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Abstract

This article describes friendships between people with and without disabilities, and is the result of a study of four pairs of friends. The study looked at how people become friends and each person's role within a friendship. It then describes the impact of living in the human service world on people who have disabilities and what that means for their friendships. **Keyword: Friendship**

AFFECTIONATE BONDS: WHAT WE CAN LEARN ... BY

LISTENING TO FRIENDS

by Zana Marie Lutfiyya

*This article contributes to the continuing dialogue about friendships between people with and without disabilities. Those interested in a monograph on this study should contact **Zana Marie Lutfiyya**, Centre on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University, 200 Huntingdon Hall, Syracuse, NY 13244-4230.*

Many people in the fields of special education and rehabilitation today have a strong desire to help people with developmental disabilities develop a wide variety of personal relationships, including friendships, with people without disabilities. It is becoming widely acknowledged that such relationships enrich the lives of both the persons with disabilities as well as those without and better enable persons with disabilities to become more a part of the community. Some human service providers are now trying to create opportunities for people with developmental disabilities to meet and develop friendships with people without.

Some of these efforts have evolved into formal programs, despite the fact that, for many of us, arranged introductions are an artificial and heavy-handed way of establishing friendships.

Our good intentions aside, we still know little about the nature and meaning of "naturally occurring" friendships that do exist between people with disabilities and those without. There are about a dozen case studies and/or testimonials available which describe either the authors' friendships with persons with disabilities (Edwards & Dawson, 1983; Forest & Snow, 1983) or the authors' observations of the friendships of others (Perske, 1988; Strully & Strully, 1985a, 1985b; Strully & Bartholomew-Lorimer, 1988).

I wanted to learn more about these naturally occurring friendships between individuals with developmental disabilities and those without. So, I spent time with four pairs of friends to learn how they had first met, developed and maintained their friendships and what those friendships meant to each of them. I conducted indepth and open-ended interviews and participant observation sessions with the four pairs of friends. Each pair consisted of one person with a developmental disability and one without. Both people in each of the pairs of friends identified themselves as friends. My intent was that the stories, words and perspectives of the people I interviewed would contribute to our understanding of how affectionate bonds which exist between people are created and maintained.

From my analysis of the data, five major findings emerged. **First**, genuine friendships between people with developmental disabilities and people without *do exist*. **Second**, each of the informants took active parts in the creation of

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their friendships. Third, the informants played different roles vis a vis their friends. Fourth, while the specifics of each friendship were unique, the informants shared similar ideas and expectations about the characteristics of friendship in general. These included the mutual, exclusive and voluntary nature of friendship; the rights, obligations and responsibilities of friends to each other and the positive regard or affection found between friends. Fifth and finally, the fact that one of the friends in each pair did have a developmental disability did play a role in the friendships. While both of the friends contributed something to the friendship, the kinds of contributions made did depend on whether or not the respective friend had a disability.

Genuine friendships

The people with developmental disabilities were in fact considered friends by the informants without disabilities. Through these and other similar relationships reported upon in recent literature (Bogdan & Taylor, 1987; Edgerton, 1988; Forest & Snow, 1983; Perske, 1988; Strully & Bartholomew-Lorimer, 1988; Strully & Strully, 1985; Taylor & Bogdan, 1987), the existence of friendships between people with disabilities and without has been documented. The people with developmental disabilities in this study enjoyed very few personal relationships and even fewer friendships (regardless of whether their friends had developmental disabilities). Although friendships among people with and without disabilities still appear to be the exception rather than the rule, some individuals with developmental disabilities are valued as friends. They are liked, loved, appreciated and viewed with respect by their friends who have no disabilities.

Joint definition of friendship

The second finding of this study related to how the friendships were formed. In three out of the four friendships studied, it was the person with disabilities who initiated the friendship. The friends actively created their friendships. The result is that they came to define their relationships with each other as friendships.

Friends play different roles

The data clearly illustrated that the friends played different roles (e.g. mentor, companion, advocate) within their friendships. One of the friendships was between two co-workers and revolved largely around work-related activities and events. One of the friendships was intense and intimate, while in the others, the friends assumed a more casual relationship with one another. One friendship was focused on a particular interest and was limited to certain activities, while the other friendships existed regardless of what activities the two friends were involved in while together. Some of the friends had frequent, perhaps daily contact, while others saw each other far less often. Two people maintained a friendship by telephone and had very little direct face-to-face contact.

Friendships are meaningful

Each friendship was meaningful for the informants. These meanings were similar across all four friendships. For the informants, their friendships were mutual relationships which involved certain rights and responsibilities on the part of each of the friends. They acknowledged that their friendships were voluntary and their obligations chosen. While in each group, both of the

friends contributed something to the relationship, these contributions differed according to whether the friend had a disability. Once a friendship bond was established, it was most often the person with the disability who made the phone calls, suggested possible activities and events and were most likely to remember holidays, anniversaries and so forth. On the other hand, it was the persons without disabilities who provided the transportation, occasionally contributed money for activities, took care of any logistical arrangements and facilitated interactions between their friends with disabilities and others.

The relationships were generally exclusive, e.g., to a certain extent the people involved excluded others from their respective friendships. Through the process of defining and maintaining a friendship over time, each of the informants had learned how to be a friend. This was not the first or only time that any had been engaged in a friendship. But by being seen as - and seeing themselves as - friends, and being treated as friends, each of the informants was able to assume the friendship role and learn something about being a friend. In this way, they were able to take part in the practice of friendship.

Implications of the study

Three themes evolved from the study and provide a basis for drawing some conclusions: The effects of living in the human service world, the enhancement of possibilities for friendship between people with and without disabilities and the avoidance of the romanticisation of these friendships.

1. Living in the human service world

First, the majority of people the informants with disabilities knew were staff and other people with disabilities. While three had had contact with their families over the years, the majority of people in their lives were those with whom they conducted the daily business of living: doctors, dentists, shopkeepers and so on. Most human service programs (schools, residences, workshops, recreation programs) effectively set up barriers between people with disabilities and most people in the community. Surrounded by staff and others receiving the same services, people with disabilities are relegated to roles of "clients", "service users", or "program participants". Family connections may be ignored or broken. Friends may be discouraged from keeping in touch. A person's history can be lost merely by entering a residential program. Bercovici (1983) found, for example, that a large number of adults with mental retardation did not view themselves as living in the "normal" community, but rather in a parallel, community-based but nevertheless institutional setting. Her subjects compared their lives in the community to that of the institution with the same staff, program structures and hierarchy of control. Such occurrences are not infrequent and the informants in our study had had similar experiences. They take place so often that they form a pattern, i.e. the "normal" existence for people with disabilities (Blatt & Kaplan, 1966; Blatt, Ozolins & McNally, 1977; Wolfensberger, 1975; Wolfensberger & Thomas, 1983).

The role of human services in the lives of people with disabilities often results in unnecessary and extensive control over at least part of the persons' lives. The staff have the authority to determine with whom a person will spend time. Agency staff may then try to set restrictions on what the clients can do with their friends and may actively try to end some relationships. Other programs

try to turn friendships between typical persons and clients into formalised volunteer relationships. Such efforts make the volunteers responsible to the agency and weaken their bonds with their friends.

While all of the four informants with disabilities did have some experiences in a freely-given and chosen relationship with someone, they did not enjoy the same number of such relationships as did the informants without disabilities.

For the informants with disabilities, the most successful way to meet new and different types of individuals was to be introduced to them through their friends without disabilities.

2. The possibilities for friendship between people with and without disabilities.

Despite the differences between opportunities and experiences, at least some people with disabilities have successfully formed friendships with people without disabilities. Through studying established friendships, we learn that both parties respect one another. The friends also experienced a mutuality in their interactions that may not be apparent to the outside observer. These feelings stem from a sense of identification between the two individuals. They come to see the "sameness" or commonalities between themselves and these serve as the basis of the relationship. This mutuality was expressed by the giving and receiving of emotional support and practical assistance, serving as an inspiration for each other, breaking rules together and by simply enjoying the time spent with one another.

Three of the people without disabilities met their future friends in situations where they were not identified primarily as "clients". One saw her friend with a disability primarily as a co-worker. Another saw a fellow parishioner with whom he shared some commonalities: They were both single men with spare time who wanted companionship - a buddy to hang out with. A third informant saw her friend mainly as an adult student like the many others who had taken her course. She also identified with her friend as a woman who had experienced oppression because of her gender. These perceptions helped pave the way for a friendship to develop. When people with and without disabilities go to school, work, attend church, live and conduct their lives side by side, the possibilities for friendship are enhanced. When individuals are in staff/client roles, it may be more difficult to establish personal relationships with each other. For two of the informants, these roles had to be transcended in order for their friendship to begin.

Friends, not heroes

In our enthusiasm to support friendships between people with and without disabilities, there may be a tendency to inflate the existence of such friendships, to exaggerate the status of these friendships in the partner's lives and to overemphasise the effect or influence of a specific friendship in a person's life. There is documentation, however, of incredible efforts made on behalf of people with disabilities by their friends (Schwartz, McKnight & Kendrick, 1987). Bogdan (1987) describes how friends helped to reunite a family and built them a new house. One woman's life was literally saved when her friends saw to it that she was removed from the abuse and neglect that she was receiving in a nursing home (Forest & Snow, 1983; Perske, 1988). These stories of heroic friendship have served as sources of inspiration to quite a few people

and have been used to illustrate the importance of friendship for people with disabilities.

While many would consider friendship in our lives as essential, it cannot serve as the panacea for all of our problems. As in all other interpersonal relationships between human beings, friends may sometimes disappoint and hurt each other. Friends sometimes fight with each other and do not always make up. Some friendships end while others may not meet the expectations and hopes of one or both of the people involved in the relationship. In the desire to encourage friendships, and to publicise certain stories in order to serve as a model for others, the mystifying and mythologising of the relationships that do exist must be avoided. To turn the real struggle of people's lives into fables is to strip the people of their reality and the true power of the friendships. For it is when friendships continue in spite of the pain and disappointment, that something beautiful has been borne into existence.

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