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ABSTRACT

This case study represents an attempt to develop knowledge and understanding of "community supports," those formal and informal supports necessary to enable people with disabilities to live in the community and participate fully in community life. The individual in the case study is a white man with severe cerebral palsy born in 1912. The study examines the supports given by a human service worker who provided personal assistance and the role of this support in connecting the subject with the community. The study offers a historical perspective on past service models and highlights the emerging shift from a program paradigm to a support paradigm. Data were collected through interviews and participant observation. Study findings are reported in terms of: surviving in institutional settings; struggling in the community; the role of the personal attendant as a staff person and a friend; and various components of support (everyday practical assistance, translating, facilitating, supporting self-determination, and interweaving formal and informal supports). (41 references) (JDD)

# SUPPORTS FOR COMMUNITY LIVING

## A CASE STUDY

**Center
on
Human Policy**

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## A CASE STUDY

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# INTRODUCTION

The phrase "community supports" has emerged as one of the key concepts in the field of developmental disabilities in recent years. The phrase is most commonly used to refer to both the formal and informal supports necessary to enable people with disabilities to live in the community and participate fully in community life. "Formal supports" refer to supports provided through services and programs while "informal supports" are based on personal ties and social relationships. While the field of developmental disabilities has acquired significant experience in the operation of formal support services and programs, it has only recently begun to explore the importance of informal social networks and personal relationships in the lives of people with developmental disabilities (Forest, 1989; King's Fund Centre, 1388; Lutfiyya, 1990; O'Brien, 1987; Perske, 1988; Snow, 1989; Strully & Strully, 1985; Taylor & Bogdan, 1989; Wolfensberger, 1983).

This newfound interest in social networks and personal connections has its roots in recent criticism of community-based services for failing to connect people with disabilities with other community members (McKnight, 1987; Smull, 1989). Most critics of community-based services argue that although community programs have been successful as an alternative to institutional services, they are facing serious and increasing problems. This criticism of community-based services has led to a call for radical changes in current community programs and the critics have outlined an alternative to the traditional service approach. This new approach should start with the person and an examination of his or her social networks and informal community supports. Then design formal support interventions which build on and strengthen the natural networks in the community (Nisbet & Hagner, 1988; Taylor, Racino, Knoll, & Lutfiyya, 1987). Smull (1989) calls this a shift from the current "paradigm of program" toward a "paradigm of support."

While the critics of community programs agree to a large extent on what changes are needed, they disagree whether the new approach should replace the current services system or if it should be added to the current services. Some critics have declared the community-based service system bankrupt and basically unusable (McKnight, 1978; Wolfensberger, 1987). One of their major criticisms is that instead of building community, professional services replace people's natural helping networks and destroy societal communality (McKnight, 1987; Wolfensberger, 1983). Others argue that although community programs are facing serious problems, the current service system should not be altogether abandoned (Smull & Bellamy, 1991). Instead they want to add new dimensions to the current service delivery: a new approach which, instead of replacing natural helping networks, builds on and strengthens informal community support networks.

McKnight (1987), who has inspired many of the critics of community programs has argued that the current social policy has failed to take into account a major social domain: the community itself. By "community" McKnight means the informal sector of family, friends, neighbors, neighborhood centers, churches, civic groups, ethnic associations, and so on. Thus, what is at the heart of the criticism of current community services is the failure to integrate people with disabilities into community life and connect them with informal networks of supports. Because relationships and connections to what is seen as "natural" community supports is at the heart of the criticism, this has resulted in recent attempts to develop strategies and programmatic attempts to connect people with disabilities with other community members. Examples of these efforts are "citizen advocacy" conceptualized by Wolf Wolfensberger (Baucom, 1980; Wolfensberger & Zauha, 1973); "personal futures planning" or "life-style planning" developed by John O'Brien and Connie Lyle O'Brien (Mount & Zwernik, 1988; O'Brien, 1987); "circles of friends" developed by Marsha Forest and Judith Snow (Mount, Beeman, & Ducharme, 1988a; Forest & Lusthaus, 1989); and "bridge-building" (Mount, Beeman, & Ducharme, 1988b; O'Connell, 1988). What most of these efforts have in common is the emphasis on interweaving formal services with informal supports. The primary goal is to promote inclusion of people with disabilities in neighborhoods, schools, workplaces, and other community environments. The emphasis is on interdependence, self-determination, choice, and empowerment of people with disabilities and their families.

The current debate in the field of developmental disabilities indicates that there is a need to clarify what we mean by "community supports." Who should provide such support and what should be the relationship between the formal service system and the informal community networks. Service providers and families need to know how they can assist people with disabilities to form friendships and become involved in community associations and organizations. Yet, the area of "community supports" and the interweaving of community networks and formal services represents an essentially uncharted territory in the field of developmental disabilities. If people with disabilities are to be successfully and fully integrated into community life--if they are to become part of the community and not merely be present in the community--then we need new knowledge to guide our way (Bogdan & Taylor, 1987).

The case study reported here represents one of the attempts to develop our knowledge and understanding of "community supports." The study examines in details the supports provided to one individual with severe disabilities and tries to answer questions such as: What are the most essential components of community supports? How can human service workers facilitate and encourage relationships between people with disabilities and other community members? What does "community support" mean in the life of an individual with severe disabilities and what does it mean for the human service worker providing the supports? How are community supports related to concepts such as self-determination, choice-making, autonomy, empowerment, and independence? What does the interweaving of formal and informal supports look like in practice? Should community supports be defined as "work" or is it more appropriate to label the activities of those who provide supports in other terms than work?

The goal of this case study is to gain an indepth understanding of what community living means for one individual with severe disabilities and learn from his struggles to become a part of community life. Looking indepth at the life of one individual and holding his experiences up to the current trends in the field will enable us to examine what the emerging support paradigm may mean in practice and what changes it could bring about in people's everyday lives. In addition to highlighting the current trends and emerging paradigm shift in community-based services this case study also gives a valuable historical perspective. The individual in this case study was born in 1912 and has experienced the past two service models in the disability field, i.e., the institutional model of services and the community-based service model. He is now, along with the rest of the field, being influenced by the emerging support paradigm.

## STUDY DESIGN AND RESEARCH METHODS

This case study it is a part of a larger long-term, indepth qualitative study of social relationships in the lives of people with disabilities. By looking indepth at the experiences of people with disabilities, we hope to identify the processes involved in the operation of formal and informal support systems and develop a better understanding of what it really means for people with disabilities to be a part of community life.

This five year research project started in July 1989 and its goal is to identify and understand how people with disabilities form social relationships with other community members, become involved in community associations and organizations, and participate fully in community life. The study employs qualitative research methods (Taylor & Bogdan, 1984). Data are collected through indepth interviews with people with disabilities, their families, service providers, community members, and other "key informants." Data are also collected through participant observation in the places and situations where the informants spend their time. A detailed field guide guides the team of researchers conducting the observations and interviews.[1]

The participants in the large study have been selected according to a sampling procedure referred to as "theoretical sampling" (Glaser & Strauss, 1967) or "purposeful sampling" (Bogdan & Biklen, 1982) whereby informants are selected because of certain characteristics they possess. A random sample of people with disabilities would be unlikely to yield many people who have strong ties and a range of relationships with other community members. Because the goal of the study is to collect information about social supports in the lives of people with disabilities it is important to identify informants who will provide information about community connections.

By the nature, qualitative research methods are flexible and open-ended. While qualitative researchers begin their studies with a research focus and a plan of action, the research design evolves in accord with the emerging findings of their studies. The study design calls for two years of data collection followed by a period of intensive data analysis stage for the following six months. Based on this analysis, the research design was refined according to the findings to date. The data analysis resulted in a series of case study reports (Yin, 1989). This case study is one of the outcomes of this first stage of data analysis.

## The Case Study

This case study focuses on a pair of people. Melvin White, a 77 year old white man who has severe disabilities and Lori Salerno, a human service worker who provides personal assistance to Melvin.[2] The goal of the study is to gain an indepth understanding of the supports Lori provides and the role of this support in connecting Melvin with the community.

Melvin has spent over 60 years of his life in state institutions for people with mental retardation. When he was selected as a participant in the study he had lived in the community for four years. There were several rationales for selecting Melvin to participate in the study. First, it was judged important to include elderly people in the study in order to gain an understanding of community relations in the lives of individuals in this age group. Melvin is the oldest participant in the study. Second, it was of great interest to learn how a person who has been cut off from society for such an extended period of time is (or is not) able to gain access to the community. Third, Melvin has severe disabilities and needs assistance in doing most things, including going places, moving around, eating, going to the bathroom, and communicating with other people. Melvin receives personal assistance six hours a day and, according to our initial information, his support person, Lori Salerno, has been instrumental in facilitating his participation in community activities and environments as well as his contacts and relationships. Lori was described to us as a "bridge-builder." We were told that Lori was Melvin's friend, as well as being his key support person. It was considered important to learn how such a relationship came about and what it means for both Melvin and Lori, as well as learning from what was described as successful ways to facilitate participation in community life. And fourth, Melvin's speech is very difficult to understand, and he has no communication board or other aids to assist him. We thought it would be important to learn how a person, who has such great difficulties communicating, makes friends and contacts with other people.

Given the reasons for including Melvin White in the study the initial focus was mainly on learning about his and Lori's relationship, and Lori's role in facilitating Melvin's communications, connections, and relationships.

Melvin and Lori spend six hours a day together, Monday through Friday, 9 a.m. to 3 p.m. They usually start the day by reading the paper. They also have their "routine," as they call it. That is, they usually do certain things on certain days. For example, on Mondays they go to the senior citizen program in the neighborhood, on Tuesdays they go swimming, on Wednesdays they most often go to the institution where Melvin used to live to visit his friends there. Fridays, on the other hand, are open for activities like going to see the doctor, or to do fun things at the spur of the moment. These activities usually keep them busy till noon. Two or three times a week they go and eat lunch at restaurants downtown and Melvin's friends sometimes accompany them for lunch. In the afternoon they attend to things Melvin needs to do around the house such as laundry, or calling Melvin's friends or relatives. They might also go shopping or attend to other things Melvin needs to get done. Their routine is quite different during the summer when they do more outdoor activities like fishing, attending outdoor concerts, going on boat tours, to a summer camp, and so on.

## Data Collection

Melvin and Lori have participated in the study for a period of two years and participant observation has been the main method of collecting data. Both of them readily agreed to participate in the study and they have made a point of involving me in the things they do together.[3] Melvin had his own reasons for becoming involved in the study. He sees the study as being important and is proud of having been asked to contribute to our understanding of how people with disabilities can become a part of the community.

I have participated in both their summer and winter routine. I have also gone with them on a whole-day trip to visit Melvin's 81 year old sister, who lives in a small town a few hours drive from Newtown, the city where Melvin now lives. I have spent time with Melvin at his apartment, gone to social events and meetings with him, had lunch with him and his friends, and attended a public hearing where Melvin testified in support of closing the institution where he once lived. I have also visited him in the hospital when he was ill with pneumonia and accompanied him when he has visited friends in hospitals. I have celebrated his birthday, gone with him to the State Fair, been invited to the baby shower he threw for Lori, and so on. Although Lori has been with Melvin much of the time I have spent with him, I have also made a point of spending time with him when Lori is not around, in order to have a comparison between her support and the support he gets when she is not around. In short, I have spent time with most of the people Melvin spends his time with, such as the people who share his apartment, the staff who work there, his friends, and the people he encounters in the community.

At the outset I conducted weekly participant observation sessions, after a period of a few months the participant observations were reduced down to a bi-weekly observation with a weekly phone contact. In addition to participant observation I have conducted in-depth interviews with both Melvin and Lori, as well as interviewing some of Melvin's friends.

The formal interviews were tape-recorded and then transcribed. Each observation session resulted in written field notes with detailed accounts of the event observed. In all, the data collected have resulted in roughly 750 pages of field notes, transcripts, and other documents such as Melvin's draft of his autobiography, the speech he delivered at the open forum, and newspaper articles about Melvin.

Through the course of the study I have come to know Melvin and Lori quite well. I know their habits, their preferences, and their modes of interacting. I have shared their world for two years and have participated in their struggles, worries, disappointments, and celebrations. I have shared some very difficult things with them, like when Melvin almost died from pneumonia at Christmas time. I also shared the happy events, such as the birth of Lori's first son. Participant observation is a labor intensive research method but it is the most effective way to learn to understand people's lives and experiences and the meaning they attach to these experiences. Like Taylor and Bogdan (1984) have noted, "We get to know (people) personally and experience what they experience in their daily struggle in society" (page 7).

## Data Analysis

In this study, as in other qualitative research, data analysis is inductive: the findings emerge from the data. Data analysis has been ongoing throughout the course of the study. After each observation or interview I wrote extensive observer's comments where I kept track of emerging themes and patterns, insights and hunches to follow up on in future observations or interviews. To the extent possible, each observation or interview has built on the previous ones, and the data already collected have guided further collection of data. In addition to keeping track of insights through detailed observer's comments at the end of each set of field notes, a couple of extensive analytic memos were written to summarize what I had learned to date and develop a plan for the coming months. I kept checks on my insights and hunches by asking follow-up questions to Melvin, Lori, and/or some of Melvin's friends. This confirmed many of my insights and led me to drop or modify others. A further check on the data analysis was built into the larger study through sharing of data and analytic memos with the research team, and a group discussion of findings. Taylor and Bogdan (1984) refer to this approach to guard against researcher's bias as "triangulation." The term triangulation is also used to refer to ways qualitative researchers draw on different types and sources of data and check out accounts from different informants to gain a deeper and clearer understanding to make sure that their insights are valid. Both these forms of triangulation were used in this study.

The analysis during data collection was refined and checked out during the intensive analysis stage. This was done by a thorough reading and re-reading of all the data, comparing different pieces of data relating to the themes and patterns already identified. At this stage new insights and concepts were developed and added to the already gained insights. The method of analysis used in this study has a strong resemblance to what Glaser and Strauss (1967) call a "constant comparative method," an inductive analytical approach for developing concepts and insights from qualitative data.

## Field Work Among People with Disabilities

A number of qualitative researchers have studied people with disabilities (Bercovici, 1983; Bogdan & Taylor, 1982; Edgerton, 1967; Ferguson, 1987; Ferguson, Ferguson, & Jones, 1988; Goode, 1984; Groce, 1985; Murray-Seegert, 1989). Qualitative researchers from the field of developmental disabilities have written books describing qualitative research methods in general, but drawing heavily upon research with people with disabilities (Taylor & Bogdan, 1984). This has provided qualitative researchers in the disability field with valuable guidelines and information. Researchers have discussed the use of qualitative research in specific areas within the disability field such as in special education (Stainback & Stainback, 1984). They have also addressed the difficulties qualitative researchers may encounter when studying people with disabilities in general (Biklen & Moseley, 1988), or addressed specific areas of concern such as ethical issues that may arise during fieldwork (Taylor, 1987). Like other qualitative researchers who have conducted field work among people with disabilities, I faced some of the problems discussed in the literature. I will only discuss one of these here: the challenge of studying people with limited use of speech.

The greatest challenge at the outset of the study was my inability to understand Melvin's sppech. Biklen and Moseley (1988) have specifically addressed problems that arise when qualitative researchers study informants whose language may be limited. They suggest that in such situations researchers should rely mostly on participant observations over an extended period of time, in varied settings, get to know the person through spending time with them in their natural environment, and use significant others to gain information. All these strategies were employed in this study. Yet, the importance of language and the dependence of qualitative researchers on language provides a challenge when field work is conducted with people who have difficulties communicating. My inability to understand Melvin made me totally dependent upon Lori to translate between us. At first I found it very difficult to figure out how to communicate with Melvin under these circumstances. I wanted to direc my interactions toward him and did not feel comfortable asking Lori questions about him, in front of him. At the same time it was hard not to direct my questions to Lori and not to look at her while talking to Melvin, because she had to do most of the talking for him. The way I handled this was to try to balance my communication between them and try to talk to both of them at the same time. It took me a few months to learn to understand Melvin's way of speaking and I am no longer dependent on Lori to translate what he says. Although these communication problems were a challenge for the first few months, this turned out to have its advantages because this gave me first-hand and very valuable insights into the communication difficulties Melvin encounters. This also helped me realize and appreciate the importance of Lori's role as a translator between Melvin and other people.

My difficulties in understanding Melvin also gave me insights into how other people may feel when they can not understand him. It takes a great deal of effort for Melvin to say one sentence and sometimes he only manages to say half a sentence at a time. If Lori is not around to translate, Melvin may have to repeat things many times, each time making more effort to be understood. I would feel very uncomfortable when Melvin had repeated a sentence five or six times with great difficulties and I still did not understand what he said. I reflected on the communication difficulties in many of my observer comments at the outset. For example, I went swimming with Melvin and Lori early on in the study. The three of us were in the van outside the apartment building and ready to take off to the swimming pool when Lori had to go back up to the apartment to get something she had forgotten. Melvin and I waited in the van and I tried, pretty unsuccessfully, to carry on a conversation with him. Afterwards I wrote the following as observer's comment:

> I find it very uncomfortable when I can't understand what Mel says. I feel so helpless and embarrassed. Sometimes I feel like I should just pretend I understand him to get out of these uncomfortable situations.

Later I discussed with Melvin how difficult I had found it when I didn't understand him and how guilty I felt for making him repeat things over and over and over again, and I still didn't get it, and would feel worse with each repetition. I also asked him how he felt about this. Melvin said he didn't mind repeating if he knew that people were trying to understand him, the worst thing was if people really didn't pay attention or pretended that they understood. I could easily understand Melvin's frustrations when people pretended they understood him, but because of my own experiences, I could also relate to why people might be tempted to pretend. Thus, although fieldwork among people with disabilities can present the researcher with some unique challenges and difficulties, these can also provide the opportunities for unique insights into aspects of human life that otherwise would remain unexplored and out of sight.

## FINDINGS

The following discussion of the findings is divided into three parts. Part I "Surviving the Institution and Struggling in the Community," provides an overview of Melvin White's life and experiences. Part II "A Staff Person or a Friend?" describes the relationship between Melvin and Lori. And part III "Community Supports: An Indepth Analysis," provides an indepth analysis of the supports Lori provides and the meaning of this support in Melvin's life. This part also analyzes Lori's role as his key support person. The last section of this case study will discuss the findings in the light of the current criticism of community-based services and the emerging support paradigm.

### I. Surviving the Institution and Struggling in the Community

This part describes Melvin White's life today and reflects on his history and experiences in the institutions and in the community.

### A Profile of Melvin White

Melvin White is a 77 year old gentle charming man. He is thin and tall and his hair is all-white. Mel, as he likes his friends to call him, is a man of peace. He wants people to be at peace with each other. Fights and conflicts bother him very much. Therefore, to keep the peace, he often keeps quiet about his needs and wishes and does not make demands on his own behalf if he thinks it might result in conflict.

Melvin has severe cerebral palsy and uses a wheelchair. He can use his feet to push the wheelchair a short distance but has limited use of his arms and hands. His right hand is turned in at the wrist due to muscle contractures and he has difficulties moving the arm which is most often tucked behind his back. He has more use of his left arm. He can move the arm and some of the fingers and uses his left hand to move things on a table in front of him, wave to people, hug them, and so on. With regard to Melvin's intellectual ability his records describe him in various ways. At one point his IQ is said to be 37, at another time it is said to be 80, he is also labelled as having "borderline mental retardation," and being "non-mentally retarded." One of his friends said: "Mel may not have been retarded on the outset, but because of his experiences he is now functionally retarded."

As Melvin has grown older he has lost some of his hearing and uses a hearing aid. Because of Melvin's cerebral palsy it is very difficult for him to speak and his speech is very unclear. "He is very soft spoken," as Lori phrases it. People who do not know him well have a hard time understanding what he says. Melvin is "not in the best of health" as he himself puts it. He has stomach problems, respiratory problems such as asthma, he also frequently gets pneumonia, and has other health problems.

Melvin is a religious man. One of his friends describes him as being, "One of the most spiritual persons I have ever met." Mel goes to church most Sundays together with this friend or other members of the congregation who come and pick him up on their way to church. He is known as "Brother Mel" at church.

Only two of Mel's siblings are still alive, his sister Marie who is 81 years old, and his youngest brother Sean, who is a little younger than Mel. Both of them live about two to three hours drive from Newtown. Since Lori started working with Mel she has assisted him to stay in regular contact with them and has made sure he can go and visit them at least a couple of times a year. Melvin has a very large extended family.

Marie alone has almost 100 direct descendants. She has 14 children, 39 grandchildren, and 40 great-grandchildren. This huge family has a family reunion once a year and Melvin has attended the family reunion the past couple of years with Lori's assistance. Before Lori started working with him, he had only managed to go to a couple of these family reunions.

Melvin has a small number of friends and a large number of acquaintances. Most of these people are former staff at the institutions where he has lived or people he got to know through the human service world.

## Melvin's History

Melvin was born in 1912 in a small town in one of the northeastern states. He is the next youngest of six brothers and sisters. Melvin was first institutionalized at the age of three when his mother became ill and he was sent to Empire State School. Melvin stayed at Empire for four years. He developed a double pneumonia and became so sick that the doctors at Empire thought he was dying. Because they thought it would be better for Melvin to die at home, they asked his parents to come and get him. Melvin's father came and brought him home. Melvin recovered from the pneumonia and lived with his large lively family until he was 16 years old.

Melvin's mother died suddenly in 1927 and Mel went back to Empire State School the next year. His second stay at Empire was initally only intended to be temporary--one or two years--but he ended up spending 45 years of his life there.

In 1973 Melvin moved to Hill Developmental Center where he lived until 1979, when he moved to Newtown Developmental Center (NDC). At the age of 72 Melvin moved out of NDC in 1985 after having spent over 60 years of his life in state institutions. He moved into an ICF/MR (Intermediate Care Facility for the Mentally Retarded) in an apartment building downtown Newtown, where he now lives with three other people who also have disabilities. It took a lawsuit to have him released from the institution. When I asked Melvin why he had wanted to move out of the institution he answered: "I wanted to be free." Two of Melvin's friends have told me that he wanted to leave the institution before he died.

The first two years after Melvin moved out of the institution he kept going back there every day to attend a day activity program. Melvin "retired" from the day activity program in 1987.

## Surviving the Institution

Melvin's life has been filled with neglect, abuse and isolation. He has had a very hard life. After spending time with him I have developed a great deal of respect for the way he has survived living under such conditions for over 60 years. Melvin's life demonstrates how some people can go through unbelievable difficulties and humiliation, and still come out of those experiences without being destroyed. Mel is sometimes bitter because of how his life has been wasted. Yet, he survived these experiences and came out of the institutions with faith in the goodness of other human beings and willingness to trust them. He has kept his dignity and is warm, friendly, and gentle towards people. He has a great sense of humor and a positive outlook on life. Melvin finds it difficult now to think about and talk about his life in the institutions. When I asked him about the institutions he said:

> The punishments, they were the bad part. Being locked up in the bathroom all day away from everyone. And the fighting. And being away from other people and the life outside.

## Struggling in the Community

Moving into the community did not bring Melvin the freedom he was hoping for. Instead he was almost as isolated as when he lived in the institution. As it turned out, the staff at NDC had made efforts to assist him to participate in community activities similar to what the staff at the apartment did. Melvin became desperate and depressed. One of his closest friends described this in the following way:

> Melvin has had periods of despair in his life but has always regained confidence again. When he finally moved into the apartment he realized that it wasn't really that much different from the institution. And again he went into a period of despair. He was just about to give up. He even stopped talking. Things became even worse after the retirement. Then he wasn't even going out of the apartment, he just stayed there all day.

Melvin's situation became so serious that some of his friends were worried that he was going to die. He was losing weight and was in bad physical condition. He seemed to have lost hope, was very depressed, and had mostly stopped talking. At this point a group of friends rallied around him and pressured the agency to do something. A creative professional within the agency "bent the rules" and came up with a solution which was called Melvin's "retirement program." This retirement program entailed hiring a staff person to work with Melvin 6 hours a day, Monday through Friday, 9 a.m. to 3 p.m. This person was Lori Salerno.

## II. A Staff Person or A Friend?

This part describes the reasons why Lori chose to become Melvin's support person, how their relationship has developed, and what characterizes their relationship today.

### A Staff Person

Lori Salerno is in her early thirties and has a degree in special education. She had been a staff person at the apartment where Melvin lives for a while when she started working with him. When the agency arranged for his "retirement program" Melvin asked Lori if she wanted to change jobs and work with him instead of doing the shifts at the apartment. Lori agreed to take the job although it meant a cut in both pay and benefits for her. She had more than one reason for wanting to change jobs. She liked Melvin and wanted to be able to spend more time with him. She also told me she had found it hard to work in the apartment because she could not devote enough time to the people who lived there. There were all these tasks that needed to be done and not much time for individual contact with each person. Lori was also tired of the shift work, the long hours (many of the shifts are 12 hours), and evening and weekend shifts meant she didn't have much time with her husband. Thus, many of Lori's reasons to take the job as Melvin's support person were practical reasons that did not have all that much to do with Melvin.

## A Friend

After almost three years of working with Melvin, Lori has become very close to him and I have watched how their relationship has grown closer over the course of the study. They have been through both hard times and good times which have served to strengthen their relationship. At this point Lori's attitude toward Melvin is characterized by care and commitment. This is mutual, as Melvin also cares deeply about Lori and regards her as his closest friend. Their relationship has little resemblance to what one typically thinks of as a client/staff relationship. A better way is to describe it as a close friendship. It is hard to describe the relationship between Melvin and Lori without sounding sentimental and being suspected of over-romanticizing. Taking this risk, I would describe their relationship as being characterized by closeness, commitment, respect, support, and humor. The stereotype of people with disabilities as needy, dependent, passive, helpless, sick, and in need of being taken care off makes it difficult to perceive them as being able to make contributions and give to others. Contrary to this stereotype, all the characteristics of Melvin's and Lori's relationship are mutual. That is, despite Melvin's severe disabilities and inability to do a number of things, he makes significant contributions to the relationship in terms of closeness, commitment, respect, support, and humor. What may sound most surprising in this context is the mutuality of support. Lori is the one who is being paid to provide support to Melvin and, as will be demonstrated later in this paper, she does provide him with assistance crucial to his participation in community life. Yet, the fact is that Melvin has become a significant source of support in Lori's life. Lori went through a very difficult period in her personal life about a year ago. Not only was Melvin a very sympathetic listener and provided Lori with warmth and emotional support, he also initiated and organized support from other people and helped Lori make some of the difficult decisions she had to make through this ordeal. Lori deeply appreciates Melvin's support and how he stood by her during these difficulties. Thus, although it is quite apparent how dependent Melvin is on Lori's support, a closer look reveals a relationship that is characterized by mutuality rather than dependency.

## III. Community Supports: An Indepth Analysis

This part presents a detailed indepth analysis of the supports Melvin receives from Lori. Observing and analyzing this support has been one of the major objectives of this study. Spending time with Mel and Lori has provided some very valuable insights into the importance, meaning, and potentials of community supports.

A close indepth observation of the supports Lori provides made me soon realize that although we have one term for what we call "community supports," this phenomenon is far from being one thing. Instead, this study reveals "support" as a very complicated phenomenon consisting of many different, but intertwined components. Although the various components that make up community supports are intertwined and difficult to keep separate in practice, it is helpful, for the sake of analysis, to keep them apart. Thus, in the following I will analyze the different components of support I have identified.

## Everyday Practical Assistance

The most visible support Lori provides is the assistance she provides with everyday practical things. There are at least three different types of such practical assistance:

Physical work. The most obvious support Lori performs is pushing Mel around in his wheelchair, pulling the chair up stairs, transferring Mel in and out of the chair, and so on. This part of the support is demanding physical labor and requires a fair amount of physical strength.

Technical work. These are things like driving the big van around and operating the wheelchair lift in the van. This also includes "technical" work and skills around Mel's health, such as medication and complicated Medicaid rules and regulations which govern much of Melvin's life in the community.

Personal work. Mel needs help with very personal things like eating, dressing, and going to the bathroom. Some of this work requires very close personal physical contact. Other components of this "personal work" consist of taking care of Mel's every day money spending and overall finances. An example of this is Lori's assistance with taking care of Melvin's will. Melvin also needs help with other personal things like calling his friends and family, buying clothes, selecting paint for his room, and so on.

In short, the support Lori provides in terms of everyday practical assistance consists of hard physical labor and taking care of some of Mel's most demanding, intimate, personal needs, like eating and going to the bathroom. If Lori wasn't there to take care of this, someone else would have to assist him with these things. In the context of community participation this work is crucial for Melvin. Much of this work is either demanding physical labor or tasks that people would ordinarily find difficult or embarrassing like helping Melvin go to the bathroom. When Melvin participates in social events in the community, Lori's support means that she takes these "difficulties" out of the way and people can enjoy Mel's company without having to worry about the "problems" related to his disabilities.

Translating

Another important function Lori fulfills as Melvin's support person is to "translate" for him. The translation Lori does goes two ways; she translates from Mel to other people, and to Mel what other people say. Melvin is very hard to understand and when people do not understand what he says Lori will repeat it. In addition, because it is such an effort for Melvin to speak, Lori often adds explanations or information about what he is talking about. The second type of translating is necessary because of Melvin's hearing loss. As he has grown older he has lost hearing and sometimes has a hard time hearing what people say. When Lori is with him she is very observant and watches whether Melvin can hear what people say. If he doesn't hear people, she repeats to Melvin what the person just said.

The difficulties Mel has in communicating become very clear when Lori is not with him. People become very uncomfortable when they don't understand what he is trying to say and find it very embarrassing to have to ask him to repeat it again and again. Sometimes people pretend they understand him in order to get out of these uncomfortable situations. People sometimes also misunderstand what Melvin says so their answers to him do not make sense because they misunderstood him. It is hard for Melvin to keep a conversation going under these circumstances.

Another difficulty that arises in situations where Lori is not with Melvin results from his hearing loss. For example, a person says something to Melvin and--because he can not hear them--he does not respond to them. This creates a very uncomfortable atmosphere and the person who just addressed Melvin usually does not know how to handle the situation. Melvin looks very disabled, people therefore sometimes assume that he is too intellectually limited to understand the question and therefore chooses to ignore them. People may also think that their question was inappropriate or offensive and that is the reason why he does not answer. Thus, when Lori is around she takes away a great deal of the discomfort and insecurities around Melvin and makes the communication between him and other people smooth and easy.

Lori also translates on a different level than just repeating words between Mel and other people. What I'm referring to is when Lori conveys to other people what Mel wants to do, what he can and can not do, what is safe for him to do because of his health, and so on. If Lori is not around to convey such things people are often insecure about what Melvin wants or what is safe for him. An example of this occurred during the visit to Melvin's sister. While Lori was in the bathroom John (who is married to one of Melvin's nieces) brought out chocolate and encouraged people to have some. John asked the old lady (Melvin's sister) if he should give Melvin chocolate. The old lady said she didn't know if it was safe. She looked at me and asked me if Mel could have chocolate. I said I didn't know, she should ask Mel, "he knows what he can eat." When she asked him, Melvin said: "Yes." The old lady did not seem convinced and said something like: "You better not choke on it in my house," and put a piece of chocolate in Melvin's mouth. When Lori returned from the bathroom the old lady asked her if Melvin could have chocolate. Lori said: "Oh yes, he loves chocolate, he eats it all the time." It was not until Lori convinced her that this was safe the old lady stopped being nervous and insecure about giving Melvin chocolate.

This form of translating what Melvin likes and what is safe for him also takes away a lot of the uncertainties and insecurities around him. Even if people understand him when he explains what he can do people seem to have a tendency not to trust what he says. Maybe they suspect that he is "too disabled" to know what is safe for him and what is not.

## Facilitating

An important component of Lori's support is facilitating Melvin's participation in conversations and social situations. If someone does not provide this facilitation it is most often impossible for Melvin to participate in group conversations. Melvin's inability to participate in group conversations is mostly due to how slow his speech is, how long it takes him to prepare himself to say something, and how long it takes him to say one sentence. Thus, it is impossible for him to "jump in" or keep up with the flow of the conversation in a group. Lori is very skilled at facilitating Mel's participation and as a team they manage to keep him a part of the conversation although Melvin does not say very much. To a large extent Lori participates in the conversation on Melvin's behalf by referring to him constantly. She tells stories about what he has done, what he said, how he acted in certain situations, what his opinion is about certain things, and so on. She also draws Melvin into the conversation by opening up a "space" for him to add a sentence. This facilitating on Lori's behalf "normalizes" Melvin's participation in social situations. The amazing thing is how skilled they have become at working as a team at this. While Lori is talking on his behalf, Melvin participates by nodding, smiling, making faces appropriate to the topic, and keeping eye contact with the people in the group. Melvin and Lori also keep an eye contact with each other while they are telling the story and they seem to decide through this eye contact when he should "jump in" and do his part of the talking.

Being Mel's support person means that Lori must play an active role in the social context they are in at any given time. At the same time Lori is really not there in her own capacities. She is there to support Mel's participation. This part of the support role is quite a challenge. Lori's character and the way she interacts with people is crucial for Mel's possibilities to become a part of what is going on. At the same time Lori cannot dominate the situation with her personal presence and opinions, because if she does Melvin falls in the shadow and "disappears." This part of Lori's support role requires a very delicate balance act on her part.

## Supporting and Facilitating Self-Determination

Lori's role in facilitating and supporting Melvin's rights to self-determination is the last component of her support role. Melvin lived in state institutions for over 60 years and is not used to making demands on his own behalf or having many choices. People who live in institutions are not expected to make demands; they are expected to obey the rules. Melvin told me that first when he entered the institution he was determined to "have my way and I got into a lot of trouble." He added that he had changed and decided to "cooperate" with the staff. In retrospect Melvin says this "strategy" (although he didn't think of it as a strategy at the time) helped him survive the institution. "Cooperation" in the context of institutional life means that clients obey the rules and the staff. Thus, when Melvin moved into the community he was not at all used to making demands on his own behalf or choices or decisions about things. Melvin also told me that the staff in the apartment didn't do much to encourage him to exercise decision making or choices. It was not until Lori started working with him that he received encouragement to make demands, choices, and decisions.

At first Melvin found it very difficult to make demands on his own behalf. Part of these difficulties have to do with Melvin's character. As described earlier, Melvin is a man of peace. He wants people to be at peace with each other and finds it very hard to deal with conflict. Therefore, he often kept quiet about his wishes because making demands could create conflict. Melvin is also a very kind and gentle person and avoids doing anything that might hurt others. This has also led him to keep quiet about his wishes. Making demands often means that he has to ask people to change the way they do things. He often assumes people will take his wishes as a criticism and be hurt. He therefore often chooses to keep quiet. A good example of this is when a new staff person at the apartment kept calling him "sweet thing" and "honey-pie." Melvin did not like being addressed in this way but he knew the woman did not have bad intentions, she was only trying to be nice to him. He was afraid that she might be hurt if he asked her to stop this. He finally got up his courage and discussed this with her, carefully explaining to her that he did not mean to hurt her but he would appreciate if she would not call him "sweetie pie" all the time. The discussion went quite well and the staff person does not address Melvin in this way any more. This was the first time Melvin got up his courage to address things like this and he feels very good about having done this. He feels especially good about having been able to do this without hurting the staff person.

Lori has played a critical role in facilitating and supporting Melvin in making demands on his behalf. This is something they discuss at great length and Lori's role has been to explain to him that he has the right to make choices about what he does, make demands on his own behalf, and exercise control over his own life. They discuss in great detail what the consequences of his demands might be, how people might react, and how Melvin could handle different situations that might come up in this context.

Much of Melvin's life has been characterized by disappointments and shattered dreams. Therefore, he is often afraid to make decisions to do the things he would most like to do, like travelling to visit some of his nephews and nieces who live in far away states. He does not want to face the disappointments if things do not work out. Lori's role has been to encourage him to make decisions like this, help him figure out how he can make things happen, and assist him in making sure that things will work out. Before Lori started working with Melvin he did not exercise much self-determination.

### Negotiating Who Does What

It has been interesting to observe how Mel and Lori negotiate and make decisions around the support Lori provides. These negotiations usually take place in at least two steps. The first step is before they go places; when they decide where to go and discuss what Mel wants to get out of the visit (or whatever they are doing), who he wants to see, what he wants to say, and so on. The second step is when they are in the situation and need to decide when Mel is going to talk and when Lori is going to do the talking. They make these decisions through eye contact or in other very subtle ways that are not very visible to other people.

### Invisible Work

The different components of Lori's support role are all equally important for Melvin's participation in community life. Without this support he would not be able to participate in social events, conversations, or other community activities. In short, without Lori's support Melvin could not be out among people and he would only be physically present if she didn't support and facilitate his participation. In addition, he would most likely not make decisions about where to go and what to do if she didn't support his right to self-determination.

Among the insights provided by an indepth analysis of Lori's support role is realizing how important it is that Lori takes care of, and takes away, the "difficulties" and "problems" around Melvin. She also takes away the uncertainties and insecurities around him. Much of Lori's support work is "invisible work" that only becomes visible when she is not there to do it and the problems and insecurities arise.

## Interweaving Formal and Informal Supports

Formal and informal supports are most commonly seen as complementary to one another. The increasing attention paid to informal supports has emphasized that the formal support services should strive to start with and strengthen informal networks of support in the community. In this view the "interweaving" is between the formal services system and community members such as family, friends, and neighbors. An analysis of the support Lori provides presents a slightly different picture. Although Lori facilitates connections and contacts between Melvin and other community members this facilitation usually does not focus on facilitating provision of support from other people. Instead, it facilitates participation where Lori provides the support needed to enable Melvin to be involved in activities and events. This does not mean that the "interweaving" of informal and formal support is absent. The way Lori interweaves formal and informal support is by providing both types of support. As a paid human service worker she provides Melvin with support the six hours a day she works with him. But outside of her work and as his friend, Lori provides Melvin with informal support such as going to dinner with him and their mutual friends, inviting him to family events with her own family, making phone calls to people who can not be reached during the day, calling the apartment on weekends to remind the staff that Melvin wanted to go to a baseball game, going fishing with him during her maternity leave, and so on. Thus, informal and formal support is something that Lori "interweaves" within her own life and relationship with Melvin.

## The Importance of the Relationship

An analysis of the successes Melvin has experienced in becoming a part of community life in the past few years reveals that the success is basically dependent upon one person. It is the support Lori has provided him with that has made the difference in his life. This leads us to an important question: Why has Lori been so successful in facilitating and supporting Melvin's participation in the community? I would argue that what makes the crucial difference is the relationship between Melvin and Lori. The mutuality and closeness of their relationship is what makes this a success. This closeness has made Lori very sensitive to Melvin's needs and wishes. It has also created the "harmony" between them and the ease with which Lori performs her role. Other people can perform the "work" needed for Melvin to participate in social events in the community, but his experiences are sometimes quite unpleasant when the support is provided by other people than Lori. For example, Melvin wanted to see a baseball game in a town five hours drive from Newtown and one of the staff people at the apartment offered to take him there. The trip turned out to be a disaster. They left on a Friday afternoon, the staff person got lost on the way and they didn't arrive till very late in the evening. They tried to check into a hotel but because the staff person did not have a driver's license or any other I.D., they could not get a hotel room. They ended up driving back to Newtown this same night.

The difficulties when other people than Lori provide Melvin with support also became apparent while Lori was on a maternity leave. The agency hired a woman, Marilyn, to take Lori's place. I accompanied Melvin and Marilyn one day to a very important lunch meeting with a professional from the agency which runs Melvin's apartment program and one of Melvin's closest friends. Melvin wants to move out of the apartment and have his own home in the community. This meeting was set up to discuss the possibilities of making this come true. The three of us, Melvin, Marilyn, and I arrived early at the restaurant. Marilyn asked Melvin what he wanted to eat and went to get the food for him. When she returned she told Melvin the restaurant didn't have the root beer he asked for. Marilyn took a long time to figure out what Melvin wanted to have instead. He told her he just wanted anything they had, he didn't care. Marilyn insisted that he would "make a choice" and told him he should decide what he wanted to drink and not just have "anything they had." It was clear that Melvin did not care what he would drink with his lunch that day. He had other things on his mind. This was quite an eventful day. First, Lori had her baby early the same morning and Mel had not heard any details about how she was doing, just a message that the baby was born and they were both "doing well." Second, the meeting that was just about to start was a big event for Melvin, and it was very important that it went well. Thus, whether he had Pepsi or Coke with his lunch was not an important issue for him at the moment. But Marilyn insisted that he concentrate on making a choice about what he wanted to drink.

This incident is a good example of how the issue of "choice" can become trivialized and how staff do not adapt to the situation and instead make people make choices about trivial things. In this case it was clearly much more important for Melvin to be able to concentrate on the meeting and being able to choose where he would live in the future, than to choose between Coke and Pepsi.

This meeting also revealed other important insights about the importance of how the role of a support person is conducted. Marilyn sat next to Melvin and did her best to make sure he heard everything that was going on. She repeated things that were being said in a loud voice for Melvin and would frequently ask: "Did you hear that sweetie?" Then she would repeat the sentence that had just been said, often without waiting to see if it was necessary or not. Marilyn was obviously trying to do her best but she overdid things. She frequently repeated things Mel had heard and her way of yelling "sweetie" and "honey" at him all the time made the situation uncomfortable. This meeting made quite clear the difference between Lori's and other people's way of supporting and facilitating Melvin's participation in social circumstances. Lori is very relaxed and secure. She knows how much assistance Melvin needs and when he needs assistance with hearing, talking, making choices, and so on. When Marilyn is around things are stressful and insecure. Marilyn overdoes things. She does more than is needed and speaks louder than is necessary. When Lori is present things "flow" very smoothly. With Marilyn things become difficult and "stiff." Marilyn makes a big deal out of translating to and from Melvin and the conversation becomes awkward and unnatural. It is clear that Marilyn is translating when she repeats things for Melvin. When Lori does the same she does it in a more natural way so it becomes a part of the conversation, instead of being a clear repetition of what someone just said.

Thus, a comparison between Lori's support and other people's support suggests that the most crucial components of the support role have to do with the personalities of the people involved and the relationship between the people providing and receiving the support.

## DISCUSSION

Melvin White's life and experiences demonstrate clearly how disability policies and practices influence the everyday life of people with disabilities. Melvin has lived long enough to experience the past two service paradigms. That is, the institutional paradigm and the paradigm of community-based services. And his life is now being influenced by the emerging paradigm of support.

Melvin's life in the institutions was characterized by neglect and abuse. After years of struggle he gained his "freedom" and moved into the community. His experiences of being in the community reflect the current criticism of community programs. Moving into the community did not save Melvin from neglect and isolation. He does not suffer from these as badly as in the institution but they still exist in his life. For example, before Lori started working with him, Mel was almost as isolated "in the community" as he was in the institution. And he still suffers from neglect. On weekends he sometimes doesn't get enough food because the staff see it as too much bother to feed him. But, despite the struggles and disappointments in the community, Melvin would never go back to the institution. His experiences highlight the problems in community programs, but he would agree with the critics that although there are problems in community programs they are a far better alternative than the institution.

Melvin's experiences in the community highlight particularly well the difficulties community programs have in achieving the goal of community integration. Melvin is living "in the community," but his primary membership in this world is still in the human service world. Most of his time is still spent in this world. He goes to a lot of "programs" like the senior citizen program, the swimming program, and he lives in a "program." All of Melvin's closest friends are from the human service world. The only connections he has outside the human service world is with his family, in church, and casual encounters in restaurants and stores. Melvin is "out" in the community but he is out among other devalued community members. He lives in an apartment in a high-rise in downtown Newtown. Most of the other people who live in the apartment building are also people who have a devalued status in society. These are elderly people, people with all kinds of disabilities, people of racial and ethnic minority backgrounds, people who don't have work, and so on. Melvin may be living out in the community but he is still living with other devalued people. Melvin's connections with other community members are very fragile and his experiences reflect the inability of community programs to help people with disabilities to establish and maintain connections with people outside the human service world. Melvin participates in quite a few community activities and has good connections with a few of his relatives and a few friends. But his connections to people and places in the community, as well as his participation in community activities are primarily dependent on Lori. If she wasn't there to support and facilitate Mel would be very isolated.

Thus, the assistance Melvin needs to participate in the community is not built into the service system. Instead, this assistance has been created as an exception to how the service system is supposed to work. Community-based services are typically over-regulated and bureaucratic (Holburn, 1990). The flexibility that exists is not built into the service system, but is created by individuals within the system who are willing to "bend the rules." This flexibility is sometimes "allowed" within the system as "demonstration projects," or they are created as emergency procedures in extreme cases when people served by the system are at risk of dying. An example of how the system can come up with flexible supports to save people's lives is described by Berkman and Meyer (1988). This was also the case in Melvin's situation. It was not until his condition had become so serious that some of his friends thought he was at the risk of dying that individuals within the system created the supports Melvin needs to become a part of community life.

Melvin wants to move out of the community program where he lives. He wants to have a real home before he dies. His continuing struggle to belong in the community and not in the service system is quite revealing of the failure of community programs to "free" people from the system and connect them with the community. Melvin's fragile successes in the community to date have been made possible and are inspired by what many have called "the emerging support paradigm." The support services that are now being developed under this new service paradigm seem to be the most promising ways to connect Melvin and others like him with the fabric of community life. Yet, we still have a long way to go and a lot to learn about people, communities, and connections before we can make community integration come true.

## NOTES

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2. All the names of individuals and places which appear in this case study are pseudonyms.
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