



Understanding friendship: Young adults with Down syndrome exploring relationships¹

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Having friends and being a friend defines us as human beings. Friends can play many roles in our lives, and without friends, life can become increasingly lonely. For young people, friends often take a counselling role in times of emotional stress, so loneliness or a life without friends who can understand the emotional contexts of friendships and "counsel" may affect a person's psychosocial quality of life. This paper describes a six session program that was designed to help a group of young adults with Down syndrome understand friendships better. The Down Syndrome Research Program LATCH-ON staff at the University of Queensland developed the program in conjunction with the Queensland Family Planning Association. During the sessions, the students explored and discussed various types of friendships and the emotions associated with them, using the students' own experiences and videos in conjunction with structured materials such as The Circle Concept (Smith, 1987) and Network Hand (Birch & Higgs, 1996). Some reflections from the authors' experiences with the program are provided. Future research directions are suggested.

INTRODUCTION

The life circumstances of persons with intellectual disabilities have changed markedly over the last 10 years (Brown, 1995). Now, with deinstitutionalisation, improved

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health care and community participation, individuals with disability enjoy extended life opportunities in a range of independent settings. These life opportunities present individuals with many more challenging life events than experienced by those of previous decades. Their lives are likely to become more emotionally disconcerting as parents grow older and perhaps die, siblings move out of home and form new families, and they themselves leave regular places of community contact such as schools and workshops. In these new and emerging independent living circumstances, individuals with intellectual disability may face situations which place stresses on them that are similar to those found by Rickwood and d'Espaignet (1996) in a study of other young Australians. The researchers found that when confronted with the stresses of modern life young people turned to their friends. Friends appeared to have a role in assisting young people to cope with the stresses, such as family expectations, employment decisions, and the development of self-identity (Rickwood & d'Espaignet, 1996). Brown, Ball, and Powers (1998) also found this to be the case with young women. Tonge and Einfeld (1991) identified a similar range of psychosocial emotional stresses in a group of adults with intellectual disabilities; for example one young man after a parent's death "was not able to satisfactorily resolve his loss ..." (p. 166). It was evident in their case studies that community services were unprepared and there was a lack of social support and counselling. Inadequate social support has also been identified by Meins (1993).

Not only is there a lack of social support, but individuals with intellectual disability may not fully understand the emotional aspects involved in the development of relationships. Myths exist about the development of personality and temperament in persons with intellectual disabilities (Cuskelly & Gunn, 1997; Gunn & Berry, 1985), and these perpetuate views that they have no feelings or, alternatively, are over-affectionate (Carmody, 1996). There have been limited investigations of the abilities of individuals with intellectual disabilities to understand the various emotions associated with friendships, although some studies have examined the ability of children to recognise emotional expressions on faces (Harwood, Hall, & Shinkfield, 1999; Maurer & Newbrough, 1987). It is considered that individuals with intellectual disabilities may not develop an understanding of emotions incidentally or from normalised environmental experiences (Abery & Fahnestock, 1994; Pueschel & Sestrova, 1997).

In addition, for those with disabilities, friendship can be limited. Loneliness is considered a particular aspect of life for a growing number of young people with intellectual disabilities (Carr, 1995; Jobling, 1989) especially as home environments change and services become increasingly overwhelmed (Braddock, 1999). Several authors have shown that in comparison to their non-disabled peers, young adults with Down syndrome lack peer friendships (Buckley & Sacks, 1987; Carr, 1995; Jobling, 1989). In such circumstances, a favourite pastime for many individuals with intellectual disabilities is watching television and many develop "friendships" with TV program personalities. These are "imaginary" friends but often are very real to the individual and it becomes difficult for them to realistically interpret these within their world. Meaningful interpretation is confounded by friendships as portrayed in "soap opera" type TV programs. In these programs friendships are dramatic, fraught with

difficulties and fabricated. Such friendships become "models" and are copied by the young person although they do not fully understand nor discern their "fantasy" qualities.

A relevant question to ask is whether young people with intellectual disabilities move beyond these limited representations of friendship to develop an understanding of the emotional aspects of friendship. In part, understanding friendship stems from the ability of the individual to develop an understanding of, and experience "having or being a friend".

This is an important consideration because all too often recreational activities are solitary or with a paid "friend". Within special settings particularly there is a tendency "... for helping relationships to be characterized automatically as friendships" (Turnbull, Blue-Banning, & Pereira, 2000, p. 138). For example, the friends of some individuals are often paid visitors, irregular contrived contacts, servants who facilitate their programs or family-orientated rather than with peers. These interactions do provide avenues for social skills training in appropriate responses and behaviours, and some effective programs have been developed (Amado, 1993; Fegan, Rauch, & McCarthy, 1993; Firth & Rapley, 1990; Hayden & Abery, 1994; Riches, 1996) but the emotional contexts within which these behaviours occur are only superficially addressed. The promise of friendship as the outcome of a particular program or the application of a particular set of strategies is a false promise (Amado, 1993). However, within a program designed to enhance literacy, friendships were being formed. Within this environment the young adults had support for their naturally developing friendships and shared with these friends the challenges of improving their reading and writing. As stated by Day and Harry (1999), it was clear that "disability" did not limit the quality of the relationship being formed or the consequences and responsibility involved in being a friend.

The program described in this paper was designed to assist these young people to understand the basis of friendships and the emotions involved in their development. With these two aims, a program of six by 1.5 hour sessions on understanding and managing emotions in relationships was developed. The participants were a group of seven young adults with Down syndrome who were attending a literacy and technology course (LATCH-ON) (Moni & Jobling, in press) at the University of Queensland as part of the ongoing Down Syndrome Research Program (Jobling & Cuskelly, 1998).

The young adults

Seven young adults (three males) aged 18 to 21 years who lived at home with their families in Brisbane, Australia, participated in the program. All had attended school: four in full-time regular schools, one full-time regular schooling until the last two years of her secondary education, and two attended special schools full-time. The group's functioning level was in the moderate range of intellectual disability, while receptive language ages, assessed using the PPVT-R, ranged from 5 years 4 months to 9 years 4 months. PPVT performance is useful information for teachers as it enables them to ascertain how to direct their instruction at the appropriate level (Dunn & Dunn, 1981).

The program

This relationship program was developed by LATCH-ON staff in conjunction with Family Planning Queensland (FPQ). FPQ is an organisation which adopts a best practice educational model based on respect for the individual, that celebrates difference and accepts all people equally. The adoption of this style of practice enables FPQ to develop educational programs which help to overcome the common perception that people with disabilities are always children and therefore cannot make decisions for themselves. FPQ considers it necessary to provide people with disabilities, who are often anxious to have a friend, with some strategies to understand and maintain friendship. Protective behaviours are also taught, as individuals can be vulnerable to exploitation and abuse by others who claim to be their friends.

Overall, this initial program aimed to link known feelings experienced by the young adults with the establishment and maintenance of personal relationships. The design of the six sessions covered aspects of relationships such as family, types of friends and acquaintances, and the emotions of hurt, jealousy, personal trust and feeling safe, as well as gender roles in relationships.

It was considered that with some explicit teaching, structured materials, video cameos, discussion questions and "brain-storming" the young adults could be assisted to develop an understanding of their own experiences, emotions and friendships.

At the beginning of each session, time was taken to focus on the establishment of group discussion rules and for participants to talk about something they liked to do, something that happened to them during the last week, or something they remembered from a previous session.

OUTLINES OF THE SIX SESSIONS

Session 1. Relationships: Hurt and jealousy

In this session the variety, scope and individual nature of relationships in which people can become involved were explored. The *Circle Concept* (Smith, 1987) was used as a resource to scaffold the activity. The young adults volunteered information and ideas which were listed on a whiteboard and discussed. After this overview was developed, boyfriend/girlfriend scenarios were discussed and the young adults were asked to distinguish between friends who are boys or girls and a boyfriend or girlfriend.

To further develop this discussion, the story of Glenda and Jim from the video "Four Stories" (1997) was used. This story raised issues of consent and permission in friendship, and the events in the video were related back to the *Circle Concept*. The young adults were encouraged to reflect on different expectations for relationships such as those illustrated in the Glenda and Jim story. These expectations can often be linked to our feelings about the relationship, for example, boyfriend/girlfriend relationships. The effects of jealousy and hurt on relationships were explored using an excerpt from video "The terrible tales of Mr Bean" (1991). In the scene used, Mr Bean and his girlfriend go on a date and she is annoyed that he is late and embarrassed by his behaviour. Mr Bean's girlfriend starts dancing with another man and this makes Mr Bean feel jealous and he angrily tries to interject. This action sees his girlfriend

dancing closer and more slowly with the other man so that Mr Bean feels sad and hurt. The young adults were encouraged to identify and discuss these feelings and, if they wished, talk about their own experiences. Again the discussion was linked to the consent and permission aspects of the *Circle Concept*.

Sessions 2. Relationships: Types and personal trust

This session was used to build on the concepts developed in Session 1. The *Circle Concept* was used to distinguish between the relationships evident in the TV cartoon program "The Simpsons." The young adults were asked to identify, based on their relationship with the central character Bart, which characters from the program would go into which circle. Their responses were recorded on a whiteboard. Questions were used to scaffold the activity. For example, Marge and Homer, if Bart's parents go in the "love circle" where would you put Bart's sister Lisa? Similarly who would go in Bart's "like," "know" and "don't know" circles?

Then the young adults were asked to construct their own circle. During this activity, discussion focused on the qualities a person should have to be put into an individual's particular circle. Questions asked to assist this discussion were "Who are your friends?" and "Where would you place them on your circle?"

The issue of trust in relationships was then explored. Once again the students used Bart's circle noting the different environments in which he establishes relationships—home, school, friends and the community—and then the young adults moved to using the *Network Hand* (Birch, Little, & Higgs, 1996) in order to identify their own relationships of trust. Each participant drew their own *Network Hand* for each environment—home, work, friends and community. These were then shared and discussed.

To complete this session, a group activity was conducted in which the young adults made a list of the qualities they felt made up a trustworthy person. This list was then used to introduce the part of the session which dealt with feelings of safety and being afraid. The purpose of this part of the session was to help participants distinguish between choosing to be afraid (e.g. a scary movie or roller coaster ride) and finding themselves in situations where they are afraid. The body sends messages of "fear" in both cases, but the difference is in the level of personal control an individual feels they have over the situation. Discussions were supported by an episode of Mr Bean in which he and his girlfriend see a scary movie. After watching the excerpt, the young adults constructed a list of fearful situations. To complete the session these issues of fear and safety were linked back to the *Network Hand* and the *Circle Concept*.

Session 3. Relationships: Me and my family

The young adults were asked to look at their own family dynamics within the framework of the *Circle Concept*. The differences and diversity of family structures were discussed with no one structure being privileged. The video "Songs of innocence: A child's view of family life" (1992), which features 13 children from nine different families talking about their experiences within their own family, was used to

generate discussion. Aspects highlighted for the young adults included:

- Brothers and sisters may love each other but don't always get along.
- Advantages and disadvantages of being an only child.
- Position in the family often influences feelings.
- Response to a new baby — the siblings' feelings and reactions.

Then a segment from the video "Feelings: knowing, expressing, coping" (1987) was used to introduce and discuss growing up and the changes that occur in family relationships as members grow older. The cooperative aspects of individual responsibility and boundaries were highlighted (e.g., being grounded, party going, choices, paying your way). These videos provided an opportunity to discuss the process of growing up, and to highlight the achievements and skills of this group of young adults. A timeline was used to illustrate the different roles and responsibilities that develop as one grows older and how these influence family roles and relationships. The young people were encouraged to identify the increased choices and abilities they develop as they mature. Important life events were identified and individual achievements and challenges discussed.

Session 4. Relationships: Having a friend

This session began by identifying the qualities of a good friend. These were written on the whiteboard and linked back to the young adults' Circle, noting the difference between people we know, people we see on television, people we like and what makes them likeable. A story called Sticks and Toby from the video "Feelings: knowing, expressing, coping" was used to support the activity. In the story Toby, who is not thin, was teased by a group of adolescents, and Sticks has to decide whether to stay with Toby or go with the group. The young adults discussed what they would do and used their Circle and list of qualities related to a "good friend" to assist their decision-making. Another story from this video—"That's David"—was used to illustrate conflicts in boy/girl relationships. The young adults were asked to consider their feelings if David had betrayed their friendship by taking someone else to a party after making an excuse that he was unable to go.

A "bad" friend list was then developed of qualities in relationships that can be hurtful, or qualities that mean someone cannot be trusted. Here the young adults revisited previous work and discussions on "feeling safe" and "trusting." The *Network Hand* was again used to support the discussion. The feeling of fear was contrasted with the feeling of being safe. Safe feelings were listed on the whiteboard.

Session 5. Relationships: Gender roles

Many influences mould a person's perceptions of who they are and where they fit in the world, and this session explored the effect of gender roles on relationships. To introduce this topic the video "Women seen on TV" (1991) was used. This video provided a critical view of the portrayal of women. It showed how women are used to sell products and demonstrated that major roles, in television programs, are largely taken by males. Men were seen to often answer for women and the video highlighted

the aggression men can have towards women. After viewing this video, the young adults generated a list on the whiteboard of ways they saw women portrayed in the media. The list was then analysed to see if there were any roles undertaken by both sexes, for example, a doctor can be male or female. Self-image was discussed as the emotional component of this session and the cartoon "Gorgeous: Starring Hermione the modern girl" (1994) was used to illustrate the lengths to which females may go to improve their self-image (e.g., plastic surgery, beauty therapy, dieting). As an outcome of this session the young adults made posters to illustrate (a) what people do to make themselves healthy, and (b) what people do to make themselves attractive.

Session 6. Adult relationships

This session explored the nature of adult relationships and marriage. Another section of the video "Four stories" (1997) was used to introduce the topic. Sue and Afeleti live in a community house and are friends. Afeleti buys a ring for Sue and asks her to marry him, they both then tell their parents with very different results. Discussion points from the video were:

- What does it mean to get married?
- What does the ring represent?
- Why would parents react in different ways?

In order to assist the young adults with this discussion, reference was again made to their Circles. If people in our "love circle" support our choice then it is usually a good choice but if they don't, then it is often because they care for us. Choices which are concerned with adult relationships are often those that cause great conflict and anger within families. Feelings of anger were now linked for the young adults to the other feelings that they had discussed — hurt, jealousy and fear. Talking to someone about feelings was important and the *Circle Concept* and *Network Hand* were used to clarify individuals that the young people could talk to because they trusted them.

REFLECTIONS ON OUR EXPERIENCES

During and after the program, the authors met to reflect on the program content, the activities, and the participation of the young adults. Overall, the students' participation met with our expectations. The students were highly motivated, enjoyed the activities and developed a very strong rapport with the facilitator. However, we did identify three challenges in developing and teaching the concepts and activities, and in coping with group dynamics. These were first, the challenges presented by these young adults as a group of learners. The second group of difficulties arose out of the literacy demands inherent in some of the activities, and third, there were issues in dealing with the friendships and relationships that were part of the social dynamics of this group. In our continuing development and refinement of this program we are focusing on addressing these challenges and the impact they have on the effectiveness of the program. In this initial account of the program we present these challenges in the form of considerations for other professionals interested in developing similar programs for young adults with intellectual disabilities.

The continuing challenge in this program was to present abstract ideas and emotions in a more concrete form. In our experience, this group of learners has difficulties in grasping abstract concepts. This difficulty was evident throughout the program. For example, activities such as *Circle Concept* rely on the participants being able to make connections between circles on a sheet of paper and significant people in their lives. Related to this was the challenge posed in trying to explain that an emotion is not a simple single entity but can have different connotations or depths of feeling. For example, it was very hard for students to differentiate between "love" for family and friends and "love" for the Spice Girls. To them, this was the same word and had the same meaning. However, using videos such as "Mr Bean" enabled the young adults to see jealousy, anger and fear explicitly expressed and causing damage to relationships. Concrete and visual representations such as videos provided a reference point for discussion and could be replayed to re-inforce the concept we were teaching.

Literacy played an integral part of the activities during the program. For example, the students were asked to brainstorm, read from the whiteboard, write lists, rank important ideas, and share their ideas with the group. The literacy demands inherent in these activities were sometimes beyond this group. This was particularly evident when the momentum demanded that students complete the activities quickly or there was a quick transition between activities. In these circumstances, the young adults often had only just begun to write or talk, or were starting to grasp one idea when the topic changed. In developing this program further we are considering ways to scaffold literacy activities more effectively. These strategies will include: reducing the number of activities in each session which require writing, focusing on other modes of communication, completing activities in shorter stages, providing participants with opportunities to talk as they complete each stage, reviewing each activity on completion, and producing visual cues such as posters to use as reference points during subsequent activities.

The third set of issues related to relationships among group members. Two of the group, prior to the program beginning, had established a strong loving relationship and considered themselves to be a couple. This relationship was well known within the group and was the cause of some tensions during the sessions. The two young adults at times felt under pressure from their peers who wanted to link the discussions to what they perceived to be a romance in their midst. The couple felt under scrutiny, were embarrassed and sometimes resisted discussing some aspects of relationships that they felt were too close to their own experiences. Their privacy was respected and in these circumstances the use of videos such as "Four Stories" enabled the group to distance itself from the more immediate context and discuss issues more generally. It is inevitable in these situations that some of the aspects of emotions and relationships discussed will have immediate relevance to the lives of the young adults involved. It is important to respect both the reality and privacy of those relationships. For this group of young adults whose social skills were at times fragile and who had limited abilities to distance themselves from their own relationships, it was important to understand that they did not wish to discuss their own relationships. Strategies such as using videos therefore need to be developed to enable discussions to take place with reference to a different set of experiences.

There were also concerns related to assisting all students to participate in the discussions. As in any group of learners, some young adults were more vocal, had more developed oral skills, or were just quicker to react than others. Our analysis of the young adults' participation in the sessions revealed that some students did not participate in the discussions unless they were invited to speak by the facilitator, and others were not fast enough to volunteer information. It became an important goal to develop opportunities for all students to become fully involved in the program. This was a particular issue as we felt that some of the young adults, because of their previous experiences and to some extent because of their disability, may not have had opportunities to discuss life issues that face them as adults in the community. Consequently, student participation was monitored carefully through observational checklists which were discussed each week. Outcomes of this monitoring involved the facilitator in adopting a variety of strategies to include all students. These included nominating students to lead activities, issuing specific invitations for students to speak and establishing an environment where everybody was given equal speaking rights.

SUMMARY

*This program of six sessions conducted over an 8 week period aimed to assist young people with Down syndrome to develop an understanding of their own experiences, emotions and friendships. It was viewed as an exercise in guided discovery using the young peoples' own experiences with materials from structured programs such as *Circles Concept* and *Network Hand*. Due to the limited number of sessions only a beginning was made at assisting them to build a framework from which they could begin to know themselves, and their feelings towards others. However, our observations suggest that the participants were highly motivated. They enjoyed the activities, actively participated and developed a strong rapport with the facilitator.*

The program included explicit teaching, structured materials, video discussions and question and answer sessions. Our reflections during and after the program suggest that in developing similar programs for other groups of young adults with intellectual disabilities, coordinators may need to address three important areas. These are first, the need to present abstract concepts and emotions in concrete ways that correspond to the cognitive and language development of the participants. Second, it is important to consider the literacy demands of the activities so that they can be scaffolded both to match and develop the literacy skills of the participants. The third consideration relates to understanding group dynamics and the social relationships that may already exist among participants prior to the program. Care needs to be taken to respect such relationships and the privacy of those involved.

This paper has presented an account of the program in its first year of operation. Thus far, we are encouraged by the students' responses, and our anecdotal observations of their enhanced friendships within the program. We are continuing our evaluations of the program in several ways. Using the qualitative data from observations, reflections and participant experiences we are refining the program so that it can be used more effectively both with this population and in the wider community. We are also adopting a number of approaches to extend the evaluation of the program

including interviewing significant others in the lives of our young adults. In addition, we will be tracing the effects of the program on a new group of young adults who will experience the program later this year.

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