Communication strategies for survival: a study of service agency and client relationships

Betty Jo Maughan

The University of Montana

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COMMUNICATION STRATEGIES FOR SURVIVAL: 
A Study of Service Agency and 
Client Relationships 

by 

BETTY JO MAUGHAN 

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Approved by: 

[Signature]

Chairperson 

[Signature]

Dean, Graduate School 

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COMMUNICATION STRATEGIES FOR SURVIVAL: A Study of Service Agency and Family Relationships

Introduction

Parents who have children with exceptional needs living in their homes may experience a multiplicity of separate, yet intricately related interpersonal support networks and services. Each of these has the potential for providing families with relief and/or for adding stress, (Jacobson & Regula 1988), depending on the ethics, attitudes and the task performance of the provider agency's staff. The link between these elements and communication patterns or styles is revealed in this study of the interactions between families of children with severe developmental disabilities and their personal care provider agency.

It is not my intent to explore a panorama of services which facilitate family coping. Indeed, a number of studies have previously been done to that end (Seybold, Fritz, & MacPhee, 1987; Smith, Caro, & McKaig, 1988; Cohen & Warren, 1985). But rather, my purpose is to identify communication factors which may undermine the very mission of support service goals--to reduce stress and, thereby, improve parental coping capacity.

The ability to communicate effectively and in a socially acceptable manner is critical to forming and maintaining interpersonal relationships. The quality of one's communication is an important part of defining the
quality of one's life (Stewart & Logan, 1993). And quality of life is precisely the foundation upon which the notion of human services is built. It follows then, that in order to justify their work, those who provide human services need to familiarize themselves with communication theory and to develop and exercise effective communication skills.

Today, the reported goals of most support service providers is to keep the cost of caring for children with developmental disabilities down (Jacobson & Otic, 1989) while enhancing their quality of life by strengthening families' abilities to raise them in their natural homes. A number of quantitative studies have been done relative to this issue (Krahn, Eisert, & Fifield, 1990; Weiss, 1991; Sherman & Cocozza, 1984; Bilkin, 1988; Darling and Darling, 1982; Rosenfeld, 1981; Boyle & Comer, 1990). Though quantitative research is indeed valuable for overall service planning, most quantitative studies do not collect the kind of in-depth data which allow for an intimate examination of individual interactions between human service personnel and their clients.

This qualitative study, on the other hand, focuses on and elaborates on specific needs and concerns of people. The commonality of the collective experiences reported herein lends credibility to the importance of this study for law and policy makers and for professionals. For though these families are part of a minority, they are
representative of a minority with extreme needs and with extensive potential impact on the financial health of the state and the shaping of future service delivery policies.

Henceforth, I shall look at how a family's capacity to cope with their children's disabilities may be undermined, in part, by the communication within the very system which was intended to enable them. I shall examine the parental perceptions of communication exchanges and analyze the effects of those exchanges. Although this was not an attempt to gather equal data, I also gathered agency responses to some of the parental perceptions and shall incorporate those responses into my analysis. Though my emphasis is parental advocacy, my recommendations for improving communication may lead to greater satisfaction for both parents and the service agency.

Literature Review

The current trend in the fields of developmental disabilities and early intervention services is to facilitate familial acquisition of adequate resources so that children with developmental disabilities can be successfully raised by their parents in their homes, rather than being institutionalized (Smith, et al., 1988; Krahn, et al., 1990; Kobe, Rojahn & Schroeder, 1991; Dunst, Trivette, & Cross, 1990; Weiss, 1991).

In recent years, our state has been publicly recognized as a leader in developing and providing state of the art
services to families of children with developmental disabilities.¹ For children with severe developmental disabilities, the expression "adequate resources" has a more profound meaning than it does for their less severely involved peers. Children with severe developmental disabilities require inordinate amounts of parental time, energy and financial resources (Seybold, et al., 1987; Weiss, 1991; Trute & Hauch, 1988; McLinden, 1990; Dunst, et al., 1990). Without significant support resources, these children are at high risk for out-of-home placement in state financed foster homes, group homes or institutions (Kobe, Rojahn, & Schroeder, 1991).

Historically, out-of-home placement options have been more costly to a state than in-home support services. However, as the mortality rate for children with severe developmental disabilities declines, the cost of maintaining them in their natural homes rises, not only because there are more families who need the support services, but also because they need significant amounts of more costly support services, such as respite (caregiver relief), personal care attendants (personal care assistance), habilitation aides (physical, occupational and speech therapy assistance), homemaker services (e.g., home upkeep and sanitation), home modifications (e.g., widen doorways, wheelchair ramps), and

¹ Mary Maloney, Program Director for the Western Montana Comprehensive Developmental Center, personal interview, December 1992.
adaptive equipment (e.g., wheelchairs, lifts, etc.). Hence, parents question the logic of policy makers who expect families to absorb the stresses of providing home care (thereby reducing public expense) without providing them with sufficient resources to enable them to provide that care on a long-term basis.

It is counterproductive for professionals to offer services based on professional handiness or assumed needs rather than family utility and actual needs (Sands, Kozleski & Goodwin, 1991). Services which are not founded on need in an individual family context run the risk of adding inordinate amounts of familial stress which, over time, may culminate in the very thing they were designed to prevent: out-of-home placement (Kobe, et al., 1991; Sherman & Cocozza, 1984; Blacher, 1990). For instance, when the activities of an entire family are severely restricted in order to meet the needs of one family member, resentment is likely to build among the other family members and the primary caregiver, who may already be on the road to burnout, is likely to get the blame. At some point, this stress will find release, either through adequate network services, family breakup, or out-of-home placement for the child with disabilities. When service providers restrict and dictate family activities rather than offer relief based on needs identified by family members, they are adding to the difficulties regardless of their intentions or their
reasons for the restrictions.

Research is often measured in quantitative terms which compare the extent and scope of available services with the kinds and amounts of services needed (Seybold, et al., 1987; Davidson & Adams, 1989). However, parents are also concerned with the quality of service, because it greatly influences the quality of their families' lives (Sands, et al., 1991; Smith, et al., 1988). Therefore, it is important that research also examine services for details which impact quality but which may not be evident in quantitative terms. It is qualitative studies which lend themselves more readily to the kind of thick description necessary for identifying those factors which impact quality.

Quality services are a product of a multifaceted system which encompasses the availability and distribution of funding, attitudes and skills of policy makers, professionals and direct service personnel, the structure of the service system, consumers of services, and the interdependency of these and other factors. Darling (1988) suggests that the recently increased advocacy and consumerism movements for and with individuals with developmental disabilities and their families may be interpreted as a response to insufficient or inappropriate resources and support from local, state and federal governments in meeting their needs. The fields of medicine, social services, and education have had to examine and
redefine their models of service delivery in response (Sands, et al., 1991). Nevertheless, in spite of the intent of some professionals to be more sensitive to individual and family needs, "most persons with developmental disabilities and their families remain intimidated by the professional dominance of...other professionals" (Darling, 1988, p.143). Parents are often viewed and treated by professionals as too ignorant or irrational to participate in service planning in a responsible manner.

Jacobson & Regula (1988), in examining community residential services, found that "service adequacy may be influenced by agency staff attitudes, skills and performance." Parental feelings of uncertainty and powerlessness are perpetuated by their lack of information or misconceptions (McDonnell, 1987) which may be accentuated by the unwillingness of professionals to pay credence to parents as valuable members of the planning team and to provide them with accurate, useful information (Krahn, et al. 1990) upon which to base their judgements. Indeed, Bilken's study (1988) showed that consumers often experience a developmental disabilities system laced with "love-it-or leave-it" options with little attention to individualized needs. Krahn, et al. (1990) concurs by reporting that avenues for consistent and responsive parental participation at the service delivery level vary with individual service delivery systems and often do not even exist.
Offering families services which meet their needs is of ethical and value-based importance. Lieberman (1989) purports that families have the right to be listened to, to be seen and understood both professionally and empathetically [emphasis added], and that empathy is an essential element to the successful delivery of quality human services. I would argue that the communication must also be dialogic (Stewart & Logan, 1993), or co-created between the service provider and the families. Families of children with developmental disabilities are clients (or consumers), not patients. They are neither ill nor incompetent. They are asking for and receiving a service. That service should be provided in accordance with the client's own hopes, plans, and attitudes toward life. Lieberman's (1989) response to those service providers whose attitude it is to fix the lives of others is, "No social worker or therapist can prescribe how other individuals should lead their lives."

Agency policies or mission statements which include statements of, or claims to consumer-based services are not viable evidence that the agency does, in actuality, render services in such a manner. And simply allowing for, or even asking for, parental input does not guarantee effective parental participation. Darling & Darling (1982), found that when clients or families are asked to make choices about services, they may be hesitant to express their true
feelings about those services "for fear of undesirable repercussions on the part of the service providers." Yet, unless consumers and their families are involved in the development of support systems and resource distribution, it is doubtful those services can be effective (Seligman & Seligman, 1980; Stotland, 1984).

In-home services have been shown to be of vital importance to the functional health of families of a child with developmental disabilities (Smith, Caro & McKaig, 1988). In Smith, et al.'s (1988) study of the New York City Human Resource Administration's Home Attendant Program, home attendants provided personal care services which included assistance with self-help skills, bathing, eating, dressing, toileting, taking medicine, and a variety of household tasks. They also took the child on walks, to play and to medical appointments. They supervised the child "both when the mother was home and when the mother went out." They served as another adult for the child to interact with: someone to go to for help; someone to offer patient discipline, companionship and a role model. They also helped with the other children in the home, and they provided child care while the parents worked, looked for jobs, or went to school.

Some of the service-related problems parents identified in this same study (Smith, et al., 1988) were: 1) frequent turnover among workers, 2) unsatisfactory home attendants,
and 3) vendor agency's ineffectual communication, interruption of services, constant training of new attendants, disorganization, restrictive policies, too many people in their homes and loss of privacy.

In summary, the literature confirms the current trend of family-centered services. The appropriateness and the caliber of those services have significant impact on the quality of life for children with developmental disabilities and for their families. Quality support resources are crucial to the ability of parents to cope with the strain of incorporating and maintaining such a child in the family unit. In fact, any negative attitudes and demeaning behaviors or communication from service personnel can undermine parental strengths (Affleck, McGrade, McQueeney, & Allen, 1982) and increase the risk for out-of-home placement of their children with developmental disabilities. For effective professional-parental cooperation to occur, professionals must provide "safe ground" for parental communication and participation in service planning and delivery. Parents have valuable ideas for reducing familial stress and thereby strengthening service delivery usefulness. If the real goals of policy makers and professionals are in-home maintenance of these children and quality use of public funds, they must listen to consumers dialogically and exhibit positive responses. Quality use of funds can efficiently and effectively encompass
consideration for the quality of life of these children and their families.

Personal Care Attendant Services

One support service available to families of children with severe developmental disabilities in this study is a personal care program administered by an independent agency and regulated under a state Medicaid contract. However, this agency's personal care services are nowhere nearly as comprehensive as those of the New York home attendant program described above (Smith, et al., 1988). As in New York's program, this agency's personal care attendants may provide assistance with self-help skills, bathing, eating, dressing, toileting and very limited household tasks. However, they are restricted from giving medicine, from taking the child on walks or out to play. And PCAs are instructed not to form personal relationships with their clients or their family members. They are not allowed to provide care for other children in the home nor, under any circumstances, are they to be alone with the child with disabilities (without another adult present).

In its inception, this personal care program was designed to serve adults with disabilities (particularly the elderly), so they could remain in their homes and out of institutions as long as possible. With the movement to keep children with developmental disabilities in their homes and with the addition of the Medicaid Waiver program in the
early 1980's, came an expansion of the personal care program to include children with excessive special needs. However, because the personal care program was originally shaped to meet the projected needs of independent-living adults and has not been effectively restructured to incorporate the unique needs of children living in a family setting, these services lack the family-focused quality which parents require and which characterize other aspects of early intervention services today.

Personal care service referrals may come from clients or their families, from social workers or case managers of other service agencies, and occasionally from physicians. Two registered nurses, who serve as case managers for clients receiving personal care attendant (PCA) services, are accountable to one of the two area directors. According to the regional office manager in Missoula, these two nurses serve a total caseload of 135 clients, which includes supervision of from 95 to 123 personal care attendants (PCAs), those individuals who provide the direct care. Two and one-half (full-time equivalent) schedulers, assign the PCAs to provide personal assistance to these 135 clients on a daily, set-schedule basis.

Because of the relatively small number of children in this state who receive PCA service (7.7%)\(^2\), and because of

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\(^2\) Personal interview and personal correspondence with state director of the personal care agency, December 1992.
policy makers' fears of financial expansion of the Medicaid program\(^3\), parents perceive a significant resistance on the part of professionals and policy makers to consider mutually satisfying ways of meeting the real needs of these children and their families. Yet, families are any child's greatest resource; if we neglect the needs of the family, we neglect the child (Lieberman, 1989).

I am the parent of a fourteen year-old child with severe, multiple developmental disabilities for whom I was the primary care giver for over twelve years. Because our family has received personal care attendant services from the same agency these parents did, I am able to identify with these parents' stressors and to responsibly interpret their responses to research questions (See Appendix A), as well as their interactions with one another. My personal frustration with our family's personal care services and the frustration expressed to me by some of my daughter's personal care attendants (PCAs) led me to question whether other families were also experiencing difficulties and if so, how they coped with them. I determined, therefore, to explore the following research questions:

\[ Q_1 \text{ What agency behaviors do parents of children who receive personal care attendant services perceive as generating stress in their families?} \]

\(^3\) Personal communication with administrator and officials of the state Medicaid Division of Social and habilitation Services, August 7, 1992.
Q2 What outcomes do these difficulties generate?
Q3 What role does communication play in either contributing to or solving these problems?

Because the number of children receiving these services is small, and because their needs are so diverse, a qualitative study seemed the appropriate route of inquiry.

Methods

Participants

This research was conducted in the form of focus-group interviews. Six parents (including two foster parents) of children with severe, multiple developmental disabilities who each receive personal care services, were interviewed in groups of three (one group was interviewed twice, once in 1992 and again in 1994). Four personal care agency personnel were also interviewed, one individually and the other three in a focus group setting. These interviews were conducted to obtain the agency's response to the concerns identified by parents.

All of the parents were aware that I was the mother of a child with severe developmental disabilities who had received personal care services. I believe this knowledge allowed them a feeling of inclusion and safety so they felt free to be frank about their experiences and feelings. My personal experience also allowed me a knowledge base upon which to ask relevant questions and to make accurate interpretations of their responses. In addition, it allowed
me to serve as a parental advocate, of sorts, when I was interviewing agency personnel.

Each participant was the parent of a child (ranging from four to sixteen years of age), with negligible self-help skills and with a functional age range of three months to three years, most in the six month range. Medical diagnoses for these children were cerebral palsy, seizure disorder, microcephaly, hydrocephaly, and post-meningitis disorders, although secondary disabling conditions included severe cognitive delay, asthma, blindness and visual impairments, deafness, cerebral palsy, a circulatory system anomaly, seizures, scoliosis, spasticity, and skeletal displacement. Each child was nonverbal and non-mobile, had eating disorders and had no toileting skills. Parents reported their children's strengths as smiles, cries, coos and facial expressions used for communication, and two children were capable of moving one limb for limited communication.

These parents had been the recipients of community-based intervention services of various kinds, through a variety of service agencies, from five to 16 years. However, they had received this agency's personal care services for only eight months to eight years. One other parent had three other children at home with serious disabling conditions and two of the parents had [non-developmental] disabilities themselves.
The parents ranged in age from 36 to 64; four were married, one separated and one divorced. Three were employed outside the home. Family yearly incomes ranged from less than $10,000 to $60,000. One family's child moved into a group home just after the first interview.

Each parent was the primary caregiver for her or his child with disabilities. In addition to those tasks regularly associated with household function, these parents were responsible for coordinating a vast array of medical, educational and support services necessary to the well being of their children with disabilities.

Data Collection

The parents' interviews were conducted in three different quiet, comfortable settings that were free from interruptions. Interviews with agency personnel were held in their offices during regular office hours. The interviews were audio taped and later transcribed by the researcher for analysis.

A focus group was chosen as the preferred interview style for parents so as to allow interaction among participants. I suspected that these parents would have many common experiences to share, that they would draw strength and courage from one another, and that they would speak more freely in the presence of other women who shared a common world view. For agency personnel, appointments were made for individual interviews. However, when I
arrived for the second interview, I found that the individual who had agreed to the interview had invited two other agency personnel to participate. I had an associate with me whom I then also invited to participate. Hence, the last interview was also conducted in a focus group format.

All parents were given a written copy of an "Agreement of Participation" (see Appendix B) which was read aloud as they followed along. I explained that the research was being conducted for a project in the University of Montana Communication Studies graduate program for the purpose of examining the role of communication in the quality of personal care attendant services they had received for their children with developmental disabilities. They were given assurances of confidentiality and were also required to agree to protect the anonymity of the other participants. They were instructed that their participation was entirely voluntary and that they could refuse to answer any question and/or choose to withdraw participation at any time.

Agency personnel were asked personally to participate, however, they were not asked to sign a participation agreement. Because of their professional status, I assumed they would understand their rights to respond or not to any questions or comments. Although I do not believe this affected the outcome of the study, I would refrain from making such an assumption in the future.

Sets of open-ended research questions (See Appendix A),
drafted prior to the parent interviews, were structured to give respondents opportunity for any response they deemed appropriate. Not all questions were asked during the actual interviews, albeit all but one were answered to some extent during the discussions. As the interviews progressed, other questions were constructed from the discussion at hand. Most questions were answered without hesitation, and those that were met with cautiousness were quickly and completely addressed when I reminded them that their responses were confidential.

In conducting this research, I consciously guarded against asking leading questions or slanting the responses of the participants. Hence, for the most part, I did little talking, but rather allowed the participants as much time and informal conversational interaction as they required. However, when they asked me questions, I disclosed unhesitantly. It was unnecessary for me to provide much direction or facilitation to the interviews as these participants were not timid. In addition, one participant in the first interview, with great deftness, assumed the leadership role of guiding the discussion. I found it less intrusive to allow her that role.

Agency personnel were told that the focus of the study was on communication between their personnel and families of children with disabilities who receive personal care services. I indicated that I had interviewed several
families and wanted to "balance out this information with information from [this agency]." One administrator indicated concern about what I meant by "balance out" my paper. I replied that I had information from families who had received services and would like to also hear from the agency that provides the service. I indicated that I had chosen this route because some families had expressed concerns about the communication they had experienced with agency personnel. Basically, I had heard consumer concerns; I needed agency responses to those concerns.

The parent interviews lasted between one and one-half to two hours with short, informal breaks. The agency interviews lasted 25 minutes and one hour respectively.

Data Analysis

I transcribed the research data from the original audio tapes using pseudonyms for the parents, their children, their personal care attendants (PCAs), and personal care agency personnel. I then read and reread the data, start to finish, four more times. Using analytic induction, two general categories became evident because of their recurrent nature and their commonality among participants. Upon further examination of the text, and utilizing Miles & Huberman's (1984) cluster analysis, I grouped discussion topics into general categories based on their recurrent nature and their commonality among participants. With each reading of the data, I refined the topics into increasingly
more specific categories. I then isolated quotes of particular interest and sorted them into their categorical groups as descriptors of analytical importance.

The two predominant themes which emerged as problematic for these families were stress and communication breakdown. There is considerable stress inherent in living with a person with rigorous needs. However, the stress these parents expressed was borne not only of caring for their children with disabilities, but also as a direct result of the agency's restrictive and paradoxical rules, their impersonal manner and intrusive behavior, fear, and poor quality services. In addition, it seemed to these parents that the direct and indirect communicative behaviors of some agency personnel, at all levels of the organization, communicated an attitude which subverted the very purpose of the service system in general.

**Stress**

When I asked the parents in the first interview what their concept of family-centered services was, the instantaneous reply was: "That's not at all what I'd like to talk about," followed by concurring laughter from all participants. In their ensuing attempt to focus on this question, the discussion moved abruptly to a discussion of personal care attendant (PCA) service-related stress. The stressors to which they referred have been categorized into restrictive and paradoxical rules, impersonal service,
intrusion, guilt, fear, and poor quality services.

**Restrictive and Paradoxical Rules**

The most prominent source of stress the parents reported appeared relative to overly restrictive, obdurate "rules" imposed as a condition of the personal care services and upon which other layers of stress appear to have flourished. Personal Care Attendants (PCAs) were assigned to a family for the express purpose of directly assisting the individual with disabilities with:

1. ...activities of daily living and/or personal hygiene. (Dressing, bathing, grooming, feeding, routine hair and skin care, toileting, transferring, walking, exercising, assistance with medications which are ordinarily self-administered).

2. Meal planning, shopping, storing, preparing and serving food.

**NOTE: FOR THE NEXT TWO TASKS... HOME MANAGEMENT AND ESCORT SERVICES MUST BE PROVIDED ONLY IN CONJUNCTION WITH DIRECT PERSONAL CARE AS DESCRIBED ABOVE AND MUST BE DIRECTLY RELATED TO A RECIPIENT'S MEDICAL NEEDS.**

3. Home Management: Assistance with activities related to housekeeping that are essential to maintaining the recipient's health and safety in the home. Examples: changing bed linens, light housecleaning, laundering, washing dishes, shopping and arranging furniture.

4. Escort Services: Arranging and/or accompanying and personally assisting recipients on trips to obtain medical diagnosis or treatment or to shop for items essential to the recipient's health care and nutritional needs (Agency's Recipient Packet, 1992, 1994).

However, varying restrictions were placed on families' access to these kinds of assistance. For instance, four of the six children included in this study were fed through gastrostomy tubes. Because of state nursing regulations,
PCAs are not allowed to feed these children even though the parents clearly felt that the risks were considerably less than feeding them by mouth:

Lyn: But they will not allow anybody but a nurse to touch a tube feeding. Which is interesting because it's much easier, I'll tell ya!

Sam: I know it! It's easier and safer than feeding them orally.

While the agency may not have had the authority to be flexible with state nursing regulations, they appeared to be just as inflexible, albeit inconsistent, in administering other rules as well. While one parent reported that her child's PCA was allowed to do anything specifically for her child, another parent reported that her child's PCA was not allowed to prepare her child's food, do the child's dishes or laundry, clean the child's living areas, or change the child's bed linens. Her understanding of the reason for these restrictions was that the PCA did not have enough time to do those things after helping the child with bathing and exercising. Medicaid allows an individual up to 40 hours per week personal care service, and this child was receiving only fourteen. Nevertheless, the agency reportedly told the family that because they were also receiving nursing services (an R.N. to sit with the child at night so the parent could sleep) through another agency, Medicaid would not allow the PCA agency to provide any more hours. The resulting restriction of PCA hours put this parent in the position of deciding whether she wanted sleep or assistance.
A second inconsistency involved a family whose nonambulatory child required lifting. This parent reported that the agency often sent this family PCAs who either could not lift the 50-pound child or who did not want to care for him. Eventually, the agency told the parent that PCAs were not allowed to lift clients and that they would not be eligible for services until they lived in a home that did not have stairs. This parent was understandably shocked when one of the other parents reported that all of her 70-pound child's PCAs routinely lifted him as needed. Furthermore, this other parent reported, her PCAs had told her that they were required to be able to safely lift 100 pounds in order to be employed by the agency, and that the agency had taught them how to lift properly.

Another particularly frustrating and paradoxical rule for these parents was that PCAs were not allowed to be alone with a child while the parent was out of the house or, in some instances, even out of the room.

Sal: My PCA is not allowed to take my daughter outside. That's socialization. But then...Kim's [PCAs are allowed to] take [his son] for strolls.

Kim: They did last summer. That was all part of the program and socialization was [written] into his PCA program. Now they tell me that they can't do that anymore.

Sal: They can't take [my daughter] out on the deck.

It appeared that little administrative forethought for family impact was given to these restrictions. As one
parent related,

I called [the scheduler and said]...I don't feel comfortable leaving [this PCA] alone in the room with Davy. And she says, "Well, you're not supposed to be leaving the room."

I said, "You mean I got to sit there and watch her do whatever she's supposed to be doing? And just sit there? I can't go in my back yard? I can't go to my basement and do something? I got to sit here and watch her? I might just as well do it myself."

One parent was told by her case manager (an R.N.) that she could not take a nap while the PCA was in her home. Furthermore, this parent was told she could not leave the PCA with her child even to go down the front walk to retrieve her mail. In fact, the PCA could no longer even push the child in his wheelchair between the school bus and the front door of her home because that was considered socialization and PCAs are not allowed to socialize with their clients! This same case manager told the PCA point blank, (in the parent's presence) that if the parent ever left the PCA alone with the child, that the PCA was to leave the child, go home (which in this case happened to be over 20 miles away) and call the agency to report the violation. When the PCA replied that she could not in good conscience leave the child alone, the case manager replied that it was not her responsibility; anything that happened would be the parent's fault because he knew the rules.

When confronted with a report of this incident, agency administrators assured the researcher that at no time had any PCA left a child unattended and that they do not direct
their PCAs to do so. When asked if they felt this parent was lying about the incident, the reply was, "Well, you know, I wouldn't say that. I would say that, you know, communication is a two-way street." This administrator went on to say that everyone interprets statements differently depending on "where you're at," and furthermore,

I mean that's the reality of us being human. That's the reality of communication. And you know, I would certainly hope that if anyone thought that that was going to happen that they would call for clarification, and you know, I can't say that woman didn't interpret whatever. I can't even say that a PCA, if we said, "Call the office immediately should this situation occur," I can't say that the PCA didn't interpret that as, "I need to leave."

Given the reports of experiences these parents had had in communicating with agency personnel, it is highly unlikely that they would call to complain about such a statement. They had too much at risk because reporting such an incident could be construed as an intention to leave the PCA alone with the child which would be grounds for a threat to discontinue services.

A fourth paradox relates to an earlier stated function of a PCA—that of taking the client to medical appointments. These parents found themselves caught in a double bind in which they could not access this service while honoring the agency's guidelines for children's services. For example, for purposes of liability, the PCA was not allowed to ride in the client's car, even if it was insured, but neither was the parent allowed to ride in the PCA's car. So, if the PCA could not ride in the parent's car, the parent could not...
ride in the PCA's car, and the parent could not leave the child alone with the PCA, how could the PCA take the child to the doctor? One parent (with three other young children) reported what she interpreted as the foolishness and insensitivity of her case manager, Terry, in the following conversation:

So, when I was talking [on the phone] to Terry [regarding a doctor's visit with PCA help], my other kids were with us, and I was just tired of fighting with her. I said, "Okay, fine, Terry. I'll have [the PCA] help us put Sandra [and her wheelchair] in our [vehicle]. Then [the PCA] will get in her car, and I'll drive my car, and we'll go to the doctor's office." And so he says to me, "Now, is the reason [the PCA] is going with you is to help you with your other children?"

Although these parents reported having never seen any such rule in writing, apparently the agency attempted to strictly defend its policy against babysitting or socialization, which reads as follows: "Personal care services do NOT include: "3. Supervision, respite care (unless on waiver)[emphasis added], babysitting, or friendly visiting [socialization]" (Agency Recipient Packet, 1992, 1994). Waiver status indicates a child whose needs are so demanding that the child is at-risk for out-of-home placement. Nevertheless, neither waiver status nor the age of the child was taken into consideration in the agency's definition of respite or babysitting. For example, under this rule, if a special needs child required PCA services after school, the child's parents were restricted from participating in after school activities with their other children unless another adult was paid to be in the house.
while the PCA was there. Not only did this seem ethically ridiculous to families, it required "double dipping" into the state's already strained resources to pay for two individuals to care for the child simultaneously (if the parents had access to respite services). Otherwise, parents remained home if they could not afford child care. Children in their teens were still considered of babysitting age. Consequently, parents who were told they were getting PCA services to relieve them of their child's constant care needs instead felt further tethered to their child.

Parental resistance to this policy prompted clarification from a state human services program officer, Medicaid Services Division of the State Department of Social and Rehabilitation Services in a letter dated February 13, 1992, to the state director of the personal care service agency. An excerpt of that letter reads:

...It is reasonable for personal care services to be provided to an older child without an adult present if that child, in lieu of his medical condition, would not require routine child care. In the latter situation, there may be an issue of liability for you as a contract agency.

This statement seemed like the solution for those families whose children would, because of their chronological age, be relatively independent in absence of their disabilities, regardless of their waiver status. Nevertheless, the service agency refused to allow PCAs to be alone with any child they served, presumably because of the liability issue, though parents did not report that that
issue was ever presented to them as the reason for the agency's stance.

Subsequent to the issuance of the above statement, Medicaid administrators, in a personal meeting with this researcher in August of 1992, defined "older child" as one who is "eighteen years old." They said they had written the rule in a broad-based manner so it could be "subject to interpretation". However, their interpretation was the only allowable one. So, even though an eighteen year-old is legally an adult in this state, they continued to define an "older child" as one who was eighteen, thus equivocating their own policy. They also stated that if parents pushed this issue, Medicaid would rewrite the rule in an even more restrictive manner. Upon hearing this report, one parent exploded, "that's blackmail!" Another parent noted that his child with disabilities would be no more capable of communicating his needs when he is eighteen than he was presently.

In addressing this issue with personal care agency administrators in September of 1994, they stated that although an eighteen year-old could be left alone with the PCA, even then, the agency would want legal authority for the PCA to access emergency medical services. But in the

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4 Personal meeting with the director of the Medicaid Department of Social and Rehabilitation Services and staff, August 7, 1992.

5 Ibid.
same conversation, they implied that parents of children under eighteen were not responsible enough to give that kind of authority to their child's PCA:

"Well, sometimes parents come to us when they are so stressed out, because they kind of like tried so hard for so long, that they don't necessarily think of... the real broad picture.

In short, these administrators stood firm on their stance that, 1) PCAs can never be left alone to care for a child under eighteen years of age, and 2) the agency is not currently willing to negotiate a collaborative solution to this problem with parents.

The following illustrates how one parent's efforts at meeting the agency's demands for adult supervision of the PCA had been undermined by agency rules. In past years, these parents had customarily left their child with disabilities in the care of a paid respite provider for two weeks each year while the rest of the family went on vacation. At that time, the agency allowed the PCA to go into the respite person's (an adult with authority to seek medical services) home to provide personal care. More recently, however, agency personnel had told this family that a new interpretation of the rules forbade the PCA to provide services in any home other than the parents, regardless of whether their child was living in another home for an extended time. Keeping in mind that respite services are also limited, this created a multiple dilemma for the family:
Now I don't know how I'm going to pay [for respite]. I was figuring there were so many hours that the PCA was coming in and helping out, so I wasn't paying [respite] for those hours. And...I know how hard it is to have [our son] 24-hours a day. And I can't expect somebody to take him for two weeks without having somebody come in and bathe him and do the range of motion, and so forth, that needs to be done. It helps them out. I know how stressful it is. And I don't want to lose these people for doing [respite].

Clearly, from the families' perspective, the agency has been communicating many paradoxical content and relational messages, creating confusion and uncertainty in their clients' lives. The stress these parents have experienced from these messages has led them to understand that their families' needs were clearly secondary to the agency's goals regardless of what the agency claimed. From a parental perspective, while the agency played semantic word games, they did little to actively seek solutions, with the family, to their needs for personalized services.

Impersonal service

Personalization of services may be considered synonymous with family-centeredness, which is the preference of parents, and indeed many other human service agencies. Family life requires the skills of a tactician to successfully maneuver its multiple individuals, with multiple layers of needs, through even a single day's activities. And one of the most valuable tactical skills is flexibility: the capacity to change procedures as outside influences change circumstances. Therefore, on-going human services for any one individual must be molded around every
other family member's needs because those services will have far-reaching effects in all of their lives.

Although Medicaid has placed a 40-hour per week ceiling on the number of PCA hours any one client can receive, this personal care agency had limited these families to an average of 25 hours per week, and as reported by some parents, to hours that were convenient for the agency rather than for the family. Furthermore, PCAs were counseled to do nothing that could be construed, in any way, as serving any other member of the family. For instance, a PCA could make cookies for her client as long as the other children in the family were not given any. Parents reported feelings of resentment in their other children as a result of perceived favoritism. Clearly, in a family setting, such restrictions keep the PCAs from operating effectively in the family context.

Parents easily recognized both family-centered professionals (whom they greatly appreciated for their insight and responsiveness to familial need), and those professionals who did not appear to see past their job descriptions and paychecks. This second type of job-focused professional, cultivated rancor:

Leanne's really nice. But Leanne has an aunt who is disabled, so she understands. And when she sits at the table, you know, like she wants to sit down with us? Andrea [my daughter] sits at the table, and she talks to Andrea. She wants to meet Andrea. She will sit and Andrea will flirt with her.

When Terry would come over, she would walk into the
bedroom, where the PCA was working with her, *pat her on the head like a puppy dog* and come out and say, "Isn't that wonderful, the relationship those two have?" [laughter, all participants]. You have no idea! You don't know what relationship means...! [more laughter].

One parent remembered personal care services as having been more personalized in years past. He felt a great loss with its new clinical character:

When I first received PCA [services], ...my PCA [came] in and got Davy; took him to her house, worked with Davy for four hours, five hours, six hours. There for a while I was having six and one-half hours three days a week. I mean it was three days a week she would take Davy. Davy wasn't in school yet, so this would give me some free time. I could come and go and.... Well, then...they threatened to take [the PCA hours] away from us, so then the PCA had to come [into my home] and do it. But we could still leave; we could still go and do whatever we needed. As long as the PCA was there, there was no need for me to be there. She was a licensed nurse, she could handle everything. And they never said anything. But in the last few years, it has progressed backwards!

These parents clearly identified a lack of dialogic communication between themselves and agency personnel as problematic to their frustration:

**Kit:** Has anybody [from West Mont] asked you what you needed? [Have] any of your nurses come in [and] sat down and said to you, What do you need? What would you like our service to do for you?

**Kim:** Yes, they have. But then they say, We can't do that. This is the rules.

**Kit:** I've never had anybody ask me.

This impersonalization was further exemplified in the agency's prohibition of PCAs forming personal relationships with the child and his or her parents. Parents did not mention ever having seen this prohibition in written form, nor was I given any such written policy. Nevertheless,
every one of these parents reported that they were not allowed to exchange phone numbers with their PCAs nor were they to contact one another directly for any reason. They also reported that their PCAs feared they would be fired if the agency found out that they had each other's phone numbers. The PCAs and the parents had been told by the agency nursing supervisors that all communication had to be channeled through the agency's main office.

These parents were confused and dismayed as to how an agency could expect them to allow a stranger into their home to care for their most vulnerable child and to witness and have ear to confidential family information without getting close enough to that person to establish a bond of trust!

Sam: And I feel if you've got somebody coming into your home everyday, and a personal relationship does not develop, there's a problem.

Jan: That's exactly how I feel, too.

These women recognized the absurdity of such an expectation, and each was able to identify one or two PCAs whom they considered valued friends even after they no longer received services from them.

Some parents, frustrated with finding person after person unsatisfactory, resorted to recruiting their own PCAs and sending them down to the agency's office to apply for work. But supposedly, the agency also had a policy against filling any requests for specific PCAs, again to prevent
"too chummy and close a relationship," so the parents' efforts at self-preservation were wasted. The researcher did learn from an agency nurse that some families were allowed to select their own PCAs because they can be so difficult to find in rural areas. However, one parent in this study who made his own selections felt that it was simply because he had asserted himself:

I told [the agency]—I insisted on doing my own hiring. I wanted to meet the people, I wanted to know who they were, I wanted to know what they were like. And then I would let them [the agency] hire them, but they were going to work for me. And I just did it that way, 'cause I've been through so many services for this, that, and the other, that I just thought, no, this is my child; she's worth it. I don't think I'm a meany, but I'm getting to be really insistent.

State agency administrators acknowledged the difficulty of supplying appropriate PCAs, but they claimed that they cheerfully matched PCA's to families who requested them:

Some families had a specific person in mind, or had somebody working with them that we, the agency, were able to hire those people and put those people on as an attendant and they maybe worked specifically with that family. For those families, things were great, you know. They could just kind of do things, and it was fine.

Still, some parents' reported that their requests for specific PCAs had been repeatedly denied. Nevertheless, this administrator went on to explain that,

...other families...did not have the community resources or an individual that they already connected with...and so the needs of that child needed to somehow be able to fit in with the scheduled hours that we had an attendant available.

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6 Personal interview with agency personnel, September 13, 1994.
From this statement alone, one can see that the administrator's expectation is for the child to fit the agency's convenience rather than the child's needs.

This administrator went on to propose that their new self-directed care component was created to allow "families a lot of flexibility that in the past I have heard about as a real source of frustration." But she also indicated that they had acquired the self-directed program only because they felt ethically pressured to absorb the service following a pilot project overseen by a private agency in another city. The personal care agency's original suggestion for a self-directed program involved no hiring agency whatsoever; rather they proposed that the client be totally responsible for recruiting, hiring, firing, scheduling and paying PCAs. But, since state labor laws require that an umbrella employer be responsible for some of those tasks, the pilot project agency did the recruiting, screening and hiring of PCAs who were then selected and scheduled by clients or their families. Evidently, the pilot met with encouraging success, and when the pilot ended, the personal care agency absorbed the new plan into their service structure. However, all agency personnel interviewed for this study indicated that "unfortunately" they "made a big mistake" in paying the PCAs in the pilot study at a "very significantly higher rate of pay than the statewide [this agency's] program." While the agency's
point of view is understandable from the perspective of losing PCAs when their pay dropped back down to a "normal" level, what they really learned was that "paying a dollar-fifty an hour more keeps staff stable." Whether state legislators, who regulate Medicaid funds, will be informed of this pilot outcome, and whether they will respond favorably remains to be seen. Nevertheless, a stable configuration of PCAs is one characteristic families repeatedly mention as vital to a well-functioning PCA service and the pilot project has shown that raising wages will contribute towards that end.

When some of the parents in this study were asked about the self-directed program, they expressed dismay rather than relief. Their anxiety seemed to be based upon a very limited understanding of the program, (those who knew of it, each said their case manager had mentioned it once). And they did not believe they had the resources, financial or otherwise, to expend on recruiting, checking references, interviewing and training care givers. They felt that the self-directed program would just be another hassle with the agency and more work than any benefit they would derive.

In personalizing services, consistent PCAs who are able to blend in with the normal family routine are most valuable. A family home does not operate in a the classical organizational management style. When a PCA is not allowed

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Ibid.
to become an extension of the family social network, a family experiences great distress. In-home services should facilitate, not disrupt, normal family structure and routines. Yet time and again, the agency's claim of "let us help" had been overshadowed by their seemingly impersonal concern which had led to stressful intrusions in families lives.

Intrusion

Families with intensive human service needs have grown to accept intrusion as an inevitable part of the package. That does not mean, however, that they are comfortable with it, nor that they are willing to let outsiders completely redefine their lives.

The mere presence of having PCAs in one's home every day is an intrusion of privacy. They are witness to family disagreements, they explore closets, refrigerators and cupboards, they discover one's grimy oven, the sticky spill on the kitchen floor, the dirty toilet bowl, and they sort through family laundry. One family summed it up this way:

...I like the family to function as a unit and when somebody's there, you feel like you can't do other things that you normally would do with your routine.

Parents of children with disabilities have learned that life is full of trade-offs. Their overwhelming responsibilities may lead them into trading some of their privacy for a portion of relief, but for these women, the intrusions had clearly progressed beyond the point of
tolerance. Some intrusions came in the form of directives from a case manager:

...[the agency] told me that they could give me as many [or as few PCA] hours as they wanted to. They could come in any time they want to. They even told me when I could put my daughter down for a nap. I mean --- this is the Nazi bit. Hi ho, Hitler! I mean he came to my house and told me that he would go into my laundry to see if there was more clothes than Catie's in my laundry.

Another particularly insensitive intrusion occurred soon after Sal was released from an extended stay in the hospital:

Sal: I got out of the hospital. I'm in my bed sleeping; sound asleep. I'm supposed to lay on my back for ten days. Terry [the case manager] made my PCA wake me up because I cannot take a nap when she's working there!

Kit: You know what, she was checking to see if you were really there.

Sal: But my husband was there in the kitchen.

Kit: You're kidding!

Sal: No, I'm not! They made me get out of bed!

Another parent related the following particularly intrusive telephone exchange between this same individual and herself:

[He] called up and said, "I'm coming up on Friday with your new PCA and I'm going to train her."

I go, "Terry, how you gonna train her? You've never dealt with---you've never even picked Andrew up. How are you going to train this PCA?"

"Um, well, you know, I'm a nurse," and I can do this and I can do that.

"You don't know how anything runs in my house. How can you...?"

"Well, I just thought that we've had a lot of problems in the past, and if I came up there and trained this PCA in
your house, that would alleviate the problem we have. You know—that you and I have."

"I'd probably have to train you first! Okay, why don't you come up on Thursday, and I'll show you how everything works, and then maybe on Friday, you can show this woman."

"I can't. I have to pick up my kids at 3 o'clock," or something, you know.

Sometimes the source of intrusion involved a lack of judgement in matching the PCA with the family:

Kit: The first time I was going to get a PCA, [the regional director] came up with a woman.... And the woman came in and sat down with Andrea and said, 'I can't do this. I will cry all night long if I have to take care of a child [like this].'

Sal: You don't need that PCA then.

Kit: I don't need her bringing it into MY home! I've been dealing with that kid for twelve years! That's my kid! How dare that woman bring her into my home! I was furious. (And Angela was in a good mood!)

Kit also related an incident that occurred when she returned home from work one evening to find that a PCA had spread her belongings out and had essentially taken over the main floor of the house so that her family, who were supposed to have been cooking dinner, had isolated themselves in the basement instead. She summed up her frustration with this and all the other intrusions quite succinctly:

Kit: ...I don't want to deal with these people in my house. I just don't want to deal with any more of these people!

Sal: Fish bowl syndrome, is what I call it.

Kit: It is! It's like I don't have a life of my own! And there's people going through your cupboards, and they're looking for this and they're cooking on this, and they're in
here, and they're in my laundry — I lost a skirt! I don't know where my skirt is. It's been gone for a month! You know, I mean, it's frustrating.

It should be noted that each of these parents had had at least one PCA who had indeed lifted a great deal of stress from their lives. However, in each of these cases, that was possible not only because the personality match was good, but in addition, because the PCA was willing to covertly circumvent agency rules and provide the real relief the family needed. But that added guilt to the family stress.

Guilt

Most of these parents expressed discomfort with some of the covert adaptations they felt they had to make in order to cope with restrictive PCA regulations. These included exchanging phone numbers with the PCAs and communicating directly with them, leaving the PCA at home with the child with disabilities while parent went shopping, to school, to doctor appointments, or to activities and lessons with other children, and so forth, allowing the PCA to help prepare the family's dinner which the PCA would then assist the child in sharing, allowing the PCA to toss family laundry in with the child's because it was counter productive to do two loads of laundry when it could be done in one, taking much needed naps or doing yard work while the PCA was working with her child, allowing the PCA to take her child to the doctor or having the PCA accompany them to the doctor in the family
car; allowing the PCA to wash a few family dishes along with the child's and other light housekeeping tasks, as well as other kinds of activities, such as engaging the child in various learning exercises. They felt as though these "sins" were necessary for keeping their family operating efficiently. So, they felt personally justified for the intangible guilt they nurtured in the process.

Kit: It's so frustrating. This is the service they're supposed to be providing to help us. And what it's taught me, is to be more manipulative.

Sal: Yes!

Kim: [and taught us] how to cheat; how to do things behind somebody's back. And I don't like doing that.

Kit: No.

Sometimes the burden of guilt was proposed openly by administrative personnel, such as a former agency director, who had informed a parent that he did not need PCAs for his child. There was no reason why competent parents could not care for them themselves. This parent was incensed! He knew how physically and emotionally draining it was for one person to provide the intensive 24-hour care these children required, not to mention fulfilling their other family responsibilities. Nonetheless, it was difficult for this parent to ignore this self-proclaimed administrative experts' blame for his inability to cope.

Fear

Beneath these parent's guilt was extraordinary amounts of fear: fear for their child's well-being, fear for the
neglect of the rest of their family, exorbitant financial worries, fear for their own health and energy to continue their strenuous role, and so forth. But these parents also found themselves fearful of losing the PCA services they had and then having to seek out-of-home placement for their children.

Some parents utilized a telephone answering service to avoid having to make unexpected justification for being unavailable while the PCA was with the child. They also reported fear of being "spied" upon:

...all [Terry] has to do is cruise by [my house] and see if any vehicles are there or not. And if it's not, he said he'll come take the [PCA] hours away.

...he told me if I wasn't satisfied, to stick my daughter in foster care or institutionalize her. ...right in front of my PCA. And I said, "Isn't that the reason why we have PCAs come to our home, so we will relieve stress from the family?"

"Oh, yes. That's what we're doing."

I said, "No, you're not! You're adding stress!"

One parent, who had on occasion left his child with his most trusted PCA, was told by a case manager that he would be required to sign a contract stating that he would not leave the home when the PCA was present. Because he knew of no other families who had been asked to do the same, he felt he was being selectively harassed. He contacted an attorney and a parent advocate to help him address the issue, after which the agency revoked their directive without further argument.

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...[the case manager] wrote me a letter and said that on such and such a day, he would be there. And I would have to be there. I will be there. So I called [the case manager], and [he] said he and Minnie [the regional director] were going to show up. So, it wasn't just going to be him; he was coming with backup. And I said, "Well, that's great. However, [my advocate] and my attorney won't be here until the following day, so would you please make it the next day at 8 o'clock."

"Well, just a minute."

And then he puts Minnie on the phone, and Minnie says, "Well, maybe we worded it a little harshly. ...you don't need an attorney."

At least one foster parent seemed to think that harassment was applied selectively to natural parents who are more at the agency's mercy than are foster parents.

Kim: I think they harass [natural] parents. I'm a [foster] parent, so they don't seem to harass me as much. Davy is a ward of the state and I am just his legal guardian. So, Davy could be put into an institution a lot quicker than what a [natural] parent could do.

Sal: The problem is that I've [seen the state institution] before. And I know what goes on there. And I swore I wouldn't put my dog there. So, see --- [they believe I'll never do it.]

Researcher: They told me I'd never do it, too.

Kit: They told me that.

Communication, while essential to any service, in this case had been stifled by parental fears of administrative repercussions. They reported being guarded in what they say and to whom.

Kit: ...I don't want to have anything to---if I can make it for a week or a month, or until Angela goes to the group home, without discussing anything with [the agency], I will be a happy person. ...I don't trust. I mean, as much as I like the nurse, Leanne, I still don't give her a lot of information. I don't give out any information that [she] doesn't need. And even with my PCAs---you know, I get such
a new infusion all the time, we're very careful about what we say. ...my seven and my nine year-olds know what they can tell PCAs and what they can't.

Sal: And what car to look for in the driveway, 'cause if that car's there [the case manager's], come in the back door. Either that, or don't come home at all. Take a trip around the [block].

In fact, the only environment in which they reported feeling that open communication was safe was in the presence of other parents who shared similar experiences and concerns.

In the following example, one parent felt she had been treated with disdain with which the other two parents readily identified:

Sal: ...I was told that my personal care attendant cannot do range-of-motion, because that's rehab. She's not supposed to even feed my child.... But the way they worked it out with me is if I would do the hours that they [the agency] wanted me to, then they would go ahead and let her [do those things]; bend the rules for me.

Kit: They blackmailed you.

Sal: Yes! They cut my hours, too...!

Kit: And there's no recourse. I mean, you call [the regional director]---well, of course, she's not going to be any help [group laughter].

Kim: She doesn't understand. She's real good at talking in symbols and coming back right then---and you're still where you were at.

A parent from the second focus group related the circumstances surrounding her discontinuation from PCA services.

Researcher: So, if I heard you correctly, you said that you finished using PCA services amidst all this confusion when they couldn't seem to get somebody in there...

Parent: Yes. And they told us that they would not [send any PCAs] until we lived in a situation [without stairs]---
actually, they weren't honest with us. The girl that was working for us at the time was making up excuses for why she was quitting.

Researcher: Like what?

Parent: That they were moving her because they wanted her to have more hours somewhere else. And it wasn't until a bit later that we were told that the reason was because they didn't want her lifting. And so, my husband, consequently, does all of the bathing [of our teenaged daughter] and he's not terribly comfortable with that, but he does it.

These women clearly did not trust the communications of this agency's professionals, and from their point of view, for good reason. The quality of communication is linked to the quality of relationships in general and, in this case, to the quality of services provided by the agency personnel.

Quality of services

The quality of the services families receive has much bearing on stress levels in their homes. In addition to how all of the issues previously discussed influence the quality of services, these parents were concerned with the quality of training their PCAs received and their overall lack of skill. Their children had complex personal care needs, yet they said their PCAs reported that the service agency's training was only minimally applicable. Parents viewed the training as geared towards the general needs of a majority group of adults with disabling conditions. They felt their children's PCAs needed training specific to their own needs.

In addition, these parents knew their children with severe disabilities could look odd and exhibit aberrant
behaviors which could evoke uncertainty and fear or even overwhelming pathos in unsuspecting people. Yet it appeared that the agency had sent some PCAs to their homes ill prepared for what they saw when they met these youngsters.

... they have in their mind, the way these kids are supposed to look, and they just can't deal with it. I don't think they have an idea of the severity of the disabling conditions that our kids suffer from. And it blows them away.

All of the parents expressed the need to have PCAs who know and like children, especially children with disabilities. One parent related a particularly stressful situation with a PCA who was unsuited to their family's needs. Her child's muscular control was severely limited.

This [PCA] just really drove me nuts. First day there, she kept saying, "I'm so nervous." So, I walked away. And my [non-disabled, teenaged child] was in the room. Henry started moving a little bit and kicked her [the PCA] a little bit with his foot. She says, You brat, you kicked me! And she backed off and wouldn't touch him. She sat there and watched TV. And [my older child] told me later what had happened and I called [the agency] and requested her removed immediately. And they said, Well, no. You can't do that. She really needs this job, and she needs some understanding.

......That was the summer that I ended up with a real [physical illness]. And the doctor said, it's stress. And I said, you get rid of one PCA and you'll get rid of a lot of stress!

Another parent had this to say about the quality of PCAs she had observed:

I would like to see somebody who wants to be able to have the skills to take care of these kids. And I think they just plain grab any old body and if they don't work, they don't work. And it's just—they need to be more skilled than they are.

An agency nurse assured me that within the last year,
they have put more emphasis on screening PCAs and that they are "real adamant about three referrals that check out." In addition, Medicaid requires that the agency provide eight, one-hour training sessions per year (this agency provides nine). Training includes such topics as body mechanics, communicating, performing range of motion therapy, operating equipment, transferring, home safety, and so forth. The initial training sessions and annual in-service reviews of the same material are mandatory for all PCAs. However, PCAs are sometimes placed with clients before they have completed all the training so they may not be fully prepared. And in-service reviews seem unduly repetitious.

All of these parents were aware that the agency required this training for their PCAs and that it was very basic. So basic, in fact, that some parents questioned the value of it at all while others complained that their PCAs didn't even know how to sanitarily wash dishes. In addition, these parents understood that each PCA would need additional training specific to their children's needs. Theoretically, the agency's nurses are responsible for providing this specialized training. However, these parents stated that they themselves had provided the specific training and that they had done so many times over. So many times, in fact, that it was one of their stress factors. They had had new PCAs in their homes so often, they were not only weary of repeating the same information, but sometimes
they found it difficult to remember what they had told one PCA and not another.

You know, I tell 'em and I tell 'em and I tell 'em, that this is what really needs to be done and then they're not doing it. And I was really getting frustrated with it. And I kept thinking, Why am I having to come in here? I might just as well.... You know, I can't do it. I can't keep it up every day and keep doing it.

In the interval between this parent's first interview in 1992 and her second interview in 1994, she had been assigned a new case manager. The new nurse arranged to have a physical therapist come to the family home to conduct and video tape a series of appropriate range-of-motion exercises with the child. To accompany the video, the physical therapist also wrote notes about how to perform the exercises. Now, this child's new PCAs have a written and visual reference for working with him. This parent offered the agency permission to use this video as part of their training program for other PCAs who work with children, but was told that would be a breech of confidentiality, even if the parent gave written consent.

The high turn over rate among PCAs (as noted by families and confirmed by agency administrators) is also detrimental to the quality of service families receive. Time and again, these parents have watched PCAs move on, reportedly because of low pay, faulty processing of time records, inadequate client scheduling, poor and demeaning modes of communication, and inflexibility of regulations. One family's PCA announced on her first PCA assignment
(which happened to be in their home) that she intended to quit the next week because she did not like the way agency personnel treated her! The family never saw her again.

Kim: ...they don't stay with West Mont.

Sal: Too stressed.

Kim: Ya. It's so stressful for them. And in the last six months, I think I went through six PCAs.

Kit: Yes. And that is so stressful.

Kim: You no more than get them trained and...

Kit: It's not worth it to [train them].

While it is tempting to believe that this rate of turnover was peculiar to these particular families, all families that participated in this research had similar complaints about their PCAs' longevity. And agency personnel, themselves, admit that it is a problem:

It's a big problem. It is a BIG problem. And I think for one thing, we're operating at minimum wage, or slightly above.... But still, basically, we're talking about entry level work.

This case worker noted that this type of job is particularly attractive to college students because they can work around their school schedules, but that this population is transient at best. And although some of them are very good workers, other activities often take priority in their lives. Hence, they are often unavailable on weekends, holidays and semester breaks, and they are prone to quit on a moment's notice leaving the agency without backup personnel for their clients. She noted that older workers
who have raised their families and are just getting back into the work force can be very reliable, but that they generally do not stay in this type of job long because they quickly learn that with a bit of outside training, they can qualify for similar but much more financially rewarding positions.

This agency nurse also mentioned PCA burnout as a problem:

...It's very hard work... and sometimes our very best PCAs are the ones who burn out, because they get so involved. And even though we try and try to tell them, "Set limits," they will burn out.

On the other hand, some PCAs seemed very comfortable with their role in these families' lives. They loved working with these children and recognized their impact on the entire family. The special individuals these parents found most valuable were those who, in spite of counsel from the agency, became family friends and "bent" the rules to meet family needs. When the family-PCA relationship was working well, both PCA and family members were apt to experience an exchange of trust and emotional support. This kind of relationship was invaluable to families and they were careful to not over tax the relationship. Reportedly, these were also the PCAs who stayed with the families the longest.

Indeed, the agency's explanation for PCA burnout was different from what families reported hearing from their PCAs, and families were fearful of losing warm, competent
PCAs as a result of perceived restrictive, disconfirming, administrative behaviors and policies:

Sal: The stress that they're under, trying to not answer the phone, answer the door. Making sure that an adult is there at all times. Because the PCA realizes what the home situation is like. They're there. They see it.

Researcher: So, you're saying that the PCA sees the real picture?

Sal: And they don't at the office.

Researcher: And they [the PCA's] don't dare tell the people at the office?

Sal: Right.

Some of the agency's strictly enforced rules put PCAs at in a distinct double bind. An example was given earlier of a PCA who was instructed to leave a child home alone if the parent left the house. Parents reported other incidents as well:

And then I had this one woman that I really liked a lot who was coming and working with Bryce. And she left and went somewhere for a weekend and wasn't able to get back in time and she called me direct [emphasis added] and said that she couldn't be there. And they fired her for that. ...She had tried to reach them [the agency] and their answering machine was on.

Another parent who had insisted on being allowed to hire his own PCAs reported the following incident:

I've gotten some really good people. But it has been difficult for me to have [the agency] keep them for me and not fire them. I had one of my PCA's fired for much the very same reason. She was not able to show up for just one of their meetings and they fired her. And she hasn't been able to get back on.

But parents reported still other problems with keeping workers:
Sam: And then there's the other ones [PCAs] that have any—that have been in the system at all. I've had them say, I won't work for [that agency]. And so, that's a problem, too.

Researcher: Why are they saying that?

Sam: Because they don't want to deal with whatever it is they are dealing with there; the management, is what I've always gotten....

Jan: Un huh. [Agreement].

Lyn: Well, with my PCA's that have worked with [this agency]...none of them have liked the person that does the book work and the hiring and the scheduling.... They've had a really rough time with her because she's really short, and she treats them ornery and stuff.

Jan: They're all sloppy now. They come to work at nine, [nine]-fifteen, nine-thirty. You call them at nine o'clock in the morning and their answering service is on. [Note: Workers are held accountable for reporting in even when there is no one to relay messages on to their clients or their supervisor in a timely manner.]

Parents want to know that they and their children will be treated with respect and caring. When they are subject to unacceptable interactions they expect swift corrective action to be taken, rather than being patronized. But this is not what experience has taught them they will receive. And when parents' attempts at discussing solutions to problems are met with perceived insincerity and disregard by professionals, they may develop a proclivity toward avoiding those communication channels and instead, may seek make-shift solutions to their problems. Service quality is, in the least, questionable when communication is consistently perceived as dysfunctional or futile because collaborative problem solving cannot occur in such an environment.
Communication

The critical element among all the factors which have influenced these parents perception of quality personal care services appeared to be caring—caring administrators and caring direct service personnel. But caring is something that must be communicated in appropriate ways before it can be believed.

They [the PCAs] have to be able to get along with us. I mean my house is a nut house. ...That's what makes the PCA program work, when they can be a part of the family. Then that takes the pressure off. ...[our children] won't click in to you if you don't care about [them]. I mean [our kids] may be retarded, but they're not stupid!

One agency administrator suggested that these women's needs could be accommodated if they would just communicate their distresses to administrators who would then work with them to find acceptable solutions to their problems. It is unlikely that their problems will be addressed if the parents do not communicate their needs, for whatever reason. But these parents felt they had already wasted their exertion on such efforts and they were not willing to expend any more valuable energy on what they considered a useless task:

Researcher: What efforts have you made at communicating to [the agency]—or anyone—about the impact of their service in your home, and how successful have those efforts been?

Kit: I gave up. I did try to explain. They came to my house; they pretended that they really cared. I sat down with the whole list of what we needed. ...and they left and immediately tried to cut everything back. I talked to [my nurse], I talked to [the regional director], and finally I gave up and I talked
to the PCA and we worked out our own system. The littler contact I have with that office, the more successful my family will run.

Sal: I did what you did. And I was told that since [I work with children with developmental disabilities], if I could handle it at work, I could handle it at home, 24-hours. And that I've got myself into the position that I am because of me, not because of the agency. And that, more or less, tough luck. And I gave up, too. I just worked it out with my PCA.

One state administrator's idea of the responsibility of establishing communication in meeting these children's needs seemed focused on other providers of services:

I guess the communication is real important with the other providers of services. Because the personal care program is connected to the federal funds and because...the federal parameters of the personal care program strictly prohibit some things, those other agencies have to come in play with providing respite or, which would fall—babysitting, and those kinds of things—would fall into place with that.

So, I can see where communication, not only between families and for whatever reason you're selecting [this agency] as a single provider—I think that's real important; but its real important that those families communicate with all of their providers. And even more importantly, that all of those providers meet and communicate regularly so that as the family identifies, this is a need, this is a need, this is a need, this is a need, that those agencies can sit down and your agency that can provide respite can say, okay, we can do this. And an agency that can provide some financial assistance or whatever can say, we can do this. And an agency that can assist bathing and feeding and those kinds of things can say, and we can do this. So, that you develop a total plan of care. That is really operating under a case management perspective. But unfortunately, there is not case management available for all the families in the state... with children....

And so, I guess, its like the family has to be a part of that case management team, too. And you have to just do it all from a team approach rather than one case manager going in and coordinating things so that the families don't have to play that kind of a role. You know, that's the nice thing about case management—it alleviates a lot of some of the anxieties and the time it takes to be able to coordinate
all those services.

This administrator did not appear to understand that in the eyes of the families, they are already an important part of the management team, or that having a case manager does not relieve families of all service coordination activities. In addition, she seemed to be contradicting her own statement about how a team functions in relation to a case manager. But in an even more contradictory manner she added,

And I think it's our responsibility to work with [the family] and put something in place that can work. It's also our responsibility to try the best we can to pull in the other services that we can identify. It's the other providers' responsibilities then as to how they interact and what they do....

The families see this as contradictory because, while agency administrators are saying they are responsible for making their services fit the needs of their clients, by not collaborating with families in individualized problem solving, they are clearly passing that responsibility on to "other providers" and then claiming that the consequences are out of their hands.

Most service organizations today have formal grievance procedures, the intent of which is to give clients some control over the quality of services they receive. This personal care agency does have such a formal process, which one administrator described as a "ladder" of accountability which progresses from the client's case manager (nurse), through proper channels at the agency's state office, to
Medicaid personnel, and to formal fair hearing procedures, if necessary. Though a statement of this procedure is included in the service packet families receive when they are first opened to services, parents in this study were unaware of its existence. When families are beginning a new service designed to give them aid, they are not expecting to need a grievance procedure and it had been years, in most cases, since these parents had even seen the service packet. After I briefly reviewed the grievance procedure for them, one parent aptly capsulized how he felt about utilizing it as a problem-solving tool.

Personally, ...because of their lack of concern, I just think it would be a waste of time. I mean, if I can't even communicate to...the nurse, and if that person can't even comprehend what I'm doing, and I go to her supervisor, and they can't, what makes me think that somebody in [the state office] is gonna grasp the idea? And you know what? My life is difficult enough. I just want it to be easy. That's what a PCA is for. I don't wanna sit down and write complaints, and go to this person---if I had that kind of time, I'd take care of Andrew myself and I wouldn't need them. You know? But I don't. ...I'm at this point--I just take the easy way out.

He, as well as the other parents, clearly felt that the end would not justify the effort of the means. So, the "easy way out" for these parents had evolved into strategies which required as little direct contact with administrative and supervisory personnel as possible. Such tactics included circumventing inflexible rules, accessing advocates, and in some cases, seeking out-of-home placement for their children. Two of these parents had their physicians prescribe a specific number of PCA hours per week.
so the service agency could not arbitrarily cut them back.

All participants indicated that they had exchanged phone numbers with their PCAs, because messages run though the service agency had a way of not reaching their intended destination. Though the agency's local office indicated that new procedures had improved message routing, families were no more satisfied with that aspect of communication in 1994 than they were in 1992.

Some PCAs were willing to make arrangements with the family to work at times other than when the agency had specified to add a measure of flexibility to the family's otherwise sequestered life style. They made trips to the doctor together, or the PCA took the child alone. PCAs were careful to not answer the phone or the door if the parents were not at home, and occasionally, a PCA would do the child's care in the PCA's home so the family could have "down" time in their own home.

These parents knew that these kinds of solutions were not only makeshift, but tenuous, at best, and that more permanent, legitimate arrangements needed to be established. They suggested that PCAs receive more child-applicable training for range of motion exercises, lifting, carrying and positioning, food preparation, getting dishes clean, making sure they did not leave the house in a mess and so forth. But their most significant suggestion contained elements of more far reaching, much needed reform:
I think in order to get family-centered service, you've got to have families develop the service, not Washington, not [state bureaucrats], ...and not [this agency]. [We need a] committee of families that live this, to write out what they need, and then they need to meet with, not the middle men, like [service agency] people, but the people, maybe at the Medicaid offices, or something, and say, "This is what we need, now you figure out how to fund this." And then, if these people—like at [the personal care agency]? If they want this contract, they have to stick to a regulation that WE will interpret.

An agency administrator was excited to report that they were rewriting the parameters of the personal care program and that consumer groups in three major cities were working on suggestions for issues such as the self-directed program, training, and multi-providers of services. But when asked if parents of children were among those consumers, she admitted that she did not know because, "It's an SRS thing." Clearly, none of the parents in this study were involved, as they had no knowledge of such activity. This administrator also noted that the agency had not told clients of their statewide plans for redefining services because the plans were not yet finalized and they did not want to get people's expectations up. When I suggested that people deserve to be informed of the direction their essential services are going and given opportunity to provide input to that direction, and that they are able to understand the preliminary nature of intentions when they are presented as such, they expressed the inadvisability of printing and mailing that much information to all of their clients.
CONCLUSIONS AND IMPLICATIONS

When these parents accepted this agency as the provider of personal care services for their children, they expected to receive sincere, consistent help with their daily needs. And while the service did provide some relief, the weight of the conditions required for that relief often outweighed its value:

You know what? If I don't have to deal with West Mont and PCAs again it will only be too soon. ...When I first thought that I was going to have a PCA, way back in the beginning, I was thrilled to death. I was thrilled to death that finally I would get somebody in there to help me. And it has been so stressful.

The subjects of this study were competent individuals who had maneuvered their way through maze after maze of professional service for many years. They were committed to all of their children and family members. But their children with developmental disabilities had required inequitable portions of their own and of their families' resources. Therefore, community support services were vital to these parents' ability to provide continual care to their children with disabilities.

These parents' found themselves in the exhausting position of constantly questioning their value, both as parents and as individuals. The study of communication, in general, has shown that self-perceptions are largely developed in context with interpersonal relationships (Stewart & Logan, 1993). Hence, under these circumstances especially, the support (or lack thereof) received from
formal support network members may have significant influence on parental self-esteem and emotional health (Seybold, et al., 1987).

The parents in this study were much appreciative of support services that were, in actuality, family-centered. However, experiences with home care services which did not practice a family-centered philosophy subverted their mental, emotional and spiritual resources well beyond what is physically, let alone ethically reasonable. While most parents of children with developmental disabilities do not appear to receive adequate support (Berger & Foster, 1976), support can contribute to more stable family functioning (Friedrich, Wilturner & Cohen, 1985). But to be effective in promoting familial stability, support must be of a quality nature. In fact, studies have found that instrumental support in the form of directives from professionals (such as these parents have experienced from this agency) may actually impair self-perceived parental competence and thereby undermine their ability to cope (Affleck, et al., 1982). Therefore, professionals should take care to engage in emotionally supportive roles characterized by empathic, dialogic communication paired with sincere efforts to collaboratively build quality services.

Recommendations for the Agency

Organizational culture. Organizational culture is comprised of a set of basic values embraced by an
organization and of the communicative behaviors exhibited by members of the organization which reinforce or diverge from those values (Pacanowsky & O'Donnell-Trujillo, 1982). In other words, the culture within an organization is not just some preexisting set of dictates for how an organization will operate. It is created, sustained and altered by communication exchanges among the people within the organization. And to a lesser extent, it can be influenced by communication coming from outside of the organization.

Organizational theory, and how it relates to organizational culture, has changed over the past several decades. It has moved through the classical model of top-down, hierarchial communication (Taylor, 1978; Tompkins, 1984), the more labor-oriented human relations theory (Tompkins, 1984), and systems theory (Tompkins, 1984; Katz & Kahn, 1978; Weick, 1979), towards interpretive and critical theories which offer closer examination of human interaction (Putnam, 1982, 1983; Deetz, 1982). But in today's organizational theory is included the postmodernist approach of organizational adaptation to irreversible change (Berquist, 1993; Bach, in press) with sensitivity to feminism (Marshall, 1992; Bullis, 1992; Martin, 1990) and ecofeminism (Bach & Bullis, 1993).

This personal care agency could benefit from an update of its organizational focus—a moving away from its old, hierarchial, medical model towards the current family-
sensitive philosophy of other child and family service organizations. After all, the agency's very being is dependent on the existence of individuals who require non-medical care in their homes. In making this shift, the development of an overall mission statement which includes commitment to preserving individual client dignity in the course of providing quality service is advisable. The participation of persons at all levels of the organization (including PCAs, adult consumers and families of child consumers) is important to the development of such a mission statement in order for it to be an accurate goal planning tool. For the purpose of the agency's existence must match the needs of its clientele from a client perspective.

Because opinion leaders and change agents are commonly found among an organization's administrators and managers, it is critical that these people be selected not only for their professional skills and knowledge, but also for their family-focused attitude and frame of reference. And since the agency's current administrative staff, as a group, does not portray family centeredness, it is essential that training be provided on the administrative level to reshape the existing focus. Administrators and managers cannot encourage in others values which they do not themselves embrace. Hence, if the organizational culture is to change in such a way that family-centered values are practiced at every level (including the direct service level),
supervisory personnel must understand and believe in such an ideology. Administratively supported in-service specific to current family-centered philosophies and service may be accessed by inviting experts of this approach to provide in-house training. Names of such experts can be obtained through the Developmental Disabilities Division of the state Social and Rehabilitation Services. In addition, the agency would be wise to send personnel to any number of annual conferences in the state which espouse family-centered principles, such as the Early Childhood Education Conference, the Developmental Disabilities Conference, the Common Threads Conference, and so forth. There, valuable relationships may form between this personal care agency professionals and the educators and developmental disability professionals who already work outside the medical model.

**Communication channels.** The agency could benefit from establishing an atmosphere of open communication throughout organization. "In an open communication relationship, both parties perceive the other interactant as a willing and receptive listener and refrain from responses that might be perceived as providing negative relational or disconfirming feedback" (Jablin, 1979). While open systems are subject to constant change (decreased stability), they are also more available to make necessary adaptations to inevitable change (increased stability) than are closed environments (Eisenberg & Goodall, 1993).
The nature of human services—humans interacting with other humans—requires an open communication system. PCAs and clients must be allowed direct communication with one another to coordinate daily scheduling discrepancies. When unexpected circumstances disrupt usual activities, the PCA and the client have an obligation to notify the agency and one another. At no time during this study did I hear parents claim a right to circumvent the agency. Rather, they expressed a need to communicate directly with their PCAs in addition to the agency. For these women, circumvention had become necessary because of the agency's aversive communication atmosphere.

In eliminating regional coordinators, the agency has somewhat flattened its hierarchy. This new configuration can benefit both the organization and its clientele, but again, only if sufficient attention is paid to the establishment and utilization of open communication channels.

Research has shown that the classical management style of top-down communication (management to subordinates) stifles employee creativity, satisfaction and loyalty (Tompkins, 1984). This agency needs a system of communication outflow and feedback so that ALL employees, including direct service personnel (PCAs) are given voice as to how to structure employment and service regulations for the benefit of all. Without this critical feedback element,
the current, top-down, directive, communication tactics will continue regardless of the new, flattened hierarchy.

It should be remembered that communication networks within an organization are a primary source of information exchange. Techniques employed to open communication may involve formal networks such as written policies, organizational memos, suggestion boxes, in-house newsletters, consumer evaluations, employee evaluations, commendations, reprimands, and so forth. But the informal flow of information that occurs amid friendly chats, in off-the-record critiques, at social events, and so forth, should not be undervalued (Tompkins, 1984). However, in a system where employees and clients feel threatened or alienated by communication "rules" (such as in this example), informal networks are more likely to pass on inaccurate information than in a system characterized by more openness. Nevertheless, the informal network is often more relied upon as a source of information than the formal network.

Given this agency's closed communication environment, the organization could benefit from a communication audit to compare and contrast the actual communication flow within the organization with the perceived routes. Mapping out actual networks and communication flow can identify weakness in the communication chain. The communication specialist could then make suggestions for maximizing network effectiveness. I would caution against conducting such an
audit among only the state administrative staff, but rather suggest that regional offices, their PCA staffs and clients be included in such a study.

It should be remembered that face-to-face communication is a critical part of accuracy and validity in information transfer, even in formal networks. Managers must learn to deliver and accept criticism in a spirit of esteem and self-growth, thereby establishing an atmosphere that breeds trust and invites communication and collaborative problem solving from their subordinates.

One communication dilemma faced by agency administrators in this study was the problem of keeping clients informed about overall service planning. Already circulating within the state are a number of newsletters with a target population of individuals with disabilities (newsletters from the state advocacy agency, a statewide parent support network, and an independent living agency network, to name a few). I would suggest that the personal care agency utilize these avenues for dissemination of information and even for requests of feedback from consumers. Keep in mind that these organizations need lead time for publishing information in a timely fashion.

Quality service. The agency may do well to give some consideration to the supervisor-scheduler-caseload ratio. While supervisors express concern about PCA burnout, their own emotional and physical resources are at their outer
limits. One person simply cannot effectively supervise 50 PCAs and address the needs of 75 clients simultaneously. Whether this situation occurs statewide, or is limited only to the service area examined in this study, service quality will be negatively impacted as long as these conditions continue.

Evaluation is another element critical to the provision of quality services. Most organizations have well-established practices for evaluating employees, but too often, those practices consist of a supervisor meeting with a subordinate once a year and giving him or her some sort of either satisfactory or unsatisfactory rating measured from some arbitrary standard. Eisenberg & Goodall (1993) suggest that employee evaluations, to be of use in improving job satisfaction, performance, and longevity, must be of a broader nature. Employees need to participate in establishing their own work goals and they must have frequent feedback from the supervisor about their task performance. Loss of temper and biting criticism, as parents said some of their PCAs had reported, lead to communication avoidance and loss of job interest and satisfaction. The motivation necessary to produce quality work is impossible unless employees know what happens to their work or that their efforts are of value to the agency (Eisenberg & Goodall).

I would suggest that two-way feedback is critical to
Communication Strategies

this process. Supervisors must also be willing to hear, accept and act upon employees' concerns about their own performance as well as the behaviors of their supervisors and the agency (Eisenberg & Goodall, 1993).

A currently popular method of self-evaluation in some organizations is the 360-degree evaluation (Special Issue, Human Resource Management, 1993; Nowack, 1993), wherein supervisors are evaluated by peers and subordinates, not only on professional issues, but in addition, on other culturally important factors such as personal attitudes, communication style, self-presentation, and so forth. In the case of this personal care agency, it would be beneficial for personal care attendants to participate in this type of evaluation of their case managers, and schedulers. Clients might also be given the opportunity to evaluate these same persons plus their personal care attendants.

Another current trend in organizational management is that of management teams (Dumaine, 1994). Persons with complementary skills can be assigned to project management teams which are structured specific to a task to be accomplished, or in the case of this agency, to meet the specific needs of a client. In the case management system under which this personal care agency operates, case managers, schedulers, PCAs and clients should be included as core members of the team. Persons from agencies who provide

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other services can be included as appropriate. Together, these persons would be responsible for planning, problem solving and task completion, after which they may move on together to another task, or they may be assigned to a new team. It should be noted that simply putting people onto teams and telling them to work together is not advisable. Rather, this agency would benefit from seeking training specific to making this management tool work before trying to implement such an organizational configuration.

In addition, because the personal care agency operates under a state contract, it is presumed that they conduct a yearly consumer evaluation. This can be viewed as a valuable informational tool rather than merely a formality for meeting Medicaid standards. It is possible and desirable to specifically design a consumer evaluation that will not only reinforce what is working well, but will also give understanding as to what the organization can do to improve services. (Again, there are experts in the developmental disabilities field in who can provide relevant training to this end.) The agency must then act to make needed improvements based on consumer opinion. Minority suggestions should never be considered unimportant simply because they are in the minority. Often, this type of feedback is a client's only opportunity to be heard. Listen and respond positively to what they say.

Finally, (and perhaps most importantly) covert,
arbitrary, administrative agendas are counterproductive both to the organizational work force and to the individuals and families they serve (Jablin, 1979). They undermine trust, and without which "there is no 'glue' to hold relationships together" (Schoel, Prouty & Radcliffe, 1988). Without trust, personalized services cannot be established and the way is left open for intrusion, fear and guilt to follow. Personal care attendants and families must be considered valuable resources in service planning. They must be asked for their input, listened to, positively responded to, and kept accurately informed as official changes occur in policies and services.

**PCA turnover rate.** A significant factor affecting employee turnover is job satisfaction (Eisenberg & Goodall, 1993). A satisfied employee is one who is compensated fairly, who works in a safe, pleasant environment, who experiences supportive work relationships, who finds his or her work challenging, and who has significant control over his or her work assignments, (p. 199). Though establishing employee satisfaction can be costly, it may be cost effective for this personal care agency in the long run.

As the self-directed pilot project described earlier indicated, raising PCAs' base pay to more accurately reflect the intensity of the work these people do is an effective deterrent to employee turnover. In addition, since parents reported that their PCAs had been venting frustrations
regarding negative interactions with administrators, it is likely that the agency could benefit from a perspective modification. To coincide with raising their base pay, the agency might employ a philosophical shift from the "entry level skills" expectation for PCAs, to an attitude of "providing direct service to human beings requires significant skills".

Requiring greater competence among direct service workers will likely raise their self-expectations, personal pride and commitment to their work. Such a philosophical shift should also help change the attitudes of administrators and managers toward the PCAs. PCAs work in jobs very isolated from the rest of the agency's administrative staff. Rather than rubbing shoulders in the day-to-day camaraderie with co-workers, their time is spent interacting with clients who suffer from severe disabilities—a stressful situation at best. Therefore, it is critical that administrative personnel actively socialize PCAs to give them support; a sense of belonging and assimilation into the organization (Albrecht & Adelman, 1984; Ray, 1987; Bullis, 1993; Bach, in press). If administrative personnel view PCAs as skilled and responsible, they are likely to communicate with them in a way which demonstrates respect, and therefore, reinforces that belief (Jablin, 1979). It might also be helpful for the agency to sponsor socials where PCAs and office
personnel can intermingle and establish a foundation for personal relationships.

I would also suggest that the agency utilize skilled, long-term PCAs in the role of mentors for newer employees. Research has shown that mentor-mentee relationships can increase employee longevity and loyalty (Kram, 1983; Bullis & Bach, 1989). Nevertheless, they can also pass along poor work attitudes, so it is critical that a family-directed attitude be actively cultivated prior to instigating this practice.

And finally, to give PCAs some measure of control over their own work, the agency might at least allow, if not foster professional-personal relationships between PCAs and their clients. While it is certainly wise for the agency to advise PCAs to guard against enmeshed relationships with their clients, committed PCAs require the dignity of deciding for themselves where to draw the line between professional and personal commitment. Families in this study strongly expressed the need for PCAs who can "fit in" with the family and establish a bond of trust between the PCA and the family.

Again to establish some measure of job satisfaction, PCAs also require some measure of control over their work schedules and what clients they work with. Currently, the agency employs schedulers to match PCAs with clients at appropriate times. This can be a very cumbersome
responsibility, because schedules change as human needs vary from day to day. So, while the agency has the need to establish general scheduling guidelines to maintain system stability, PCAs must be empowered to make some of the minor scheduling decisions. This agency has indicated concern that PCAs would abuse flexible scheduling privileges, which may be the case if scheduling were the only change the agency were to make. However, in concert with the other recommendations made herein, increased job satisfaction and commitment should be an effective deterrent to such exploitation.

**PCA Training.** If this agency chooses to raise its skill expectations for PCAs, they should also provide training beyond that required to establish basic personal care skills. If PCAs are required to invest their time in training, it must be applicable and worthwhile. Ask PCAs and consumers what training is needed; incorporate their suggestions into training programs. Engage in effective teaching techniques—move away from the sterile medical model toward, again, a more personal educational approach which encourages self-motivation and discovery. Wilbert J. McKeachie's (1986) book, *Teaching Tips*, contains a number of teaching strategies which the agency could find valuable. Although the book is targeted specifically toward a college population, much of the information is applicable to any adult audience.
Training programs can be expensive and time consuming. The agency may want to expand their own proposal for coordinating services with other agencies to include coordinating training with other agencies, thereby sharing expenses. If clients or their families are willing to contribute to training, by all means, invite them. For no one knows better what clients need and expect from human service workers.

Finally, training must be accessible to the PCAs. Adopt flexible training schedules so that training is more available to PCAs. In addition, pay for the time they spend in training, and/or the registration costs of training outside the agency (e.g., state and national conferences).

Conflict Resolution. Conflict has been defined as an expressed struggle between two or more interdependent people who perceive scarce resources, incompatible goals and interference from the other in achieving those goals (Hocker & Wilmot, 1994). Each of these conflict elements have been identified by the persons in this study to exist in their relationship with agency employees. The agency's personal care service would not exist if persons with disabilities did not require care or could get that care elsewhere. The number of PCAs, the number of PCA care hours allowed by Medicaid, even the kinds of activities allowed are limited. There are certainly some goals which these families and the agency do not appear to share and clearly, each has the
power to interfere with the other's purposes.

Attempts at conflict resolution can be helpful or they may exacerbate existing conflict (Hocker & Wilmot, 1994). So far, the parents in this study have perceived the more destructive aspects of conflict. Regardless of how many times the agency may say their intended purpose is to relieve stress so that clients may remain in their homes, as long as clients and their families perceive they are subject to explicit or implied threats, harassment, and/or impersonal concern by agency personnel, the agency can expect resistance to their policies. When content and relationship messages do not match, the relationship messages (which are usually the nonverbal component) are those most likely to be believed and acted upon (Stewart & Logan, 1993). And when both parties are engaged in defensive behaviors, such as seems to be the case in this study, they get locked into a destructive communication spiral which perpetuates itself. Resolution requires that at least one party, and preferably both, conscientiously break out of the spiral and move toward real resolution.

Since this agency and clients are both claiming the same major goals—to take stress out of the home and to keep persons with disabilities in their homes—I would suggest that the bulk of their disagreements are born of communication obstacles rather than goal differences. People tend to acquire communication styles, or patterns of
communication which they habitually use (Hocker & Wilmot, 1994). While no one style is considered "right" for every situation, certainly, some are more appropriate for maintaining interpersonal relationships than are others. This appropriateness is determined, in part, by the context in which the communication occurs (Wilmot, in press).

If the agency wishes to remain competitive in its ability to deliver quality human services, it is paramount that they engage in productive conflict strategies long before clients resort to covert actions or formal grievance procedures. Therefore, I would encourage this agency to invest in communication-focused conflict resolution training as a vital part of their new image.

Recommendations for Consumers

First and foremost, believe in yourself. Do not buy into anyone's implications (including your own) that you are an incompetent person. Life is a difficult. When we accept difficulty as an inevitable part of life, rather than ours or somebody else's fault, we can get on with living and problem solving.

Secondly, clarify your needs. A common agreement among disability services personnel, legislators, educators and other professionals in my acquaintance, including this agency's administrators, is that those people who actively communicate their needs are more likely to have those needs met than those who do not. If professionals do not seem to
be understanding what you are saying, try saying it another way. Take responsibility for your observations, thoughts, feelings, actions and requests (Adler & Towne, 1987). For example, "I need you to do this," or "When you do (____) I think (____) and I feel (____). Then I respond by doing (____). What I really need is (____). In engaging in such specific communication, you leave little room for misunderstanding; you may even discover what you really need is something other than what you have been asking for. Either way, you have benefitted. Remember, you are the reason for the personal care agency's existence; you are the reason people at that agency have jobs. Providing service to you is their charge. You have the right to expect collaboration from agency personnel in meeting your needs.

Next, exhibit calm persistence. Staying calm is not the same as being passive and one does not have to be aggressive to be assertive. But consistently declaring your needs and intentions is sure to get and keep their attention. Repeat your requests over and over and over until your needs are clarified and acceptable solutions are in place. When you avoid communication, you add to the problem, not the solution. Remember, you both want the same thing—quality, in-home, personal care. Keep that focus in your persistence.

Utilize the skills of professional or lay advocates, including yours and your child's physicians. Knowing when
one has exhausted one's personal resources is admirable. In an independent-minded society such as ours, asking for help takes great courage and can therefore be viewed as a sign of strength. And having the foresight to ask for help before one's personal resources are depleted is a mark of wisdom! Communication is the key to collaborative problem solving. Maximize your use of it.

In addition, be willing to participate in state service planning or politics. Voice your concerns and needs to state and federal legislators, and to state SRS administrators. Serve on planning committees, task forces, coalitions, and so forth. I know these activities are difficult when you are responsible for a child with disabilities, but find some way of actively participating. And do not wait to be asked to participate. Without your voice, the changes you need may never be addressed.

Limitations to this Study

The most obvious limitation to this study is my personal bias. Having been the parent of a child who received services from this agency, I have personally experienced frustration in dealing with some of their personnel. However, I have made every effort to report these parents' perceptions only as they related them to me. Secondly, there were few families available who received services from this agency and some of those declined to participate. In addition, I sampled from only
one region of the state. Consequently, the sample size was small and though it may reflect problems that are salient to one region, it may not be representative of other areas.

Services to families of children with severe developmental disabilities was the focus of this study. It would be advisable to compare the results of a similar study amongst the agency's other service populations, independent living adults with disabilities and the elderly. And a study of the internal communication among agency personnel would also be advisable.

And finally, some of the agency personnel whom I interviewed also knew I had received their services and, in fact, had had previous interactions with me regarding my difficulties with that service. One of these individuals seemed quite comfortable talking with me and easily answered all my questions. However, the administrators in the focus group appeared rather defensive at the beginning of our interview. I expected to be interviewing only one administrator from that office; instead, I found myself facing three of them. I was surprised, but was not averse to the arrangement. Nevertheless, I was taken back by their opening responses to my first question. It seemed they avoided the question altogether and went directly to giving me information which they hoped would justify the agency's policies and behaviors. Since I had neither made accusations nor, at that point, revealed any specific
parental concerns, it may be possible that the administrator with whom I had made the appointment perceived some kind of threat from me and had related those concerns to the others she invited to participate in the interview with her.

It should be noted that the administrators' behaviors distracted me, also. In the beginning, I found myself focused on their perceived defensiveness rather than what they were saying. Hence, it was difficult for me to get my thoughts back on track and redirect the interview towards parental concerns. Fortunately, my associate was able to break the ice by personally identifying with some of the administrators' professional concerns. From that point on, they all seemed more direct with their comments.

Summary

The common themes found within interchanges in this research were first, immense stress stemming from parental interactions with the personal care service agency and secondly, ineffective communication. Parents found the agency's rules to be overly restrictive, disruptive to their lives, and in some instances, dangerous for their children.

From my parental advocate perspective, those administrative personnel who did not seem to share the ideology of fulfilling families' needs based on a family-centered conviction were particularly problematic. They either did not invite or did not respond positively to parental requests. Hence, families saw their needs being
neglected time after time while their stresses mounted and the service became more of an intrusion than a relief.

These parents lived in fear, both of harassment at the hands of personal care service professionals and of losing personal care services. They found little upon which to establish a bond of trust because they perceived the service agency as self-serving and disinterested in fulfilling their real needs. They saw themselves as being "blackmailed" into compliance with unfair, arbitrary rules in order to acquire needed services.

Parents and service personnel alike felt that low wages attracted unqualified, poorly trained personal care attendants (PCAs). Lack of social support from colleagues and other factors which lead to low job satisfaction had also led to a high turnover rate among PCAs. This required parents to spend inconceivable amounts of time and energy training and retraining new PCAs themselves.

Communication with the personal care agency had become something these parents feared. Communicating parental concerns to service agency administrators was perceived as dangerous or useless, hence, it only escalated familial stress. To compensate for their foiled needs, families resorted to formulating covert strategies for circumventing some of the agency's policies in hope that they might acquire some measure of normalization in their families' lives. As a result, they suffered feelings of guilt for the
manipulative games in which they engaged to maintain family stability. This is particularly unfortunate, for open communication is a critical problem-solving tool.

Any one or two service-related stresses may be tolerable, but the amalgamation of many may grow steadily unbearable. The parent who was, at the time of the interview, preparing for his daughter to move into a group home, indicated that fifty percent of their decision for their daughter's placement stemmed from the stress they experienced as a result of their experiences with this personal care service organization. Another parent in this study was actively seeking other avenues for personal care services, reportedly for similar reasons.

Weiss (1991) claims that parental ability to cope with stress decreases as the child's age increases (Weiss, 1991) and some may argue that this factor alone accounted for the stresses these families felt. I would argue that agencies need to be more sensitive to relieving stress as parental ability to cope with it increases, regardless of the child's age. The parents of the older children in this study appeared to be the least willing to continue permitting the agency's perceived insensitivity to interfere with their lives, but they were not necessarily the parents with the longest exposure to personal care services. In fact, those who had had prolonged contact with the agency could remember times when the service was more helpful than stressful.
These parents were not so much concerned with how long they had been coping with stress as they were with how to relieve their present stress, much of which they perceived to be the direct result of their interactions with the personal care agency.

The findings herein strongly suggest that poor quality personal care services can, in fact, undermine a family's ability to cope with the stresses of caring for their children with developmental disabilities. There also appears to be a strong correlation between the quality of personal care services these families received and the quality of communication between the families and agency personnel. The quality of the intra-agency communication also impacted the quality of service delivery to families.

Professionals must do more than make claim to a family-centered service delivery. They must constantly self-evaluate to make certain they are truly cultivating an atmosphere which invites and rewards familial participation. This includes making significant efforts toward evaluating the individuals they employ not only for their credentials, but also for philosophies and attitudes which are consistent with family-centered values of human dignity, respect, trust, integrity, empathy, and advocacy for the consumers they serve.
REFERENCES


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APPENDIX A

RESEARCH QUESTIONS
RESEARCH QUESTIONS FOR PROFESSIONAL PAPER

1. How would you describe family-centered services?

2. Compare and contrast your family life before and after the birth of your child(ren) with disabilities.

3. Did it change after the birth of your child(ren) with disabilities? If so, in what ways?

4. What events led up to your request for personal care services for your child(ren) with disabilities?

5. What were your expectations of personal care services for your child(ren)? How were your expectations met or not met?

6. In what ways have the personal care services your child(ren) receive or have received impacted yours and your family's lives?

7. Discuss the specific communicative behaviors of any of the personal care service personnel with whom you have interacted.

8. What impact have those communicative behaviors had on the services you receive, on your attitudes toward the service personnel, agency, and/or your family members, on your behavior, on your self-concept, and on your family members' lives.

9. What accolades and/or recommendations might you have for the personal care services available in [the state where you reside].

10. With whom do you feel comfortable or safe talking about the personal care services you receive and why?

11. Who do you consider your most effective advocate for any of the services you receive or need and why?
FOCUS GROUP 3 QUESTIONS

1. Two years ago when we met, you each indicated the advantages and disadvantages of personal care attendant services in your homes for your children with severe developmental disabilities. In what ways have those services improved? Deteriorated? Remained the same?

2. Have your personal care agency's policies changed within the past two years? If so, in what ways?

3. What effects, if any, has the change in the personal care agency's administration had on your child's personal care services? On the impact of these services in your home?

4. If the personal care administrative personnel were to claim they are meeting your needs within the bounds of Medicaid guidelines, what would your response be?

5. If Medicaid claimed they were meeting your needs within the bounds of their responsibility, what would your response be? What would your child's and your families lives be like without the assistance you get from Medicaid?

6. Has the personal care agency's PCA service adapted to meet the changing needs of your family in the past two years? In what ways?

7. Two years ago, you each had suggestions for improving personal care services for children. I am interested in what improvements you see as important at this point in time.
APPENDIX B

AGREEMENT OF PARTICIPATION
AGREEMENT OF PARTICIPATION

This research is conducted by Betty Jo Maughan, as part of the requirements for a Masters of Arts in Communication Science.

I am conducting this research as part of the professional paper I will be writing for my program of study for a Masters of Arts degree in the University of Montana Communication Science department. The purpose of this study is to examine the effects of communication on families of children who receive or have received personal care services in Western Montana.

Information collected and reported will be identified only by a pseudonym. Your actual name will not be connected to any responses you provide. In addition, any potentially identifying information will be couched in a covert framework in order to maintain confidentiality. In agreeing to participate in this study, you are also agreeing to protect the anonymity of the other participants.

Please feel free to express your candid opinions regarding your understanding of the developmental disabilities service system in Montana, your satisfaction and/or dissatisfaction with any aspect of the personal care services you receive or have received, the impact these services have had on you and your family, and your personal feelings about any dimension of these services including your suggestions for improvement, if any.

The results of this study will consist of a statement of purpose, an explanation of how the study was structured and carried out, how participants were selected for this research, general demographic information about the participants, a description of research data, and my judgements and conclusions regarding that data. The writing process of this paper will be closely monitored by my academic advisor and the finished professional paper will be presented before my graduate committee and/or in a colloquium at the University of Montana for any interested persons. In addition, an abridged version of this paper may be submitted for presentation at communication conferences and/or for publication in professional journals and therefore, may be cited by other researchers or by advocates of the human service delivery system.

Your participation is entirely voluntary and you may withdraw your participation at ANY time. By reading and signing this statement, you are indicating your informed acceptance of participation. Nevertheless, you may chose to not comment on any topic and you may terminate your participation at any time.
If you would like a summary of the results of this study, please provide below an address where you receive mail.

______________________________
(Signature) (Date)

______________________________
(Mailing Address)
APPENDIX C

PARTICIPANT DEMOGRAPHICS QUESTIONNAIRE
PARTICIPANT DEMOGRAPHICS

1. How long have you received community-based intervention services for your child(ren) with disabilities?

2. How long have you received personal care attendant services for your child(ren) with developmental disabilities?

3. How old is your child with developmental disabilities who receives personal care services? _________________________

4. What is your child's primary medical diagnosis?

5. What secondary disabling conditions does your child experience? ________________________________________________

6. At what approximate age-equivalent does your child with developmental disabilities function? __________

7. What skill strengths does your child have?

8. What skill deficiencies does your child have?

9. What is your relationship to your child? (natural parent, grandparent, foster or adoptive parent?)

10. Who is the primary caregiver for your child?
11. How much help do you receive from other family members for the care of your child (use a percentage if you wish) __________

12. How effectively do you feel you advocate for your child and why? __________

13. What services are you responsible for coordinating for your child? __________

14. If your child is no longer living at home, please indicate the elements involved in your decision for out-of-home placement and describe your satisfaction with his/her placement. __________

15. Your marital status __________ Your age _____
   Occupation __________ Hours/wk _____

16. Spouse's occupation __________ Hours/wk _____
   Spouse's age ______

17. Please list the following information for all other children you have:

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18. Are there other members of your household who require special care for any disabling or serious medical conditions? If so, list his/her first name, age, and nature of disability. 

19. Please indicate the range of your family's average yearly income at the present time:

$0 - $9,999 ______  $10,000 - $19,999 ______
$20,000 - $29,999 ______  $30,000 - $39,999 ______
$40,000 - $60,000 ______  Over $60,000 ______