family ADVOCACY

Record

102

File Number

10076

Author: Lutfiyya, Zana

Title: Materials on relationships

Original source: -

Resource type: Written   **Publication Date:** 01/08/88

Publisher Info: The Centre on Human Policy, Syracuse University

Abstract

This American article was written in response to requests for information on how to develop and support relationships between individuals with disabilities and those without. By living in service structures, most people who have disabilities develop relationships with paid staff and become "clients". The impact of this is discussed and the article provides some strategies for increasing and encouraging opportunities for disabled and non disabled people to meet and interact. **Keywords: Friendships**

MATERIALS ON RELATIONSHIPS

Prepared by:

Zana Marie Lutfiyya
The Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, New York 13244-2340

August, 1988

CONTENTS

PART I: Overview Article: Reflections on Relationships Between
           People with Disabilities and Typical People

PART II: A Brief Annotated Bibliography of Related Readings

Zana Marie Lutfiyya
August 1988

Preface

This article was written in response to requests for information on how to develop and support relationships between individuals with disabilities and "typical" people. This area is receiving a lot of attention, and a variety of programmatic efforts to "build bridges" between the human service and "citizen" worlds are underway. This article describes some of the factors that seem to influence the possibility of relationships. A short annotated bibliography on relationships is included at the end.

Zana Marie Lutfiyya

Reflections on Relationships Between
People with Disabilities and Typical People

*Basically we should look at how we live--the different
relationships we have, the choices we make, and so on--and aim
to ensure that our friends with handicaps have the
same sort of fulfilling lives we have.*

- Nicola Schaefer

Common Experiences of People with Disabilities

It seems trite to assert that people with disabilities possess the desire and need for
relationships with other human beings. Don't we all? Yet at a recent training session
with the staff from a residential program, the lack of relationships in the lives of people
with disabilities was clearly pointed out. Thinking of the people they worked with, the
staff determined that none had "best friends". A few of the residents could claim one or
two "close friends" while two enjoyed warm ties with their families. All of the residents
knew half a dozen or so "acquaintances" with whom they maintained casual contact.
The majority of the people the residents knew were staff, other residents, and the people
with whom they conducted the daily business of their lives; 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 their
community. Surrounded by paid staff and others receiving the same services, people
with disabilities are made into "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. Such
occurrences are not infrequent. They take place so often that they form a pattern--the
"normal" existence for people with disabilities.

It doesn't have to be this way. Some people with disabilities are well-loved, treated with
respect and encouraged to remain connected with their families, typical peers, and
people they have known in the past. However, it is important to recognise some of the
other dynamics that exist in the lives of people with disabilities.

"Us and Them": Being Seen as Different

The heart of this matter lies in how most non-disabled people view their counterparts
with disabilities. Over time our society defined people with disabilities as somehow
different than the rest of us, and in need of specialised care. The view that individuals
with disabilities are in some ways essentially different from the rest of us results in
several types of experiences. People with disabilities are separated from their families
and communities, cast into roles of dependency and passivity, and even when physically
present in some community settings, are kept at a social distance from the other
members of the community.

Separation

The pattern of the historical removal of people with disabilities from our society is well-documented. Large numbers of individuals were placed into large congregate-care facilities for the avowed purposes of education and training, medical care, family relief or social control of unwanted segments of the population (MacMillan, 1977; Scheerenberger, 1983; Wolfensberger, 1977). Some concentrated efforts were also made to sterilise certain groups to prevent their propagation and also to kill them outright (Lusthaus, 1985; Werthan, 1973).

The enforced segregation of people with disabilities from the daily life of their communities reinforced the belief that some people are so different that they cannot fit in or successfully contribute to their society. Typical community members lose the chance to meet, get to know, and be with individuals with disabilities. The opportunities for people in both groups to grow up together, and form attachments with each other are often lost.

Clienthood

By entering a program, most people with disabilities are turned into "clients". During this process, a person is cast into a dependent and passive relationship with the staff and other caregivers. When the client role becomes life-defining, the person can become lost and emphasis is placed on the person's deficits. Teachers, doctors, therapists and other workers are hired to correct the problems seen as inherent in the disabled person.

As a "client", a person learns to show the acceptable behaviours at the right times in order to get by. Consider the following incident. The author recently met two young women who shared an apartment and received support from visiting staff people. The women set up menus, bought food, and cooked the meals, all with the staff's onlooking approval. Once left to their suppers, the women would throw out these meals and prepare the food that they wanted to eat.

Given the above dynamics, it is not surprising that there is little mutual respect found in many relationships between program staff and clients. As part of their jobs, the staff attempt to control the lives of their clients, who in turn try to maintain some control over their own lives. While the staff may define the client's behaviour as manipulative, self-destructive and so on, they in turn may view that staff as capricious, inconsistent or simply out to get them (Bogdan & Taylor, 1982; and Lovett, 1985).

A common part of any client's life that is under the control of staff people are the individual's contacts and relationships with others. Both children and adults with disabilities may be restricted from visiting their families or friends, from developing relationships with others.

Being a client can create barriers in the development of reciprocal and nourishing relationships with others. Through rare or a complete lack of opportunities, people with disabilities become slowly desperate for connections with others that are not governed by control (McGee, Menousek, & Hobbs, 1987). As virtually all people served by human services agencies are "clients", the area of relationships between people with disabilities and typical citizens needs to be addressed.

The People in Our Lives

Most of us take the notion that humans are social beings for granted and are surprised to learn that others may not have the same range of friends, family, and acquaintances as

we do. Most of us would agree that there are degrees of closeness or intimacy across our own relationships. We acknowledge intimates or "best friends" as those few people who are closest to ourselves--at least in terms of understanding and support. They are the ones we can turn to, in any situation. Next come our friends, and then acquaintances-- friends of friends, people who are not strangers. We "know" this latter group, but not well. Finally are the numerous people whom we see regularly, but for specific purposes; the postman, doctor, shopkeeper and so on.

Developing and Maintaining Relationships

Helping someone to meet people and make friends can be difficult. Formal, programmatic efforts to do so contradict our society's notion of how relationships are formed. We do not think of ourselves as reliant upon arranged marriages, strict kinship obligations, or planned introductions between people who might be "good for one another". The possible exception to the latter case are potential business associates, where purely utilitarian needs are considered appropriate.

Arranged introductions seem an artificial and heavy-handed way to establish relationships. And yet, some human service providers are attempting to do just this in order to surround people with disabilities with a number of friends and close ties. These efforts are made in order to overcome the barriers that prevent more naturally occurring relationships from taking place. Despite the obstacles, it cannot be denied that warm, reciprocal relationships between typical people and those with disabilities exist (Bogdan & Taylor, 1987b; Strully & Strully, 1985; Taylor & Bogdan, 1987). Along with the growing recognition of the importance of such relationships are human service staff hired to "build-bridges" between people with disabilities and typical people (Bogdan, 1987; Johnson, 1985; Walker & Salon, 1987).

Both popular wisdom and the literature on this subject suggest several factors that may be involved in the development and maintenance of relationships. What is still not resolved is precisely how these factors are related to each other and their impact upon individuals.

Some Qualities and Dimensions of our Relationships

It appears that at least six characteristics experienced by typical people in their efforts to meet others and develop relationships may not be as available for people with disabilities. These qualities of our relationships include opportunity, diversity, continuity, relationships that are freely chosen and given, and intimacy.

Opportunity

Typical people can take advantage of numerous opportunities to meet and get to know other people. We meet others through our families, neighbours, school/workplace, cultural, civic, and recreational events, church, synagogue. We also come into contact with innumerable individuals simply in conducting our daily affairs--buying food, getting the car fixed, taking care of our health needs, hair cut, mail received or sent. In our western culture, it requires effort to avoid meeting new people.

For many people with disabilities, such opportunities are simply lacking, and they possess extremely limited opportunities to take part in activities and events where they can meet their typical peers. We read of adults who did not know what rain was

(Rothman and Rothman, 1985), or a woman who had never sat by a lighted fireplace (Bogdan & Taylor, 1982). And even when people with disabilities may be physically present in a community, a variety of circumstances conspire to keep them apart from their neighbours (for example, program rules and restrictions, transportation, poverty).

Support

Providing adequate opportunities for people with disabilities to meet and interact with valued citizens in positive ways must be the first step towards the building of meaningful relationships. Hand in hand with these opportunities must be adequate support for both the person with disabilities and the typical people involved. One woman wanted to go to church, as she had not attended since she was a child. A church of the right denomination was located, the priest contacted, and a parishioner agreed to sit with Helen during Mass and accompany her to the coffee hour afterwards. For Helen, this effort was not enough. She did not know how to behave in church, and smoked cigarettes, talked, and swore during the service. Not surprisingly, the parishioner became uncomfortable sitting next to Helen, and soon stopped coming to pick her up. Helen needed someone comfortable enough to direct her actions quietly while in church-- suggest going out for a smoke, or waiting, being quiet. Initially, a staff person sensitive to Helen's need to attend church and to the limits of appropriate behaviours might have made the difference, by minimising disruptions, allowing Helen to attend church and meet others in the congregation. This staff person could then encourage a member of the congregation to support Helen, in the hope that a friendship would develop. Enhancing relationships between people with disabilities and typical citizens is not accomplished by throwing unprepared and unsupported individuals together.

On the other hand, support, instruction, and guidance must never be confused with restricting a person's opportunities to meet and form ties with other people. Human service programs have historically controlled and limited the opportunities available to individuals with disabilities.

Diversity

At a party once, one man suggested that even with only ten people in the room, one of us would know someone who came from, or have been ourselves, to virtually any country in the world. The first sceptic named Borneo only to learn that one woman's Malaysian secretary was born on the Island of Borneo. A coincidence perhaps, but if we stop to think about it, we know an incredibly diverse range of people with differing backgrounds, interests, jobs, education etc. Although we not may choose to associate with, or become close to everyone we meet we have the opportunity to select our friends from a large number of very different people.

Unfortunately, the same cannot be said of many people with disabilities, especially those who were raised apart from their families and neighbourhoods. People served in both institutional and community-based settings may experience little contact with people other than fellow clients and staff people. Along with increased opportunities for people with disabilities to meet typical citizens must come the support to get to know a variety of individuals.

As we introduce people with disabilities to more people, we must also give up some of our control over their lives. The excessive control that human service staff now exercise over their clients would be socially inappropriate in the types of relationships that we wish to encourage. We must constantly discern the line between adequate support, guidance and

protection and the over-protection that unnecessarily restricts a person in his/her movements and associations.

Continuity

Many of us thrive on opportunities to meet new and interesting people. But as we continue to meet new people, we are sustained by those we have known for a long time. The continuity we experience in some of our relationships over the years is an important source of security, comfort and self-worth. Human beings learn to trust each other within long-term, stable relationships (Maslow, 1954; McGee, Menousek, & Hobbs, 1987).

Many people with disabilities do not enjoy the same continuity in their relationships. Children may leave their families for foster care or residential education programs. Staff people, social workers and case managers can come and go frequently, causing a disruption in a person's life. Wolfensberger (personal communication, mid 1970s) likens many people's experiences to a "relationship circus" where staff and professionals dance in and out of a person's life, each in turn demanding instantaneous trust from the person with disabilities. An observer in a supported apartment program learned that her five months' observation gave her some seniority over most of the support staff (Lutfiyya, 1987).

The service providers who surround people with disabilities must learn to support and not to stand in the way of long-standing relationships of the people they serve. Assisting people to stay in touch is essential. Letters may need to be written and read, phone numbers dialled, transportation provided. Helping a person to remember birthdays, anniversaries and other important occasions are ways to maintain ties. Some people may need help to remember and cherish the history of their connections with others. Some individuals may need assistance during a visit or social event with a friend or relative; such as how to be a gracious host (or guest), how to carry on a conversation, or observe other social graces.

Freely given and chosen relationships

For the most amazing reasons, others like us and love us because they want to. Our spouses, lovers, and friends all choose to be with us and we choose them. We are surrounded by people who accept, love and tolerate us and we do the same for them. When this is not the case, we think that something must be wrong somewhere, and seek to rectify the situation. Popular culture and our books of wisdom assert that this is as it should be.

Many people with disabilities enjoy few close relationships with others, and even fewer unpaid relationships (Johnson, 1985). The main source of relationships for a lot of people with disabilities are their families, program staff and other clients. Given the lack of opportunity and support to meet people in the community this should not surprise us. Yet it can be difficult to appreciate what life is like for people who know no single person who spends time with them because they want to, not because they are paid to do so or are involuntarily placed in the same setting.

Too many human service program practices prevent freely-given relationships from developing. This includes practices such as requiring someone to become an official agency volunteer, attending a training course before meeting the clients, restricting visiting times and placing the typical people in positions of control. When freely given relationships do occur, human service agencies often deny the importance of the

relationship. One young woman met a three year old girl living in a children's rehabilitation hospital. Abandoned at birth, Rose lived with several debilitating physical conditions making some movement and handling painful. The woman visited Rose, read her stories, sang songs, rocked her to sleep. One week when Judy came to visit, she found another child in Rose's bed. Rose had died a few days earlier. When Judy, the woman, questioned why she had not been contacted, and why no memorial service was planned, she was offered grief counselling. The staff also expressed surprise over Judy's attachment to Rose.

All of this is not to deny that some paid relationships are characterised by genuine warmth, caring and even love. But it is essential to recognise this quality in our relationships and its absence from the lives of many people with disabilities. Our goal must not simply be to introduce people to others, but to create the environment that will encourage typical members of our communities to voluntarily choose to form relationships with people whose lives have been marked by separation and loss. Human service staff hoping to support friendships between people with disabilities and typical community members can be direct in their efforts. They can ask themselves, "Who seems to be interested in this person?"; "Who likes this person?" and "Who wants to spend time with this person?".

Intimacy

With its many meanings, the word intimacy may be confusing. It is used here as an expression of the closeness, comfort and trust that people may feel for each other. Intimates can express thoughts and feelings that they share with no one else. Despite the difficulties in determining how a person defines those s/he is "closest to", most people have (or aspire to) a few "intimates".

We are just beginning to recognise that many disabled individuals have no one with whom they share a close, intimate relationship. Some may claim such a connection with another, and find this closeness is not shared by the other person. It would be easy to interpret this "fantasy" as a result of the person's cognitive impairments. But if at least one intimate connection with another human being is vital for each of us, this "fantasy" may be necessary for the individual's functioning. There is no easy answer for those who want to support intimate relationships between people with disabilities and their typical peers. All humans struggle in their search for intimate connections with other people.

Learning from the Relationships of Others

Two themes emerge from a reading of the available literature on the development and maintenance of relationships between typical and disabled people. Often those engaged in the relationships do not see their involvement as unusual or worthy of note. They almost take the relationship for granted (Bogdan & Taylor, 1987b). Secondly, the reduction of barriers and the increase in identification between the two potential friends appears important in creating a mutually respectful relationship (O'Brien, 1987).

The possibility of relationships

It is important not to deny the history of any individual or of a group of people. We must never forget the generations of abuse and neglect visited upon people with disabilities, nor lose sight of the tragic pasts (and present circumstances) of the individuals with whom we work today. But we must also believe that a variety of accepting relationships between typical and disabled individuals are possible (McKnight, 1987). We must provide

opportunities where people can comfortably come together to meet each other, and we must lean to recognise when we are standing in their way.

Increasing identification

Through studying established relationships, we learn that both parties possess a mutual respect for the other. Partners also report a reciprocity 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. Bogdan & Taylor (1987b) suggest several bases of identification held by the non-disabled person that might account for their acceptance of people with disabilities. These include family ties, religious or humanitarian beliefs.

People involved in Citizen Advocacy (O'Brien, 1987; Wolfensberger & Zauha, 1973) attempt to create and support a variety of relationships between disabled and non-disabled individuals who live in the same community. They pay close attention to the process of increasing the identification of the two people with each other, especially when the commonalities may not be obvious.

Conclusion

A mark of real acceptance of individuals with disabilities in our communities can be found in the real relationships they enjoy with typical people. It is probably not possible to create such relationships despite the efforts of people in the human services to do so. However, the opportunities for disabled and non-disabled people to meet and interact can be increased and encouraged. The dilemma for human service workers is the recognition that their programmatic presence may in fact serve as a barrier to the development of the desired relationships.

References

Bogdan, R., & Taylor, S.J. (1982). Inside out: The social meaning of mental retardation. Toronto: University of Toronto Press.

Bogdan,R. & Taylor, S.J. (1987a). Conclusion: The next wave. In S.J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp.209-213). New York, NY: Teachers College Press.

Bogdan, R. & Taylor, S.J. (1987b). Toward a sociology of acceptance: The other side of the study of deviance. Social Policy, Fall 1987, 34-39.

Boles, S.M., Horner, R.H., Newton, J.S., & Romer, L. (1985). The neighborhood living project: A community residential model for citizens with severe handicaps. Eugene, OR: Specialized Training Project, University of Oregon.

Forest, M., & Snow, J. (1983). The Joshua committee: An advocacy model. Leisurability, 10(1).

Johnson, T. (1985). Belonging to the community. Madison, WI: Options in Community Living and Wisconsin Council on Developmental Disabilities.

Johnson, T., & O'Brien, J. (1987). Carrying Options' story forward. Madison, WI: Options in Community Living.

Lovett, H. (1985). Cognitive counseling and persons with special needs: Adaptive appproaches to the social context. New York, NY: Praeger.

Lusthaus, E. (1985). "Euthanasia" of persons with severe handicaps: Refuting the rationalizations. Journal of the Association for Persons with Severe Handicaps. 10(2).

Lutfiyya, Z.M. (1987). [Unpublished field notes].

MacMillan, D.L. (1982). The mentally retarded in school and society. Boston, MA: Little, Brown & Company. (1st published in 1977).

Maslow, A. (1954). Motivation and personality (1st ed.). New York, NY: Harper.

McGee, J.J., Menousek, P.E. & Hobbs, D. (1984). Gentle teaching: An alternative to punishment for people with challenging behaviours. In S.J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities. New York, NY: Teachers College Press.

O'Brien, J. (1987a). A guide to lifestyle planning. In B. Wilcox & G.T. Bellamy (Eds.), A comprehensive guide to the activities catalog. Baltimore, MD: Paul H. Brookes.

O'Brien, J. (1987b). Learning from citizen advocacy programs. Atlanta, GA: Responsive Systems Associates.

O'Brien, J., & Lyle, C. (1986). Strengthening the system. Atlanta, GA: Responsive Systems Associates.

O'Brien, J., & Lyle, C. (1987). Framework for accomplishment. Atlanta, GA: Responsive Systems Associates.

Perske, R. (1980). New life in the neighborhood: How persons with retardation and other disabilities can help make a good community better. Nashville, TN: Abingdon Press.

Perske, R. (1988). Friends circle to save a life. TASH Newsletter, 14(1).

Rothman, D.J., & Rothman, S.M. (1984). The Willowbrook wars. New York, NY: Harper & Row.

Schaefer, N. (1978). Does she know she's there? Toronto: Fitzhenry Whitseside.

Scheerenberger, R.C. (1983). A history of metal retardation. Baltimore: Paul H. Brookes.

Strully, J., & Strully, C. (1985). Friendship and our children. Journal of The Associaton for Persons with Severe Handicaps. 10(4).

Taylor, S.J., & Bogdan, R. (1989). On accepting relationships between people with mental retardation and nondisabled people: Towards an understanding of acceptance. Disability, Handicap & Society, 4(1), 21-36.

Taylor, S.J., Racino, J.A., Knoll, J.A., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

Taylor, S.J., Biklen, D., & Knoll, J. (Eds.). (1987). Community integration for people with severe disabilities. New York, NY: Teachers College Press.

Walker, P., & Salon, R. (1987). Supporting people in the community: A case study of the residential program--Centennial Developmental Services, Weld County, Colorado. Syracuse, NY: Center on Human Policy, Syracuse University.

Wertham, F. (1973). The German euthanasia program. Cincinnati, OH: Harps Publishing.

Wolfensberger, W. (1973). Program analysis of service systems, PASS (3rd ed.). Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1977). The origin and nature of our institutional models. Syracuse, NY: Human Policy Press.

Wolfensberger, W., & Thomas, S. (1983). Program analysis of service systems' implementation of normalization goals. Toronto: National Institute of Mental Retardation.

Wolfensberger, W., & Zauha, H. (Eds.). (1973). Citizen advocacy and protective services for the impaired and handicapped. Toronto: National Institute on Mental Retardation.