

Almost Friends

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ABSTRACT

A survey was conducted of human services professionals working with individuals with developmental disabilities regarding issues related to friendship. Seventy-six percent agreed that there is a difference in friendship between people being paid to be with a consumer of services and those choosing to be with that same individual. The authors concluded that it appears that those individuals serving persons with developmental disabilities are “almost friends” in that although they are potentially friendly, they are paid to be with those with whom they interact, and that for these and a variety of other reasons are not able to be real friends.

Keywords: *almost friends, community integration, developmental disability, friendship, intellectual disability*

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Millie is a woman with intellectual disabilities who lives in a group home with four men. The provider of her home has, generally speaking, sought to facilitate for her the best life possible. She has allowed her to develop relationships with people in the community, particularly at church. As a result, Millie is part of a ministry that includes persons with disabilities at her church, she attends a weekly women's Bible study, and she has become known at the church. On several occasions, she has stayed overnight at a hotel as a participant in the church's women's retreats. Several of her friends from the church are university professors who regularly engage her to speak to students in education classes about her life, including experiences growing up in an institution and as a special education student. A local Christian college invites Millie to speak to students each semester, once again about her life experience and how her Christian faith intersects with that experience. Several families invite her to participate in holiday celebrations, so she becomes a regular guest at Christmas and Thanksgiving. For her fiftieth birthday, Millie was part of a celebration with a couple from the community who were also celebrating their fiftieth birthdays. Millie also has a boyfriend at church, and they enjoy being together at social events. They talk about getting married, but she says she isn't ready to commit to such a relationship. Her life is full and quite typical in many respects.

But then there is a change in her social worker. The social worker states that because of Millie's assigned group home level, she must be accompanied by a paid staff member from the group home for any event outside of the home in which she participates (a false claim). The group home cannot afford a staff member focused exclusively on her "needs" (although there really isn't any need for such a person, as evidenced by the past ten years of her life), so all of her activities with the social network that she had developed are terminated and she remains at home with the four men, with no change in sight. Millie's friends in the women's group at church literally cry over her situation. Believing the information given her, the director of the group home (who, interestingly, is the wife of a pastor) tells Millie that they are "taking a break from church." This is clearly not Millie's choice or what she would desire; however, she acquiesces either because she doesn't want to hinder the longstanding relationship with her home provider, or because she simply doesn't know what to do. "We sure miss you!" her friends at church say—to which she responds robotically, "We are taking a break from church."

Wounding

“The most important thing in life is friendship and those in human services act as if they didn’t know that.” That is how Dr. Hans Reinders (2011) addressed the plenary session of the American Association on Intellectual and Developmental Disabilities (AAIDD) National Conference. Regarding the story related above, which is largely a true story, why couldn’t the human service staff just leave the situation alone? Why couldn’t the group home provider support Millie’s full life? Against all odds, a woman with intellectual disabilities was integrated into the community. She was known, loved, and respected as a friend, as a girlfriend, and even as a regular speaker at a local university. But none of this mattered to the human services workers in her life, because the *most* important thing appeared to be that services were administratively convenient, and that she had a label that had been given to her by a professional. That Millie’s life was filled with friendships with community members was truly irrelevant. The label was more important than the fact that, remarkably, she had developed a full life; more important than the fact that her success at social integration was a one-in-a-million victory; more important than her wishes for her life.

“Wounds,” as they are referred to by Wolfensberger (2001), have to do with the social consequences of being devalued. Wolfensberger was not the only one to use the term “wound”; authors such as Nouwen (1972), Vanier (1992), and Wilke (1977) have also recognized the pain felt by people as a result of being devalued by society, and have used the term to describe the experience of individuals with impairments. The nature of these wounds is that they are persistent. It is not that a person is wounded and then heals, leaving a scar. Rather, it is a continual type of wounding, where healing is extremely difficult. A physical wound is something that can heal over time with the proper medical treatment. However, these types of wounds seem to be addressed best through relationships, through friendship, and through change in the social environment.

Thomas (1990) states that “disability is a form of social oppression involving the social impositions of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (p. 577). Relationships with others are vital in order to have a healthy life. Our relationships with others are the basis of society. These encounters affirm our existence, foster growth, help ensure stability, and give us a sense of place and purpose (Robinson, West, & Woodworth, 1995). When a person is involved in a relationship they are sharing part of

their life with another individual, and as a benefit they are getting a glimpse into another person's life. But too often, people with disabilities are only receiving "treatment" and are exclusively thought of as "clients" (Conner, 2010; Wolfensberger, 2000). Could it be that they are considered unable to have, or unworthy of, friendships with community members?

Friendship and Almost Friendship

It may be that state regulations, policies and procedures contribute to those with disabilities having difficulty forming friendships (Amado, 1993). Community members are unregulated and can disrupt the management of persons served by human services. The result is that the lives of many individuals with disabilities are filled with what might be called "almost friends." That is, they have people who are reimbursed to care for their needs; however, these people are either unwilling, unable or not permitted to take the extra step to become a friend. They are in relationship because they are paid to be in relationship.

Though services delivered according to the medical/rehabilitation model may result in many needs being addressed, the approach can also dehumanize a person. As consumers, people with disabilities are able to receive services that address their specific needs, whether medical/rehabilitation or job and life skills training. However, those who serve people with disabilities may not be trained in social interactions, how those with disabilities might perceive them, how to facilitate involvement in the community, or in how to develop friendships (Grenot-Sheyer, Coots & Falvey, 1989). Case providers and case workers are not required to make, and are perhaps even discouraged from making, real friendships (Conner, 2010).

According to Nirje (1969) there are four goals that need to be addressed in order for someone's life to change from being viewed as a devalued individual to a valued part of society. First, devalued individuals need to be taught competencies and skills that help minimize the functional impact of their disability. Second, they need to develop skills and behaviors that will facilitate acquiring valued roles in society. Third, they need to use learned behaviors and skills to be active participants in their community. Finally, as a result of being physically present and a part of the community, they need to build secure relationships within the community.

Wolfensberger (2001) would further advocate that people be given valued roles as a means to gain the good things in life. In the example provided, Millie had achieved the roles of church member, Bible study

participant, university lecturer, friend, family member, and girlfriend among others. Through these roles, her life was full. However, the state agency and group home together stripped her of these roles and replaced them with what they felt was the most important role: intellectually disabled, group home resident. Why is this is the most important role?

Amado (2011) described the conflict or tension between “safety” for state wards and efforts at community integration for the same. The tension appears in our society as well: safety always trumps community integration. Why would this be the case, when these goals may be at least equal in importance? Certainly care providers should not be cavalier in allowing just anyone access to an individual with impairments. However, people should also not be prohibited from living real lives through equally cavalier overprotection. If nothing “bad” ever happens to you, you can be sure you are not living a real life. But in the case of our example, nothing untoward had happened in nearly ten years within the network that Millie had developed. In fact she was thriving; she was blossoming. But that was irrelevant to the human service/group home workers. There was literally no consideration of the fact that she had developed a real life outside of the definition of her as a “person with disabilities.” Her only “real” life was that orchestrated by her caretakers. Her community-integrated life appeared little more than a dalliance: something permitted as if it were a reinforcement for being good in her regulated life. Like a page out of Michel Foucault, the regulated and permitted lives of this woman betrayed the power of those over her (Drinkwater, 2005). Relatedly, recognized “friendships” were only with her regulators, although they were arguably not friendships at all.

Swinton (2004) states “[t]he priority of friends is the personhood of the other and not the illness” (p. 43). This emphasizes the contribution of friendships in making a person who they are. Friendship provides identity to a person. Reinders (2008) and Yong (2007) also emphasize the importance of friendship in their writings. They point out that though services have improved for those with disabilities, the most important aspect of one’s life is meaningful friendship.

Those with disabilities “will live as strangers in a strange land” says Reinders (2008, p. 123). The quote speaks volumes about the isolation that those with disabilities go through in their lives. They are perceived as not fitting into society’s mold, and as being different. Depending upon their impairment, before they are even born they may already be considered a devalued person. This is an aspect of the culture to which they are forced

to acclimate.

Because of the negative stigma projected on those with impairments (Mcvilly, Stancliffe, Parmenter, Burton-Smith, 2006), those without disabilities may feel that they would have nothing in common with someone who has an impairment, making it more difficult to build long-term relationships. In part because of this fact, it is thought that people must be paid to be in the lives of those with impairments. The paid individuals are, hopefully, friendly and professional, yet they are still paid to be in relationship. Referring again to the idea of wounds mentioned earlier, wound nine of Wolfensberger's (2001) eighteen wounds is stated, "absence or loss of freely given relationships and substitution with artificial/boughten ones" (p. 108). This form of wounding is too often the experience of those with disabilities.

Human service workers themselves may be confused by their relationships, particularly when it comes to individuals with intellectual disabilities. Whether it is due to their kindness, confusion, or impairment, people with intellectual disabilities will refer to case workers as their "best friends," not understanding that if those case workers were not paid, they would no longer be in their lives. Whether due to a job change, client case-load change, or job loss, caseworkers move on with their lives when they no longer have job responsibilities toward a person. This disconnection with the consumers of their services does not in any way make them bad people. But it does clearly indicate that they are not friends, as friendship is not dependent upon one member of the friendship being paid to be with the other.

Once again referring to the example of Millie, it is arguable that the wound described above, the wound of exclusively paid relationships, represents the generally accepted strategy used by human services to assist those with disabilities. The paid nature of these relationships may also disqualify them from being referred to as true friendships. Rather, they are "almost friendships" if they occur at all. Even those who are chosen by service providers as "favorite clients" are not friends, and many are not chosen. Could it be that human service providers are satisfied with those with disabilities having their lives populated by almost friends? The idea of real friendships in the community appears to have been abandoned.

Friendship is seemingly so simple; everyone knows what they are looking for in a long-lasting friendship. All people look for someone who they can tell their secrets to, someone who will just listen and not talk,

someone who will understand what they are going through in their lives, someone they can count on for help and support in difficult times, and someone who can relate to them (McVilly, Stancliffe, Parmenter, Burton-Smith, 2006). However, friendship may not be as simple as it might seem at face value. This study sought to investigate issues related to friendship through a survey of human services workers.

Methodology

A survey was developed to query human service workers about issues related to friendship and those with intellectual and developmental disabilities. The survey was shown to various experts and their input used in revisions. The survey was then piloted among a group of individuals having the same characteristics as the potential survey respondents. On the basis of this input, the survey was once again revised. It was then duplicated and handed out to a group of human service workers who were gathered to receive work-related training at a large West Coast facility that is responsible for services to persons with developmental disabilities. Prior to the training, the survey was distributed and then collected. Respondents were asked to answer the questions to the best of their ability. The sample was specifically selected because of their history of working and having close contact with those living with developmental disabilities. Data was analyzed by completing frequencies for each response.

Results

The respondents consisted of 56 adults; 3 were male and 53 (95%) were female. Eighty percent (n=45) of those surveyed had regular, direct contact supporting people who have a disability. The remainder worked as support or managerial staff for the organization. Those surveyed ranged in length of employment from five months to 19 years (mean 7 years).

In question 1, 69.1% of respondents agreed that friendship is defined as “bonding and having a connection with a person who can respond back either verbally or physically.” However, 54.5% disagreed with the statement in #3 that “bonding and friendship are one in the same.”

In question 2, although 55.5% of respondents indicated that their duties include facilitating the development of friendships with consumers,

Table 1
Survey Results

	Question	Strongly Disagree		Disagree		Undecided		Agree		Strongly Agree		56
		n	%	n	%	n	%	n	%	n	%	
1	Friendship is defined as “bonding and having a connection with a person who can respond back either verbally or physically.”	3	5.5	11	20	3	5.5	24	43.6	14	25.5	55
2	My duties as a caretaker/case worker include facilitating the development of friendships with my consumer.	1	1.9	8	14.8	15	27.8	24	44.4	6	11.1	54
3	I consider bonding and friendship one in the same	0	0	30	54.5	5	9.1	13	23.6	7	12.7	55
4	An individual who is paid to provide services to someone who has a disability has the potential to become a friend to that individual.	1	1.8	7	12.5	5	8.9	32	57.1	11	19.6	56
5	My consumer and I are equal in social class.	2	3.7	13	24.1	5	9.3	18	33.3	16	29.6	54
6	I am permitted by my employer to develop friendships with the individual with whom I provide care.	6	10.9	22	40	11	20	14	25.5	2	3.6	55
7	There is a difference in the friendship between people who are paid to be with a consumer and people who choose to be with a consumer.	2	3.6	3	5.4	8	14.3	27	48.2	16	28.6	56
8	The person I care for, I would care for free of charge.	4	7.3	5	9.1	14	25.5	21	38.2	11	20.0	55
9	In order to have a friendship with someone, there needs to be verbal communication.	11	20.0	36	65.5	3	5.5	2	3.6	3	5.5	55

Table 1 Continued
Survey Results

	Question	Strongly Disagree		Disagree		Undecided		Agree		Strongly Agree		56
		n	%	n	%	n	%	n	%	n	%	
10	People with disabilities have the potential to make friends.	0	0	2	3.6	1	1.8	13	23.2	40	71.4	56
11	I have friends who are my age peers with the same types of disabilities as those for whom I provide care.	6	11.1	25	46.3	7	13.0	10	18.5	6	11.1	54
12	People with disabilities need friends.	0	0	1	1.8	1	1.8	11	19.6	43	76.8	56
13	I have attempted to facilitate friendships on my own time with people with disabilities.	2	3.6	16	29.1	7	12.7	25	45.5	5	9.1	55
14	State regulations, policies and guidelines hinder me from making friendships.	6	11.5	16	30.8	13	25.0	12	23.1	5	9.6	52
15	I am evaluated on the basis of the number and quality of friendships my consumer has.	16	32.0	26	52.0	6	12.0	2	4.0	0	0	50
16	I have received training on how to facilitate friendships for my consumer.	11	21.2	25	48.1	4	7.7	12	23.1	0	0	52
17	Friendship between people can be with someone who cannot speak or communicate.	0	0	3	5.7	1	1.9	27	50.9	22	41.5	53
18	My consumers' friends are mostly those with disabilities and very few without disabilities.	0	0	11	21.2	9	17.3	24	46.2	8	15.4	52
19	My consumer is able to make friends on their own.	2	3.9	11	21.6	15	29.4	20	39.2	3	5.9	51

27.8% didn't know if that was part of their duties. Additionally, although 76.7% indicated that someone who is paid to provide services has the potential to become a friend to a client (question 4), only 29.6% of respondents indicated that they have friends who are age peers, with the same types of disabilities as those to whom they provide care (question 11).

Also in question 2, although 55.5% said development of friendship is part of their duties, in question 6, 50.9% disagreed and 20% were unsure of whether they are even permitted to develop friendships with the individuals for whom they provide care.

Although 76.7% of respondents indicated they have the potential to provide friendship (question 4), 76.8% also agreed that there is a difference between people who are paid to be with someone and those who choose to be with someone (question 7). Yet in question 2 once again, 55% of respondents considered the development of friendships with service consumers a part of their duties as a caseworker/caretaker.

Question 11 responses indicated that only 29.6% of respondents had friends with the same types of disabilities as those whom they serve, in spite of the fact that in question 13, 54.6% stated that they have attempted to facilitate friendships in their own lives with people with disabilities. These respondents either have 1) difficulty finding or making friends with individuals with the same types of disabilities as those whom they serve, 2) don't attempt such relationships, 3) are unsure about how to develop such relationships, or 4) are unsuccessful in developing such relationships.

In question 2, 55.5% of respondents indicated that their duties include the development of friendships; however, in question 15, 84.0% disagreed that they are evaluated on the number and quality of their clients' friendships.

Based upon question 3, it appears respondents were unsure of whether bonding and friendship are the same, with 54.5% disagreeing and 36.3% agreeing.

If, as in question 5, respondents consider themselves "equal in social class" to their consumers (62.9% agree), one might think there would be a greater likelihood that friendships would develop.

In question 4, 76.7% of respondents indicated the potential to become a friend with someone they are serving. Yet in question 6, 50.9% indicate they are not permitted to develop friendships with individuals they serve. In reality, they are unsure as to whether state regulations and policies encourage or prohibit their formation of friendships with service consumers. Also in question 6, 20% were undecided and 29.1% agreed about

whether they were permitted. Similarly, in question 14, the responses were mixed, as 42.3% disagreed, 25.0% were unsure, and 32.7% agreed about whether state regulations, policies, and guidelines hinder them from making friendships with consumers with disabilities.

If 58.2% of respondents would truly be willing to care for their client “free of charge” (question 8), what type of relationship has developed between caseworker/care provider and client? What also does this imply about how support services might be developed in the future? If only 29.6% have friendships as stated, another category of service might be described as unpaid non-friends who provide supports.

Interestingly, 85.5% of respondents indicated that there need not be verbal communication for friendship to occur (question 9), and 92.4% agreed that friendship can occur with someone with communication issues (question #17).

Once again, caseworkers/care providers indicated that they are not evaluated on the basis of the number or quality of their clients’ friendships (84.0% for question 15). With the large caseloads these workers have, one can probably assume they will not provide services on which they are not evaluated.

Respondents also note in question 18 that consumers mostly have friends with disabilities and very few without disabilities (61.6% agree). There was a mixed response to the ability of consumers to make friends on their own (question 19), which is as might be expected because of variance in the characteristics of the individuals being served. However, it appears the 45.1% in question 19 who state consumers are able to make friends on their own are largely making friends with others with disabilities. This might be a reflection of the opportunities that are provided to have friendships with those without disabilities or the involvement of those without disabilities in their lives. Where might people with disabilities find friends in the community?

Although in question 12, 96.4% of respondents indicated that people with disabilities need friends, it appears that apparently little is being done to facilitate such friendships. Of these same respondents, however, 94.6% agreed that people with disabilities have the potential to make friends. Whether this is with others with disabilities, with paid staff, or with other community members is unclear.

Finally, respondents largely (69.3%) had not received training on friendship development (question 16). This statement supports the

validity of the survey in that responses indeed point to a need for training of caseworkers and care providers.

Discussion

This survey yielded some interesting yet conflicting information. About two thirds of respondents reported that they are not developing friendships with same-age peers having the same types of disabilities as the consumers they serve. In point of fact, human service workers are unsure whether they are even permitted to have friendships with their consumers. Half of the respondents responded that they were not permitted to develop friendships. Nearly 75% of respondents agreed or strongly agreed that being paid results in a different type of relationship with someone than choosing to be in relationship with that person, without pay. We have referred to this relationship as an “almost friendship.” In addition, although there might be the expectation that facilitating friendship development is a part of human service workers’ responsibilities, they are not evaluated on this basis—implying that if someone is not evaluated on a particular job responsibility, there is less likelihood that they will perform that aspect of their work. Most of the friends that consumers have are with others with disabilities. As McNair (2008) indicated, these relationships are not to be disdained, yet they do not bring the same network connection benefits, nor perhaps the same “potency” that friendships with those without developmental/intellectual disabilities might bring.

Conclusion

The obvious conclusion is that there is a dramatic need for training and the development of policies to bring clarity about relationships in human services, particularly between those providing services and those being served. Approximately 77% of respondents disagreed that they had or didn’t know if they had received training about friendship. Such training might typically include a variety of areas. What does friendship mean? Respondents appeared not to know. Is one permitted, according to agency regulations, to be a friend with someone they are paid to serve? Half of the respondents indicated they were not permitted and others were unsure. What role does friendship development play in the responsibilities of human service workers? The overwhelming majority of

respondents indicated that those in the position of evaluating services appear not to care. Finally, who is it that will befriend individuals with developmental disabilities? Of those surveyed, only 29.6% have friends with the same types of disabilities as those for whom they care. It is also important to recognize that there are many individuals in the community who would benefit from friendship but who are not on an individual caretaker's caseload. Even if friendship between consumers and caseworkers is forbidden, not everyone is on a caseload. So, caseworkers should feel free to develop relationships with other community members. However, if experts will not develop friendships with persons with disabilities in their own lives, whom do we expect will develop such relationships? It is not surprising that nearly 80% of respondents indicated that consumers' friends are mostly those with disabilities. The results indicate that those without disabilities, including the experts, are not choosing people with impairments as friends. The current best hope for friendship with people without developmental disabilities appears to be with their almost friends: people who are paid to be with them. Sadly, it appears that those of us in human services are satisfied with this.

A 1990 paper by Hutchison proposed six new roles for professionals in human services. First, formal services should recognize their limitations for relationship development and rely more on connecting people with informal community groups. Second, rely less on getting people into programs exclusively for persons with disabilities which rarely lead to development of community relationships. Third, traditional volunteer programs should be evaluated and changed to be better vehicles for friendship development. Fourth, attempt to develop more reliance on community members for "services" rather than being completely reliant on paid services. Fifth, remove segregation in services such that there would be enhanced possibilities of participation with community members. Sixth, recognize the limitations of human service professionals to actually facilitate friendships, looking instead to age peers, community members with common interests, and others who are already community-connected. McNair (2008) described the church as playing the role described by Hutchison (1990) in the community. Human service workers would be wise to consider employing churches in their efforts to develop friendships for their clients.

These findings seem to support Reinders' contention about the importance of friendship in life as not being reflected in the perceptions of those

in human services. Individuals having the most responsibility and the most authority—those in positions of making decisions about the lives of those with developmental disabilities in their care—appear unprepared, unwilling, or ill-equipped to make friendships with community members happen. As Vanier (1979) put it, “[i]n the end, the most important thing is not to do things for people who are poor and in distress, but to enter into relationship with them, to be with them and help them find confidence in themselves and discover their own gifts” (p. 142).

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