The Qualifying Game: A Search for Services by Individuals with Disabilities

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Abstract: Increasing attention has been paid over the last decade to enhancing the quality of the everyday lives of individuals with disabilities. Quality of life is maximized when an individual is integrated into society, can participate in decisions that impact their life, and has access to adequate services. Self-determination is a central element in the multifaceted construct of quality of life (Schalock, 1996; Wehmeyer & Schwartz, 1998). The purpose of this study was to illustrate the dynamics among the constructs of quality of life, self-determination, service provision, and what participants in this study labeled "the qualifying game." This study was part of a larger Project of National Significance conducted by the Texas Planning Council on Developmental Disabilities (1996) that used a focus group technique in order to obtain in-depth interview information about the experiences, needs, and life issues of persons with severe, chronic disabilities, and their families. Sixty-seven individuals who represented a variety of ethnic and cultural groups, as well as a wide array of disabilities, were participants in these focus groups. A grounded theory methodology (Strauss & Corbin, 1990) was used to analyze the qualitative data and to derive central categories. Results found were that self-determination, along with other components of quality of life, was highly dependent on the acquisition and maintenance of necessary support services. What is suggested is that quality of life is only possible when individuals with severe, chronic disabilities have access to essential services.

Over the course of the last decade increased attention has been paid to enhancing the quality of the everyday lives of individuals with disabilities (Dennis, Williams, Giangreco, & Cloninger, 1993; Schalock, 1996). Definitions of quality of life (cf. Schalock & Bogale, 1990) vary but researchers generally agree that the construct includes an overall satisfaction with one's life and a sense of well being. Some research studies include quantifiable factors such as levels of social and physical integration, or indicators such as marital and work status to their construct of quality of life (e.g., Newton, Ard, Horner, & Toews, 1996; Stark & Goldsbury, 1990), while other researchers (e.g., Halpern, 1993) focus on general outcome domains such as physical and material well-being, performance of adult roles, and personal fulfillment. Still other researchers (e.g., Karen, Lambour, & Greenspan, 1990;

Sands & Kozleski, 1994) emphasize that the concept of quality of life must include a component of choice and the ability to adopt a lifestyle that satisfies one's unique wants and needs. Despite this myriad of conceptualizations of quality of life, there is "growing consensus in the research for a conceptual model of quality of life that is multidimensional and interactional" (Hughes, Hwang, Kim, Eisenman, & Killian, 1995, p. 634).

One basic tenet that all researchers in this area seem to endorse is that quality of life can only occur when a person's basic needs are being met (Goode, 1990). Quality of life is maximized when an individual is integrated into society, can participate in decisions that impact their life, and has access to adequate services. Numerous researchers (e.g., Bradley, Ashbaugh, & Blaney, 1994; Hanson & Carta, 1995) have identified the need for a comprehensive, coordinated system of services that addresses the support needs of individuals with disabilities. Such a system is essential for individuals with disabilities as their quality of life will increase when these services are effec-

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tive. In fact, the effectiveness of support services has been used as a measure of quality of life in individuals with disabilities (e.g., Dennis et al., 1993).

While there appears to be a close relationship between the quality of life of individuals with disabilities and the quality of services that they receive, the relationship between these constructs has not been directly explored. There is a crucial need, however, to directly examine the perceived service and support needs of individuals with disabilities and their families as this input can greatly contribute to the quality assurance of service programs (Westling, 1996). Programs should be evaluated to assess whether the services they offer actually assist individuals in achieving satisfaction with their lives.

Self-determination is a central element in the multifaceted construct of quality of life (Schalock, 1996; Wehmeyer & Schwartz, 1998). Self-determination refers to "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life which are free from undue external influence or interference" (Wehmeyer, 1996, p. 22) and includes the concepts of choice, self-advocacy, and independence (Nirje, 1972). Self-determination is seen as directly contributing to an enriched quality of life (Schalock, 1996) and, in turn, individuals who report a higher quality of life appear to be more self-determined (Wehmeyer & Schwartz, 1998). Self-determination is also closely linked to the provision of support services for individuals with disabilities in that support services enable individuals with disabilities to participate in making decisions about their own life. In addition, when an individual with disabilities becomes more self-determined he or she is then more successful in advocating for the services that they need. Finally, self-determination can been seen as a call for systems change in that it places the voice and the needs of the individual with disabilities in the foreground of the battle for quality of services (Hughes & Agran, 1998).

This study presents a conceptual model of how individuals with severe, chronic disabilities perceive the necessity of support services in becoming self-determined and how self-determination is both dependent upon and a result of access to needed services. It explores the integral role of support services in the pursuit of quality of life by individuals with disabilities and the connection between overall quality of life and what individuals with disabilities in this study labeled "the qualifying game." The summary of this research is an attempt to further refine recent conceptual models of quality of life through a grounded analysis of direct reports from individuals with disabilities and their families.

Method

This study was part of a larger Project of National Significance conducted by the Texas Planning Council on Developmental Disabilities (1996), which was exploring whether to change the definition of developmental disabilities to be more inclusive. This portion of the project used a focus group technique in order to obtain in-depth interview information about the experiences, needs, and life issues of persons with severe, chronic disabilities and their families. Focus groups are commonly used by social scientists, political analysts, and marketing researchers as a method for gathering research data. A focus group is essentially a group interview that is guided by a moderator (Morgan, 1998). The moderator typically introduces questions or a topic to a group of individuals who have been selected for the focus group because they share some type of commonality of experience or characteristic. The resulting discussion of the focus group members is collected as data and is usually recorded, transcribed, and then analyzed by the researcher. A primary advantage of focus groups is that they are an effective method by which to elicit rich and generative data from a selected group of individuals.

Research Questions

Research questions were formulated by a work group, which collaborated with the Texas Planning Council for Developmental Disabilities. This work group functioned as an advisory committee and was comprised of 17 representatives from state agencies, consumer groups and service organizations. The work group targeted the following questions as primary in this study:

1. What are the service and support needs

of persons with severe chronic disabilities?

2. What issues, barriers and opportunities exist currently in the lives of persons with severe chronic disabilities?

These questions were selected by the work group to determine whether the service and support needs of individuals with disabilities varied given the age of the onset of the disability or the number of functional limitations demonstrated by the individual with disabilities.

Participants

Six communities across the state of Texas were chosen as sites for focus group meetings. These communities were chosen in an attempt to obtain a sample that was both culturally diverse and that represented the various geographical areas of Texas. Participants were from urban, suburban, and rural areas, and from unincorporated Hispanic communities along the Texas-Mexico border.

Once the six communities had been selected, paid advocates and service providers in the communities were consulted to identify possible participants. However, paid advocates and service providers themselves were asked *not* to participate, as it was believed that their presence would inhibit the candidness of responses from the other participants. Potential participants were then contacted by telephone by the area coordinator and were given a brief description of the study. Interested potential participants then were sent a packet of information about the focus groups, which contained a letter of introduction, and overview of the project, an agenda for the meeting day, and a copy of the consent form. Packet information was provided as an audiotape, in Braille, or in Spanish if requested by the participant.

The individual participants who attended the six focus groups represented a variety of ethnic and cultural groups, as well as a wide array of disabilities (see Table 1). These participants represented areas of chronic disability that occur across the life span, including disabilities acquired after age 22. Members of each group included individuals with severe disabilities, family members, or unpaid advocates. Each individual focus group was limited

TABLE 1

Demographic Data from Focus Groups

Participant/Description	Number	Percentage of sample
Family Status		
Family Members	36	54%
Individuals with disabilities	31	46%
Total	67	100%
Ethnicity		
African American	2	3%
Anglo	46	68%
Asian American	2	3%
Hispanic	15	22%
Native American	3	4%

Areas of Disability Represented: Alzheimer's, Cerebral Palsy, Cystic Fibrosis, Deaf, Diabetes, Mental Illness, Polio, Mental Retardation, Mobility Impaired, Multiple Sclerosis, Seizure Disorder, Traumatic Brain Injury, Visual Impairment.

to 12 to 15 participants to facilitate fluid group discussion.

Focus group meetings were held from 9:00 a.m. to 2:30 p.m. with an hour break for lunch. Specific meeting sites in each community were chosen based on accessibility, required accommodations for participants, and recommendations by area coordinators. Accommodations required by the participants were carefully considered to facilitate active participation. Interpreters for people who were Deaf or Spanish speaking were provided and ongoing supports were monitored. Care was taken by the group facilitator that all individuals had ample time to participate and respond to questions.

Focus group questions

Focus group discussion centered on three primary questions presented along with follow up probes. These questions included:

1. What helps you live the way you want and manage your own life?

2. How are you getting the help you need right now?

3. The mission of the Texas Planning Council on Developmental Disabilities is to create change so that you have the opportunity to live the way you want and

manage your own life. If the Texas Planning Council on Developmental Disabilities were to represent all of you here today, how might they help you?

Focus Group Procedures

Focus group meetings were well attended: Eighty-five percent of those who had been invited to participate attended a focus group meeting. All participants actively contributed throughout the meeting day. In response to the first focus group question, a lively two-hour long discussion usually occurred in which participants freely shared their personal experiences and discussed those of other members of the groups. Often, because the groups were so conversant, the focus group facilitator simply guided the group discussion so that every participant had an opportunity to share. As such, the role of the focus group leader was minimized while the contributions from the group participants were maximized. During the lunch break, although the focus group was not formally convened, participants continued to share stories and information as they shared their meal. By the time the afternoon session took place, the meeting had taken on the characteristics of a support group in that participants exchanged information and suggested strategies for future advocacy activities and often gathered each other's names and telephone numbers for future reference.

Focus Group Data Analysis

Initial, overall impressions of the groups and issues raised by the participants were written in field notes immediately following each meeting. Facilitator probes used in earlier focus groups were critiqued and refined for use in subsequent meetings. Audiotapes were made of each focus group meeting and then transcribed and read by the first author within two weeks of each focus group meeting. Each focus group generated between 4 to $4\frac{1}{2}$ hours of taped conversation rendering 62 to 114 pages of transcripts per group. Approximately 25.5 hours of tape were transcribed, which produced 568 pages of data.

After the initial reading, transcripts were analyzed using a grounded theory methodology developed by Strauss and Corbin (1990). Following this methodology, each transcript was examined line by line and then coded with conceptual labels as part of the open coding stage of analysis. In open coding, ideas and themes generated by the participants are categorized conceptually and given a label. This process was intermingled with the ongoing data collection, so that open coding continued to take place as later groups were conducted. The conceptual categories emerging from open coding were constantly compared and analyzed. Such analysis allowed the researcher to generate and verify emerging central issues from the focus groups. This theory generating activity is generally referred to as the constant comparative method of analysis (cf. Glaser & Strauss, 1967) in that the activities of participant data collection, coding, and analysis are interwoven.

Emerging concepts resulting from open coding were then classified and grouped into categories. The characteristics and properties of each of the categories were then examined. After the transcripts from the first three focus group meetings were coded and categorized in this manner, categories across these transcripts were compared to analyze overall patterns in the participants' responses. During the coding of the last three focus groups, initial codes and categories were verified and refined. Individual participant stories were then reexamined closely to understand how the categories interacted.

Once open coding of all focus group transcriptions was completed and the classification of concepts into emerging categories had begun, the first author independently analyzed the data using axial coding. In this process, connections between categories and resultant subcategories were examined and several main categories or phenomena were identified as central issues in the participant data.

At this point in the analysis, the researcher felt that a verification of the initial categories and analysis was necessary. A second researcher (the second author), experienced with grounded theory, was consulted. This researcher examined and verified the initial stages of analysis. As such, the role of the second researcher was to perform an audit of the methodology and to confirm the catego-

ries and preliminary results of the first researcher. The second researcher conducted an independent open coding on the transcripts from all focus groups and listed the resultant codes and categories. These categories were compared to those obtained by the first researcher. Jointly, the two researchers then compared their obtained conceptual categories and agreed upon a working set of categories. Axial coding (establishing connections between categories and subcategories) was then conducted separately by the researchers on categories that had the richest source of properties or characteristics. From these categories, the researchers then identified a central category (the central phenomenon).

In the final stage of analysis, the researchers jointly used selective coding to systematically relate all categories to the central phenomena and to validate those relationships. In selective coding established categories are placed in the paradigm model suggested by Strauss and Corbin (1990) and identified as antecedent conditions, contexts, action/interaction strategies, intervening conditions, or consequences of the central phenomena. The central phenomenon was then defined in terms of its properties and dimensions as well as the context within which it resided. The theoretical model was validated again against the original data from each focus group.

Results

All six focus group meetings provided a rich source of information from individuals with severe, chronic disabilities and their family members. Participants appeared comfortable when responding to focus group questions and participated in lengthy, detailed discussions. Participants often shared personal experiences and emphasized similarities in their experiences as they discussed particular issues raised by the group. In the following section, quotes from focus group data will be given that illustrate the category discussed. These quotes are deliberately printed as actually stated by the participants in the focus groups.

Central Phenomenon and Context

At every focus group meeting, the central issue of the entire group discussion related to the goal of acquiring services. Acquiring services, which included seeking supports and accommodations in the community, was portrayed as a daily survival issue that overshadowed all other issues or concerns in the lives of the individual with disabilities and their family members. As the sister of a man with severe disabilities pointed out:

> I filled out four identical six-page questionnaires to four different agencies asking me the same questions. I've been fighting it for two years. I still don't have any extra money. I still don't have Medicaid. I still don't have anything. I have no place to put the boy. That boy is deteriorating everyday like you say. We're just both deteriorating. Just being locked up at home. And fighting the bureaucracy and the agencies and the incompetency. . .

The goal of acquiring services was greatly influenced by the existing service delivery system that was seen by the participants as being insufficient. Focus Group discussions, as a result, took place against a contextual backdrop in which support services were repeatedly described as costly and scarce. One young father with a son who had multiple disabilities explained it this way:

> There are services available and whether or not somebody accesses them is purely just luck of the draw. It's just dumb luck. If you happen to be in the right place at the right time and know the right people, then maybe you might be eligible to receive services. That's if you don't make too much money.

In addition, accessing services was dependent on the ability of the individual or family member to physically contact the service agency. A mother from South Texas shared that:

> Transportation for a lot of our families to even get to an agency, if they get an agency, they can't even get to the agency. Transportation is a major problem for a lot of them. We don't have a lot of adaptive bus lines. Grant ADA [the Americans with Disabilities Act] is out there but it's like it's non-existent.

The social service delivery system was described by participants as a very closed system in which individual service agencies lacked awareness and information about what other providers were doing. Referrals to other agencies were rare or nonexistent and this lack of knowledge enhanced the fragmentation of service delivery that was often found in the system. As one participant from a large metropolitan area pointed out after years of working with service agencies:

> And no one would tell me that, even though I asked about 15 individuals from both agencies before I even went out there. None of them give you that information. They probably didn't know themselves.

The process of qualifying for services appeared to be fragmented among the different agencies as well. Agencies used different checklists and definitions for providing services and appeared to have separate criteria for describing the same category of disability.

On occasion, exemplary cases were shared in which the attention and caring of an individual service provider helped an individual gain more independence. However, at every focus group meeting, participants reported a pervasively negative or apathetic attitude among service providers. A mother of twins with severe disabilities presented this view most succinctly:

> Everything doesn't cost money. It takes understanding and caring, and we don't have that in the people who provide services.

Causal Condition

In these groups of individuals with disabilities and their family members, the presence of a severe, chronic disability in the family formed the precipitating event, or causal condition, that led to the search for services. Across the multiple categories of disabilities represented in the groups, individuals talked about their personal loneliness and desperation that resulted from being socially isolated. As a daughter who was the primary caregiver for her mother with Alzheimer's disease shared:

> It's desperation as well. It's frantic despair. Sometimes you think, "I can't do this another day. I just can't do it."

Another defining characteristic of participant families was the need for support services to meet the often overwhelming limitations and barriers that are associated with living with a disability. Participants from all focus group meetings indicated that without acquiring basic supports, individual and family health ability to earn a livelihood, and independence were all compromised. During one focus group session, a young couple with a son who was diagnosed with autism shared:

> . . . and families don't always have the resources to provide this themselves. In fact, we don't because we've had to give up so many other areas of our lives- sometimes our jobs. We don't have that income because sometimes, at that point, we just lost our will to fight it any further.

Every individual with a severe, chronic disability is unique and the constellations and priority of needs of that individual and their family are also unique. However, all of the participants in these groups were highly motivated to seek services. The search for necessary services is fundamental in the lives of all persons with disabilities. Participants shared that meeting these needs required continual monitoring in order to maintain services and supports that were fundamental to their lives.

Organizing Construct

A dynamic and overall organizing construct that emerged from study data focused on the process of identifying, gaining and maintaining life-giving services. This process was what participants themselves referred to as the "qualifying game." The following dialogue between a woman with cerebral palsy and the focus group leader illustrates how participants perceived the nature of this construct:

> Participant: It's all a game. The "game of qualifying. . ."
> Focus Group Leader: I think your idea of a game board is excellent. What would we call this? The "game of qualifying?" The "game of services?"

Participant: The "game of life." The "game of a disabled life."

Participants shared that constant change and information gathering is a primary feature of the game. However, entry requirements for services, rules for qualifying for services, and information concerning services was difficult for these consumers to obtain. During a meeting in a major metropolitan area, one man with disabilities who was employed at a service delivery agency shared:

The rules change as the person you talk to changes. The joke is call [the agency] three times and get three different answers.

Consumers were not the only players confused by the game. Occasionally, service providers were also confused and passed misinformation onto the consumer. As one woman with Multiple Sclerosis explained:

I called [the agency] to inquire about their PASS Program, which I was told there was no such thing. They didn't know what I was talking about. I was reading this out of one of their brochures and they still argued with me. So I hung up and called back and got a different person who knew exactly what I was talking about and mailed me the information.

Consumers of services see themselves as ultimately responsible for making sense of the game. The burden of acquiring accurate information thus rested with the individual seeking services and made them highly dependent upon those that provide services. Participants shared that there existed rules and strategies that appeared to help them negotiate the game. Participants believed it was necessary to gain knowledge not only about services but more importantly, how to play the qualifying game.

Participants shared that the "qualifying game" was synonymous with "the game of life with a disability." Individuals with disabilities felt that they must know the right questions to ask, have partial knowledge of the answers to those questions in order to appropriately frame their questions, and know the language of the service agency. The participants' engagement in the qualifying game was a result of the complexity and difficulty of accessing needed information about services and supports from agencies and agency personnel. Because the game was complex, few individuals had knowledge about how to gain access to services. Thus the qualifying game limited access to services that were already insufficient to meet the needs of those who were qualified to obtain them. This game-like nature of service provision included constantly changing criteria for entry into the game, making the rules of qualifying difficult to comprehend, making accurate information difficult to disseminate, and causing endless waiting lists. One participant who was the primary caregiver for two children with disabilities as well as a husband with a mobility impairment shared:

What it is, is it's not qualifying for respite care but it is the waiting list. A lot of the facilities have only certain amounts of slots or certain amount of children at a time they can serve. And they are in need of some respite care. In many situations, it is an emergency need. It's not planning a vacation or planning to get away- it's something comes up within the family and they need time to do and deal with those situations and there is no service that we have been able to find where it's an immediate need for some sort of respite care. In dealing with some of the agencies, many times what we have found is, again, the waiting list. Even for day-care facilities, for sheltered workshops, for other agencies throughout the Valley here. It's a waiting list and many times our parents, our children are not able to get in.

Participants stressed that although their ultimate goal was to acquire services, this goal was based on basic survival and independence needs. Even when the ultimate outcome of playing the game was only additional information on how to play, the participants felt that this information alone allowed them to feel more personal control over their lives. Personal control, a sense of independence, and inclusion in their communities were seen by participants, as basic human needs.

Barriers to Obtaining Services

Eight different categories that emerged from focus group discussions affected how readily individuals with disabilities and their families were able to acquire services. These categories functioned as what Strauss and Corbin (1990) refer to as "intervening variables" in that they functioned to either constrain or facilitate the numerous strategies that the participants used in order to seek services.

Gatekeepers. Participants in the focus groups made repeated references to individuals who functioned as "gatekeepers" to needed services. These gatekeepers were individuals who played a vital decision-making role within the service delivery system. Often, direct service providers were described by focus group participants as being gatekeepers who protected the access to services, rather than facilitating consumer access to these services. The primary focus of the service provider was seen as establishing an eligibility criteria that was based on a checklist of identified limitations rather than on identified individual service needs. Consumers and family members indicated that at times it seemed service providers exercised arbitrary discretionary powers to determine individual eligibility.

Level of knowledge. Participants in the focus groups described that knowledge was needed in a number of key areas in order to obtain services. First, they needed knowledge about their disability itself and its corresponding medical diagnosis in order to determine where to begin their search for services. Second, they needed knowledge about agencies and organizations that provided services to individuals with disabilities. During focus group meetings, participants spent much time sharing information on how they had obtained services. The belief of the participants was that the more knowledge they had about available services, the more likely they were to be able to obtain those services. Third, they needed knowledge about the criteria for eligibility for services. In this way, participants could monitor the accuracy of information provided by the agency and determine in advance if they were likely to qualify. Participants revealed that if they were not aware of the qualifying game that needed to be played with a particular agency, they might unwittingly disqualify themselves or their family. Finally, they needed knowledge about their legal rights to access to services. Those individuals in the focus group who were aware of their legal rights believed that they were more successful in receiving the services to which they were entitled.

Accessibility and availability of services. Primary constraints that prevented individuals with disabilities and their families from obtaining services were long waiting lists or seeking services that simply did not exist. These constraints were due to the lack of funding, or in some cases, from the low pay that service providers received for their work. As one participant from a rural setting shared:

> . . . we've had vacancies at [name of agency] for a child psychiatrist. We don't have pediatricians down in the Valley because pay-wise we can't compete with going elsewhere. Our teacher turnover is tremendous. You look at our want ads on a weekly basis and our schools are turning over teachers-they talked about the aides changing, you know every couple of days they'd have someone else and we can't keep case managers, we can't keep social workers, we can't get any of the doctors down here because they cannot compete on a salary level.

Lack of or limited information and long waiting lists for services were described as common barriers among all focus group participants.

Economic status. The economic status of the family limited the services that they received. All of the participants in the focus group discussed the high cost of services and their inability to privately finance services that they needed. Those families who had more financial resources reported that they often did not qualify for public assistance programs, while those families who did qualify for these programs reported they had to strictly limit their earnings so that they did not lose needed benefits.

Presence of a family caretaker. A family caretaker was described by participants as the primary person that assisted the individual with the disability with personal care, supervision, or interpretation services. In this study, the family caretaker was usually the parent, spouse, or child of the individual with the disability, although it was occasionally a sib-

ling. This person played a key role in supporting the independence of a person with a disability. The presence of a family caretaker affected the extent to which individual with disabilities could access other services. Ironically, however, the presence of a family caretaker was also seen as limiting the amount of additional assistive care that an individual received. If a family caretaker was available to offer support services to the individual with the disability, then the individual was restricted from receiving additional assistant care. The family member was thus responsible for providing the services that, in other cases, would be provided by an attendant or medical staff.

Perception of disability. How others, particularly service providers, viewed the family or individual with the disability affected the extent to which the family was able to obtain services. The perception most disturbing to participants was when others emphasized what the individual with the disability could not do, rather than what they could do. Perceptions of service providers, family members, educators, and the community members at large greatly enhanced or constrained an individual's ability to obtain services and function independently.

Communication. Communication was a factor that directly affected the individual with the disability. When communication was limited, the individual was also severely limited in obtaining services. Difficulties in communicating included not only individual issues such as speech impairments, deafness, mutism, or limited English but also language barriers unique to the service delivery system. Focus group members shared that it was important to learn the technical vocabulary or jargon of individual service providers. Only when participants learned important key phrases could they inquire about and discuss services. They had to know the questions to ask and the language with which to ask them. Without this language, communication with service providers was limited or did not occur.

Strategies Used to Obtain Services

Focus group participants described common strategies that they used to obtain needed services. These strategies centered on five predominant categories and were often used to acquire services and overcome barriers to receiving or maintaining services.

Being assertive. To acquire services, participants shared that it was necessary for participants to be extremely assertive. Assertiveness was used to obtain information about available services and to advocate for disability rights. Family members as well as individuals with disabilities felt they had to learn assertive behaviors. As one young mother shared, "I learned that with my daughter, you have to be an aggressive parent. Because no one else is going to do it for you." Agencies that existed for offering services to individuals with disabilities were often viewed as entities that had to be confronted in order to obtain information and services rather than organizations that offered support.

Community services also had to be confronted and educated about the rights of individuals with disabilities. Participants described that it was difficult to change both community services and the service system for individuals with disabilities. However, a strategy for possibly doing so was through organizing together to campaign for legislative action. This type of organizing was seen as a type of group assertiveness and group advocacy. A participant who had retired from the military and was a full-time caretaker for his wife with Alzheimer's explained:

> Individuals harassing- that's one thing but as groups harassing- you ask any of your Congressman, Senators, Representatives or Council members of [name of city]. If a group comes and says we've got 250 members who are voting people who want you to do something- they can answer that. But you can go up there and scream your head off but the one person- it don't bother them. It's the old squeaking wheel process. The more the group squeals, the louder they hear because this affects their pocket book as being voted back in. And it goes from the city all the way to the President of the United States.

Despite extensive agreement among the participants that assertiveness was necessary, some participants with disabilities pointed out that they had some fear of doing so. These

participants shared that if they challenged the system they might anger service providers and then not receive the services that they so desperately needed. One woman with cerebral palsy explained:

It's the fear of retaliation from a personal attendant. And if you make waves then there is the fear that the attendant will get back at you in some way and you are in a vulnerable situation when- or I'm in a vulnerable situation when I'm in bed, not in my wheelchair, and can't get to a phone.

Changing economic status. Participants repeatedly discussed the high costs of necessary services and the difficulty in obtaining services through public agencies. Families had to carefully monitor their income as a change in economic status might mean the loss of services that they then could not afford to pay for privately. Some families consciously chose to impoverish themselves in order to qualify for a wider range of services. All participants recounted stories of economic struggle, while many told stories of financial ruin. One young mother shared her personal struggle to provide for her children:

We didn't have any Medicare or anything. . . And one day one of the twins got real sick and we didn't have any insurance or anything. So we were afraid to take them to the hospital so we took him to the doctor and he said, "Well, this kid is almost dying." And we took him to the hospital- we made arrangements with the hospital to make payments little by little but it was so hard for us because we didn't have any insurance or anything. So finally. . .after two years and a half years by ourselves, you know, paying the bills and all that. We finally got Medicaid- but sometimes my husband has a chance to go to college or do something better than his job but we say wait a minute- if you get a better job we're going lose our Medicaid and everything now.

Choosing to depend on public programs was not seen as a positive choice and participants were aware of how choosing to do so placed their entire family at economic risk. Managing these financial challenges was made more difficult as information about qualifying economically for services was hard to obtain and complicated. This can be seen in a quote shared by young father with cerebral palsy:

. . . say you have a trust fund that wasn't set up appropriately or you don't know the rules in setting up the trust fund–your trust fund knocks you out of any available service. So you have to run that trust fund completely down which means you haven't got a back up. The family has no kind of support for emergency situations. If for any reason, you're on the program and you get cut- you made a little too much that month or not enough- you get cut, you don't have anywhere to fall.

Another participant summed up his focus group's discussion by explaining that ". . . it's all financial issues. It's real complicated. To be independent and disabled, you have to be very, very rich or very, very poor."

Gaining knowledge. Participants used the strategy of educating themselves about the service system in order to obtain services more effectively. Participants believed that the more knowledge they had about how to qualify for services, the more likely they were to obtain services. However, this knowledge also included ways to circumvent the gatekeepers who were seen as preventing access to services. Service providers were seen as not forthcoming with information that would help families become more educated about the service system. In fact, the information about services that was most helpful and most reliable came from other individuals with disabilities or their family members. Agencies seemed uninformed about what services were available from other agencies or even departments within their own agency. As a result, families often did not receive proper information or referrals. Focus group meetings were replete with examples echoing what this one mother shared:

But no one agency tells you about the other programs. [Name of agency], if you called for client management, you're only going to find out about client management. They're going to say you don't qualify- "Oh, is there anything else that I qualify for?"- "I don't think so, no." Because the only program they know is the one they're working

on. So you think you've already talked to DHS, you've found out about all their programs and therefore you don't qualify. And there's several of them out there that would fit you just perfect so you're up a creek.

Participants talked about networking to obtain badly needed information about available services. They explained that the search for knowledge must be intense, comprehensive, and continual.

.You make every meeting, you're everywhere, you're talking to anyone. If you see someone in the grocery store you tell them your story. You hope someone gives you a piece of information that someone hadn't. You chase every false lead, you know, where some people say you're paranoid, you're obsessed. No, you're desperate!

Moving to obtain services. Individuals with disabilities and their families who lived in rural areas appeared to have the most difficulty obtaining services. Many families had chosen to relocate to cities where these services were available. One young man with cerebral palsy explained his story in this way:

And actually I moved away from Houston for about four years. I moved to West Texas and I came back to Houston because Houston has the services that I need. Now the services here certainly need improvement. But at least having some services like transportation- having those services is better than having none.

Others traveled long distances to obtain services that were needed intermittently. Participants from a South Texas focus group spoke about the lack of trained professionals, including teachers, doctors, translators for the Deaf in South Texas, and that it was not unusual to travel over 200 miles to San Antonio for services.

Using attendant services. Attendant care is a primary and pivotal service in that it functions both as a fundamental support for individuals and families as well as a strategy used to obtain other services. Individuals with disabilities need attendant services to gain access to the community, pursue employment opportunities and in some cases, get out of bed, dressed and fed. A young woman with cerebral palsy shared:

Well, I can't get up in the morning unless I have somebody who will come and help me get, up, get dressed. I can't get to work if I don't have transportation.

Deaf individuals particularly point out, that without an interpreter, they were often unable to obtain basic health and transportation services. Attendant services were inevitably described as expensive. Yet these services are so vital that other goals in life are sacrificed in order to maintain eligibility. As one participant with cerebral palsy explained:

The attendant care- I would like to say "affordable attendant care"- which we do not have, I feel, at this point and time. Those of us who are working are taking a beating and we end up suffering. A lot of people out there are not working because they can't get insurance or can't afford attendant care. It's just a major problem.

Summary

All groups participated in an open and forthright manner- requiring little encouragement from the facilitator to share personal experiences. The active, intensive participation of focus group participants was an efficient method by which to gather a large amount of rich information concerning the lives of individuals with severe, chronic disabilities and their family members. The focus group questions were explored from multiple points of view and yet resulted in themes that proved to be consistent across group meetings and categories of disability. These themes came together to form the following storyline that illustrates how a severe, chronic disability influenced these participants' lives:

Having a severe, chronic disability created a need for services that were scarce and costly in the existent service system. Financial assistance was often need to obtain these services and individuals, at first, knew very little about how to obtain them. Individuals with disabilities and their families began going to doctors, agencies, social workers, and teachers, none of whom were completely satisfactory in either providing them with services, referring them

for services, or in being empathetic about their needs. Often, these sources were seen as being uninformed, inept, insensitive, or unhelpful. Nevertheless, they were the gatekeepers to the services that the person with the disability desperately needed. These gatekeepers had the power to make decisions regarding the individual's eligibility for services and to refer them to other services, provide them with services, or to deny them services.

Persons with a disability and their families had to become educated, assertive, and persistent to obtain services that were controlled by the gatekeepers. They had to learn the "language" of the service system and its gatekeepers. They came to understand that it was essential to network, to learn about the services available to them, and to self-educate themselves about their rights. They also learned that it might be necessary to withhold information from the gatekeepers about the economic and personal resources to which they had access.

The resulting skill with which the qualifying game was played by the family and the individual with the disability determined the level and appropriateness of the services that they received. However, once a person qualified for services, they might not actually receive those services because of shortages or long waiting lists. The level of services that an individual ultimately received subsequently affected his or her inclusion in the community. The level of services received or not received also influenced the level of stress, both economic and emotional, experienced by the individual with the disability and their family.

Discussion

Analysis of this data provides a picture of the support needs, barriers, and issues that were common in the lives of a widely diverse group of persons with severe, chronic disabilities. Throughout the focus group process, participants focused on the commonalties of their life experiences, rather than the differences their disabilities presented. What was particularly salient about their common experience was the struggle they had- "the qualifying game" that they played in order to obtain services.

Ultimately, programs for individual with dis-

abilities should attend to the goodness-of-fit between the outcome of services and the quality of life of the individual (Dennis et al., 1993). Little quality assurance seemed to be implemented by the agencies that provided services to the individuals with disabilities in this study. In addition, service providers and agencies did not seem to be working together to provide a comprehensive system of care for these individuals. Hanson and Carta (1996) point out that "service systems and agencies with whom. . . families interact must build collaborative support to provide comprehensive services" (p. 209). For the participants in this study, the delivery of services was disjointed, confusing, and difficult. The resultant picture was one of people who struggled to live an independent and self-determined life. Their struggle however, was thwarted by barriers that demanded strong personal tenacity and ongoing self-education to overcome.

The individuals with severe, chronic disabilities and their families in this study had to develop assertive behaviors in order to successfully overcome barriers to needed services. When an individual is born with or acquires a disability, they and their family members are thrown into intense interaction and communication with a variety of service professionals. Yet key personnel, including educators and medical professionals, were often seen by participants in this study as barriers to overcome, rather than as resources. Turnbull and Ruef (1997) point out that family members must become "the initiators, catalysts, and choreographers of attaining inclusive lifestyle supports . . ." (p. 222). Further investigation is needed to gain a more complete picture of the nature and process of how individuals with disabilities and their family members acquire an assertive attitude and behavioral style.

Family members and consumers reported that their strongest source of support and accurate information came from other consumers or family members. Networking has been found by Cunconan-Lahr and Brotherson (1996) to be an important component of self-advocacy and self-determination. Support groups often serve an important function as not only an emotional support but as an active information center for individuals with disabilities. Learning from others who had "been down the road" appeared to be a better source

of information for the participants in this study than the "experts." Further research may provide insight on what makes this form of information gathering especially helpful for individuals with disabilities and their families.

Many issues were raised in the focus group meetings and they appear to apply to both the life of the individual with the disability and to the life of the family members. Isolation was experienced by both individual consumers and their family members. Hughes et al. (1995) point out that social relationships and interactions are essential components in assessing quality of life. When a disability occurs in a family, both the individual with the disability and their primary caretaker can become isolated and at-risk for a decrease in their quality of life. Thus, many of the limitations and barriers that are felt by individual consumers are also present in the lives of their family members as well.

The degree of choice an individual with disabilities is able to exercise has been shown to be significantly limited when compared to adults without disabilities (Sands & Kozleski, 1994) and choice is an important component of self-determination. There exists a related discrepancy as well between the achieved needs and desires of people with disabilities and their expressed dreams. Many of the necessities that individuals without disabilities take for granted, go unmet for individuals with disabilities. The concept of a "hierarchy of needs" (Maslow, 1943) which can be seen as starting with the basic needs of hunger and thirst, and then ascending to the higher level needs of esteem and self-actualization, assumes that we have our basic needs met so that we can fulfill higher order needs as we progress through life. Yet, it is important to keep in mind that vast differences exist in the progression through this needs hierarchy for individuals with disabilities. Life with a disability changes this process in that appropriate services must be present to support the basic needs of individuals with disabilities. If an individual with a disability is not able to acquire necessary services, it becomes difficult for them to move up this hierarchy. Consequently, the acquisition of services should be seen as a basic fundamental need for individuals with disabilities who seek self-actualization and increased quality of life.

From this study it appears that self-determination, along with the other components of quality of life, is dependent on the acquisition and maintenance of necessary support services. As was the case in this study, and has also been noted by Bambara, Cole, and Koger (1998), systemic barriers that limit access to individualized and flexible services also limit the development of self-determination. What is suggested here is that the components of quality of life, such as self-determination, social inclusion, and physical well-being, are only possible when individuals with severe, chronic disabilities have access to needed services. The individuals and family members in this study, however, believed that they must play a "game of qualifying" to obtain services. Life for both the individual and family members was set within an indifferent social service framework that defined the rules of this game. Some of the individuals in our study described that they occasionally became too tired or too discouraged to continue to play. They found that not "playing the game" led to a decrease in the services that they received and a subsequent decline in their quality of life. Ultimately, these individuals with disabilities and their families, out of desperation and increasingly limited choices, discovered that they were forced to again wearily rejoin the qualifying game.

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