversation was a lot broader and more mature*
F	Mary	*Love it there…I always wanted to go to Uni…It was different. It felt like going to TAFE on the first day but much bigger…I reckon its changed my attitude...*	*She enjoys meeting new people…anything that's interesting Mary enjoys doing as along as its not too hard for her.. She enjoyed going to Uni.*
G	Ruth	*I like it…like the lecturer…go on computers…E mail people. . good fun…meet new people…I like Uni…DeCafe..get a Coke …good feeling…*	*She definitely likes the DeCafe and seeing other girls from school…she'd come every day if she could….its provided her with a broader contact with people*
H	Brian	*Something I have to do …I got up*	*The experience of being in the*

		early…there was a thing on my fridge…I found a new way to do it …[put my bike on the train] at Goodwood go to Blackwood and ride down Shepherd's Hill Road to Uni	amphitheatre and in a new environment was good. Just by being there was an experience in itself…
I	John	[Uni] gives you a chance to regain what you couldn't do at school…A lot more friendly people, people you can get along with…Wasn't a bad feeling at all, I made friends with someone…	NO PARENT INTERVIEW
J	William	It's [Uni] good for you…It gives you knowledge for the outside world…It's OK …you learn all different subjects…a good feeling…going to the DeCafe…having BBQs…go the library…go to the church on Mondays	NO PARENT INTERVIEW

Academic staff were also very supportive of the Up the Hill Project. The table below details the voluntary involvement of academic staff at Flinders University with the Up the Hill project and provides a snapshot of their perceptions.

Table 3-9: Perceptions of academic staff towards Up the Hill participants' university experience. (Lobban, 2002, p. 132).

Lecturer	Were you happy to have a participant in your class?	Would you have another participant in your class?	Did you have to adapt your lecture delivery?	Do you think that the participant gained self-confidence during the time in your class? Any evidence of this?	Personal impact of having a participant in your class –any other observations
1	Yes	Yes	Almost no special adaptation required. – seven out of eight participants supported required no adaptation	Definitely… participants going independently to the DeCafe, to the library, showing off their student ID card to friends	I felt that the mentor seemed to get in the way of the social contacts…that the mentor became the responsible person for the participant…
2	Yes	Yes	Not really…maybe a little more explanation regarding the assessment	Oh yes the level of interaction with other students in the class increased - conversations increased.	Its been terrific having the auditing students there. .I think that the BEd students really benefited also
3	Yes	Yes	Not really. Needed to be aware of the specific needs of each participant and just go with	Yes I think I it assists in their self image	I think it was terrific… challenged me in terms of facilitating participation… enriches the class and enriches the

			it…		participant, works better when the mentor is withdrawn to allow greater inclusion.
4	Yes	Yes	Not really. Each participant and the mentor needed to be approached individually…	Yes. .had the benefit of seeing some of the building of self-esteem at the end of semester get togethers…seeing them being presented with certificates	Very positively predisposed to this project..can see value for the students in the class….an added benefit …a contributing member
5	Yes	Yes	No… gave participant a copy of course outline and introduced her to some other students in the class	Yes I did notice Hillary did gain confidence as she attended more classes…made a few comments in class	It was good for me and good for the class…the student [who made friends with Hillary] said she found it really valuable
6	Yes	Yes- but some thought has to be given to topic selection – not to pick one that is too theory based	No not really. Participants blended into the class well and were not noticeable they… seemed very keen to learn	Wasn't in a position to see a lot of activity outside the classroom, however could see that the participants were not ostracized or excluded	Mentor seemed to get in the way of making friendships – became a barrier to associating with other university students.
7	Yes	Yes	Not really. ..adaptations are made for many students No extra work at all	Its been good to see them grow in confidence	Social interaction at a superficial level otherwise fitted in well
8	Yes	Yes	No did not adapt class, however considering the needs of the participants I could have been given notice in advance. Happy to change the format	The participants' ability to relax and concentrate in the environment improved	It was good because it challenged me to think creatively about the delivery of the lecture
9	Yes	Yes	Lecturer has to get participation going in class so some adaptations required	Yes the participants going to the DeCafe…confidence in coming to class..coming without the	Redirects your awareness and focuses you as a lecturer- the lecturer has to model acceptance for it to work

				mentor after a few weeks	
10	*Yes*	*Yes*	*No informed tutorial group of the project's goal…why participant was there*	*I think she did begin to participate more toward the end…*	*It was a good idea*

5. CONCLUSION

The research data suggested strongly that including students with an intellectual disability in university has a benefit for both non-disabled students and those students with an intellectual disability alike. These findings, consistent with the experience of other IPSE programs in Canada and Finland also highlighted the major contribution to the self-esteem and self-concept of young people with an intellectual disability that attending university can make. Extending social networks of Up the Hill participants also had a flow-on effect, increasing awareness of intellectual disability throughout the university. The research also showed that supportive academic staff and positive attitudes by mentors and Up the Hill staff were crucial to the success of the IPSE program.

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