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# How People with Disabilities Communicatively Manage Assistance: Helping as Instrumental Social Support

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## Abstract

While social support is often conceptualized as a temporary need in crisis situations, people with visible physical disabilities face an ongoing challenge of balancing the need for instrumental social support against receiving unwanted help on a daily basis. Our goal was to study instrumental support interactions from the perspective of support recipients; in this case, people who are disabled, focusing on how physical assistance is communicatively managed with strangers and newer acquaintances. A qualitative/interpretive analysis was carried out on transcripts of in-depth interviews with 30 participants who had visible physical disabilities. Participants and interviewers discussed how help was communicated and managed with nondisabled others. Results detailed the physical assistance initiated by people with disabilities, assistance initiated by nondisabled persons, and how people with disabilities manage unwanted assistance. Practical applications for communication and behavior of both people with disabilities and nondisabled persons are discussed.

Keywords: disability communication, helping, social support

We are supposed to be forever thankful to all the wonderful nondisabled people in the world who make our lives miserable in the name of helping us.<sup>1</sup>

Researchers across disciplines have highlighted the importance of social support, "verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's experience" (Albrecht & Adelman, 1987, p. 19). A great amount of the scholarship on social support has been applied research, as supportive communication is vital to health and well-being. In fact, scholars have referred to social support as "the cornerstone for the quality of human life" (Albrecht, Burleson, & Sarason, 1992, p. 149). Much scholarship on social support has been dedicated to determining the physical and psychological benefits of receiving support (e.g., Albrecht & Adelman, 1987; Braithwaite, Waldron, & Finn, 1999; Cutrona, Russell, & Rose, 1986; Dickson-Markman & Shern, 1990; Gottlieb, 1988; McColl, Lei, Skinner, 1995; Orr, Thein, & Aronson, 1995; Pierce, Sarason, Sarason, Joseph, & Henderson, 1996; Rohe & Krause, 1998).

The way that social support is most often conceptualized in the literature does not match well the situations faced by people with visible physical disabilities. First, giving and receiving support is most often conceptualized as a temporary, rather than permanent, need. Many researchers studying supportive interactions have focused on support given to people in response to stressful life events, for example, during bereavement, serious illness, or family distress (e.g., Cutrona & Suhr, 1992; Lehman, Ellard, & Wortman, 1986; Winstead, Derlega, Lewis, Sanchez-Hucles, & Clarke, 1992). One exception is scholars who look at supportive relationships as a convoy of relationships following one across the lifespan (e.g., Kahn & Antonucci, 1981). Research on support in crisis situations is a useful resource for professionals as well as for laypersons who are communicating to support friends and family. When focusing on social support during times of extraordinary stress, no matter what the cause, we would expect the time-frame for needing various types of social support to be finite in most cases. Once a bereavement period, health emergency, or other crisis passes, the need for support will diminish or end.

However, some people will find themselves facing issues surrounding social support for the duration of their lives. People with permanent physical disabilities represent one group for whom the need for different types and amounts of support and assistance will remain constant throughout their lives. Thus, studying people with disabilities offers a context in which to understand social support as a permanent, rather than temporary, need.

When a person becomes disabled, especially sudden onset disability, there will be an acute need for support at the beginning. People will need support for esteem and emotional needs as well as help adjusting to, and functioning with, a disability, most often in the form of information and physical assistance (Braithwaite, 1990, 1996; Crewe & Athelstan, 1985). However, as a person's condition stabilizes, he or she should be able to work toward functioning as independently as possible, depending on the particular type of disability the person experiences (Braithwaite, 1990, 1996; Cunningham & Coombs, 1997; Pardek, 1998; Soule & Roloff, 2000). Even when the need for high levels of informational, esteem, and emotional support has declined, many people with permanent disabilities require varying degrees of physical or instrumental support with tasks associated with mobility and self-care (McColl et al., 1995). Thus, we can think about disabled persons' need for support on a continuum – from periodic need for some people, to an almost continuous need for others.

A second trend in the support literature has been to focus on the types of support given. Researchers have attempted to categorize social support behaviors used to provide social support to others (e.g., Barbee & Cunningham, 1995; Cutrona & Suhr, 1992; McColl et al., 1995). While there have been a myriad of category systems (e.g., Barbee & Cunningham, 1995; Cutrona & Suhr, 1992; Gottlieb, 1985), the typology by Cutrona and Suhr (1992) is representative and provides a very complete description of support types. Their Social Support Behavior Codes Framework is a coding system that identifies five supratypes of support: informational support, tangible assistance (often called instrumental support), esteem support, emotional support, network support (connecting the person to others), with 23 subcategories of behaviors.

When we examined the social science literature, we noticed that scholars have paid the greatest amount of attention to emotional support and esteem support (Burleson, 1994), which is doubtless very important (Albrecht & Adelman, 1987; Dunkel-Schetter, 1984; Lehman et al., 1986; McColl et al., 1995), and which have been positively linked to health outcomes (e.g., Query & Kreps, 1996; Query, Parry, & Flint, 1992). However, there has been much less focus in the literature on instrumental or tangible support, which Barbee and Cunningham (1995) operationalized as "something active or physical to help the seeker; gives money or a loan; offers to help now; offers to follow up in the future" (p. 389).<sup>2</sup> For people with disabilities, instrumental support in the form of physical help or assistance may be something they have to cope with on a daily basis, from family and friends as well as strangers and new acquaintances (Braithwaite, 1987; Cunningham & Coombs, 1997; Pardeck, 1998). Previous researchers have indicated that most people with disabilities do not have the problem of receiving too little assistance, rather, they often receive more help than they would like or need, especially from strangers or people they are just beginning to know (Braithwaite, 1987; Cunningham & Coombs, 1997; Soule & Roloff, 2000). People with disabilities are continually faced with managing interactions involving instrumental support, especially in new relationships, thus we chose to focus our attention on interactions that take place during these early stages.

The issue of instrumental support is a salient one for people with disabilities and was the focus of this present study. Many people with disabilities do need assistance from others in varying forms and amounts (Braithwaite, 1987; Soule & Roloff, 2000). For example, they may need assistance with issues concerning mobility or self-care, ranging from periodic help opening a heavy door, to the continuous help of a personal care attendant. While instrumental support is needed in varying amounts, people with disabilities quite often report that they are offered help they do not want or need (Braithwaite, 1987; Cunningham & Coombs, 1997; Soule & Roloff, 2000). Braithwaite (1987) found that communication concerning help plays a central role in the lives of people with disabilities, especially as they deal with strangers or people in the early stages of new relationships. In fact, when Braithwaite asked people with disabilities about their greatest communication challenges when communicating with nondisabled people, they mentioned the issue of managing assistance as one of their primary *communication* challenges with nondisabled strangers and new acquaintances.

For nondisabled people, the issue of helping raises a very practical problem: how and when should assistance be offered or given to people with disabilities? This is a question that nondisabled people struggle with, especially when interacting with strangers or acquaintances who are disabled. People with visible disabilities face this issue every day, with very mixed success (Braithwaite, 1987). Consulting the literature and talking with nondisabled people suggests that the issue of providing help places them in somewhat of a double bind. They are operating under competing norms of "help the handicapped" and "let others stand on their own two feet." Braithwaite and Braithwaite (2003) pointed out that Americans usually conceptualize persons as individuals and choice makers. However, when nondisabled persons encounter a person with a disability, this model of personhood creates a serious dilemma. With this double bind in effect, it is little wonder that nondisabled persons wonder "what to do" in situations when they perceive that a person who is disabled may need their assistance (McColl et al., 1995). In addition, Soule and Roloff (2000) pointed out that it is difficult for nondisabled people to provide assistance without threatening the face of the person who is disabled. Therefore, the first goal of the present study was to describe interactions between disabled and nondisabled people involving instrumental support for persons with disabilities.

A third trend in the social support literature has been to focus on support providers rather than recipients of support. For example, there has been much research focusing on the social support providers coming from family, spousal, and friendship relationships (e.g., Gallagher & Gerstel, 1993; Leach & Braithwaite, 1996; Samter, 1992), formal sources (e.g., Cohen, Teresi, & Holmes, 1985; Pardeck, 1998), and support groups (e.g., Braithwaite et al., 1999; Query & James, 1989; Query & Kreps, 1996).

In contrast, there has been much less research focused on the *recipients* of social support (e.g., Dunkel-Schetter, 1984; Lehman et al., 1986). Even when the recipients of support are studied, they tend to be presented in a reactive versus an active role (McColl et al., 1995). Since there has been a much greater focus on support providers than on recipients, a second goal of the present study was to focus on the perspective of the recipients of support, in this case, how persons with disabilities manage instrumental social support.

Finally, while it is useful to understand different types of support behaviors available, communication scholars have called for moving beyond individual behaviors and perspectives and begin conceptualizing social support as an interactive process, studying support as "the *messages* through which people both seek and express support; studying the *interactions* in which supportive messages are produced and interpreted; and studying the *relationships* that are created by and contextualize the supportive interactions in which people engage" (Burleson, Albrecht, Goldsmith, & Sarason, 1994, p. xviii). When focusing on social support as interactive, Goldsmith (1992) pointed to the necessity of viewing "how givers and receivers of support interactively manage communication acts" (p. 265). For people with disabilities, especially for those whose disabilities are visible to others, the need to solicit assistance and/or the need to manage offers of assistance is a common occurrence (Braithwaite, 1987; Thompson & Cusella, 1988). Thus, a third goal of this study was to study communication within instrumental support interactions.

In sum, the purpose of the present project was to study instrumental support interactions from the perspective of support recipients, in this case, people who are disabled, for whom instrumental support is an ongoing issue, focusing on how assistance is communicatively managed with strangers or newer acquaintances. The ultimate goal of this project is to provide insights and applications for both support providers and recipients on how to communicatively manage instrumental support interactions.

### Helping as Instrumental Support

Early researchers have worked to understand how and why people help one another. Social Exchange Theory (Roloff, 1981; Thibaut & Kelley, 1959) is a useful theoretical lens that emphasizes that giving and receiving assistance is potentially both rewarding and costly for the receivers as well as providers of help. For example, investigators found that if the potential helper received positive messages concerning providing assistance, then there was an increase in helping behavior (Davis et al., 1999; Isen & Levin, 1972; Jones & Burleson, 1997). For help providers, altruism brings a sense of reward (Batson, 1997), which Isen and Levin (1972) labeled as the "warm glow hypothesis." If people feel good about helping others, then they will continue to provide assistance (Isen & Levin, 1972). Other scholars argued that altruism is combined with the desire to feel good about one's self (Cialdini, Brown, Lewis, Luce, & Neuberg, 1997). The "modeling hypothesis" also provides an explanation for helping behavior (Bryan & Test, 1967). That is, when persons see someone else provide assistance, they are more likely to follow suit, especially if failure to provide help would result in negative or guilty feelings (Bryan & Test, 1967). Researchers found that potential helpers will weigh the perceived costs and rewards of assistance in order to decide whether to help or not (Batson, 1997; Batson et al., 1997; Cialdini et al., 1997; Davis et al., 1999; Jones & Burleson, 1997; Neuberg, Cialdini, Brown, Luce, & Sagarin, 1997).

#### Costs and rewards of assistance for persons with disabilities

There has been limited research that has examined helping within the context of disability (e.g., Braithwaite, 1987; Stephens, Cooper, & Kinney, 1985; Thompson & Cusella, 1988). As potential providers of assistance, nondisabled people weigh the costs and rewards of providing help to people with disabilities. For example, Stephens, Cooper, and Kinney (1985) found that people weighed the costs of helping against feelings of social responsibility. Even when costs of helping a person with a disability were high, nondisabled people would provide assistance because they felt it was the right thing to do. Ungar (1979) found that potential helpers weighed the rewards of providing assistance and meeting social obligations against the potential discomfort of interacting with a person with a visible stigma (a person with an eye patch and facial disfigurement). The research revealed that visibly disabled people received less assistance than a nondisabled person. From these and other studies, we suspected that the type and severity of disability would affect the willingness of the nondisabled individual to offer instrumental support (Batson, 1997; Cialdini et al., 1997).

For people with disabilities, there are both costs and rewards to receiving assistance. People with disabilities constantly weigh the potential embarrassment, threats to the face, and perceived dependency against having their needs met (Braithwaite, 1987; Goldsmith, 1994; Schneider, Major, Luthtanan, & Crocker, 1996; Smith & Goodnow, 1999; Soule & Roloff, 2000). Accepting assistance may place the nondisabled person in a "one-up" position and give them greater control over the relationship with the person who is disabled (Emry & Wiseman, 1987; McColl et al., 1995; Orr et al., 1995; Rohe & Krause, 1998). Accepting instrumental social support can be a double-edged sword for people with disabilities (Braithwaite, 1987). In addition, accepting help in one situation increases the chances of receiving more help (often unwanted) in future encounters with that person (Orr et al., 1995).

How do people with disabilities manage these potential rewards and costs and communicate in helping situations? In an earlier project, Braithwaite (1987) asked people with visible physical disabilities to describe communicative challenges they had with nondisabled strangers or people they were just getting to know. One issue that cropped up in this study was that people with disabilities identified one of their greatest challenges came in how they communicated in helping situations. Braithwaite found that nondisabled people often do offer help, but it was very unclear whether offering help was acceptable to people with disabilities. Interestingly, the disabled respondents were about evenly divided on the issue, with some saying that offering or providing help was fine with them, while others were adamant that help should not be offered or provided unless requested. Braithwaite (1987) also found a series of strategies that people with disabilities used to ask for assistance, ranging from very direct to very indirect strategies. Braithwaite (1987) suggested continued research into these communicative encounters, a call answered in the present study.

Researchers found that people with disabilities often receive assistance that is unsolicited, unneeded, or unwanted (Braithwaite, 1987; Cunningham & Coombs, 1997). Amazingly, interviews with persons with disabilities revealed it was not uncommon for nondisabled persons to give assistance, even when the person with the disability had explicitly refused assistance, for example, pushing someone's wheelchair immediately after being told that help was not needed (Braithwaite, 1987). Unwanted help comes with a price for the person with a disability, ranging from feelings of inferiority or loss of face (Schneider, Major, Luhtanen, & Crocker, 1996; Soule & Roloff, 2000) to physical danger, if help is given improperly or unexpectedly (Braithwaite, 1987). These costs often outweigh the benefits of receiving assistance. How, then, do people with disabilities communicate when assistance is unwanted? Smith and Goodnow (1999) concluded people with disabilities respond to unsolicited support by assertively ignoring or rejecting the support, actively discounting the support, or by accommodating or avoiding a situation where unwanted support may be offered. Braithwaite (1987) found that people with disabilities drew from a variety of direct and indirect strategies. Thompson and Cusella (1988) observed that people with disabilities did not refuse assistance when it was given, nor did nondisabled people refuse to give assistance when asked. They did note some instances when it was perceived that people with disabilities needed assistance but they did not receive it from nondisabled persons. Perhaps most importantly, they found that there was surprisingly little verbal interaction between the disabled and nondisabled persons preceding or during helping interactions. These findings are quite preliminary and, at times, contradictory.

In sum, there is a need to study social support from the perspective of support receivers, especially those people for whom instrumental support is a permanent need, such as persons with physical disabilities. While the literature reviewed on assisting behavior provides some preliminary insight into the costs and rewards of instrumental support between people with disabilities and nondisabled others, this area of inquiry is still in its beginning stages. Clearly, the issue of helping "is one of the most difficult challenges both disabled and able-bodied persons face" (Braithwaite & Labrecque, 1994, p. 291) and research into this issue has very real and practical implications for everyday communication of both disabled and nondisabled persons alike. As more people with disabilities are living and working in the community, there is a need to study communication and instrumental support from the perspective of people with disabilities, most of whom will need to confront this issue on a daily basis, especially from strangers or people they are just getting to know. How do people with disabilities communicate and obtain the assistance they need and in ways that will not be too costly for them? How do people with disabilities handle offers of assistance that they do not need or want? Similarly, for nondisabled persons, how and when should they offer or provide assistance for a person who is disabled? Understanding instrumental social support in this context of disability should provide us with insights that we can translate to other contexts of instrumental social support. Hence, the following research question guided the current study: How do people with disabilities communicatively manage solicited or unsolicited instrumental assistance in interactions with nondisabled others in early phases of relationships?

#### Method

The design of this study was in the qualitative/interpretive tradition as we sought to describe recurring patterns of behaviors and meanings from the experiences of the disabled participants (Coffey & Atkinson, 1996; Creswell, 1998; Denzin & Lincoln, 1994; Huberman & Miles, 1994; Leininger, 1994; Strauss & Corbin, 1990). Thirty adults with visible physical disabilities participated in research interviews. None of the participants had significant communication disabilities (e.g., deafness or speech disabilities) to avoid compounding the communication issues being addressed in the study. We made an effort to invite participants varying in age, type of disability, length of disability, and occupation.

#### Participants

Participants were located via a snowball sampling method, including announcements made at the students with disabilities office at a southwestern university, announcements in classes, and personal contacts of the interviewers. Thirty participants (15 men and 15 women, mean age = 46.25 years) participated in the interviews. The length of disablement of these individuals ranged from two months to 59 years (mean = 22.6 years). Five (16.6%) of the participants had been disabled since birth while the remainder (83.4%) experienced the onset of their disability in adolescence or early adulthood.

In terms of disability type, 12 (40%) of the participants experienced paralysis or mobility disability; and 17 (56.6%) of the participants had a physical disability due to disease (four had arthritis, four had muscular dystrophy, three had cerebral palsy, three had polio, and

three had multiple sclerosis). One participant experienced a temporary disability and was using a wheelchair for a lengthy, but fixed, period of time. The education level of the participants ranged from 7th grade to a Ph.D. degree. Fifteen of the participants had some college education or had obtained a bachelor's degree.

The first author and five interviewers conducted the interviews. The first author completed half of the interviews and the interviewers completed the other half. The first author conducted a training session including viewing and critiquing a sample interview, working with the interview guide, and each interviewer carried out practice interviews until they and the first author were confident they were ready to proceed. One interviewer and a disabled informant participated together in a semistructured, focused interview format that targeted informants' perceptions and experiences in situations when they interacted with nondisabled persons concerning assistance (Leininger, 1994; McCracken, 1988). Interviewers met the participants at a place of their choosing and all interviews were audio taped. Data gathering ceased when recurring patterns were identified and a point of saturation was reached (Leininger, 1994).

Participants were instructed to focus on "helping situations you encounter with strangers or people you are just getting to know." Participants described how often they needed help, the type of help they needed, the locations where helping interactions occurred, how they solicited the help they needed, and how they communicated and handled unwanted help. Participants were asked to describe situations, if any, when they needed help and did not receive it. Participants discussed a variety of different real and hypothetical situations when they would have to deal with assistance. For example, they described the last time they received help from a nondisabled person; what they would want to happen if they dropped their packages at the mall; and how they would handle a stranger's or acquaintance's offer to get them food and drink at a party. Participants were asked to describe how nondisabled persons are supposed to know what to do or not do in potential helping situations and were asked to provide them with advice on how to interact. Finally, participants described the communication process involving help and talked about how these encounters would progress ideally.

#### Data Analysis

The interview audiotapes were transcribed verbatim, yielding approximately 310 singlespaced pages of text-based data for the present analysis. We sought to pay attention to both the entire narratives that the informants shared about their experiences, as well as how we were categorizing these data (Kvale, 1996) as we identified patterns in their responses. The notes from the interviews were analyzed via a qualitative content analysis using a constant comparative method (Strauss, 1987; Strauss & Corbin, 1990). This involved the stages of open and axial coding. Open coding is an inductive process in which data are compared to prior data, looking for similarity or difference. As data are judged to be different, a new coding category is added. Open coding is iterative, and categories are added, combined, and revised in an emergent manner until the coding categories as a set do not require further modification (Creswell, 1998). Once open coding was completed, we moved to the second stage of axial coding. In axial coding, the researcher seeks connections among the open coding to identify emergent themes while continually comparing them for similarities and differences to existing themes. Each time a new theme emerges, a new category is created (Creswell, 1998). The two co-researchers worked independently and then together to check and merge our analyses, which had produced few differences, mostly in labeling. Finally, the transcripts were read again and the analysis checked, to ensure the accuracy and consistency of the categories, looking for any rival-explanations of the findings (Miles & Huberman, 1994).

#### Results

The analysis of the interviews revealed four main categories of managing instrumental support in the form of physical assistance: (a) physical assistance needed by people with disabilities, (b) assistance initiated by persons with disabilities, (c) assistance initiated by nondisabled persons, and (d) unwanted assistance managed by people with disabilities.

#### Physical Assistance Needed by People with Disabilities

In this first section we arranged these data to be able to describe instrumental support needed and managed by people with disabilities: (a) frequency of assistance needs, (b) types of assistance needed, (c) managing needed assistance, and (d) failure to help.

#### *Frequency of assistance*

We first asked the respondents to estimate the frequency of assistance they needed from strangers or people they were getting to know. Not unexpectedly, we found that need for assistance differed depending on the type of disability a person had, ranging from hardly ever to needing assistance up to 20 times a day. Most respondents stated they usually did not need much help and emphasized the difference between needing help and wanting help. "In the average day I don't need help, it's only rare instances that I do" (#3:1; this notation from interview transcripts are cited by interview number and page number in the transcripts). While the participants indicated they needed little assistance, they estimated that nondisabled people offered them help quite often, ranging from several times a day to 15 times a day.

The physical context also affected the frequency of assistance needed. While many people with disabilities reported that they did not need much assistance in their own environment (e.g., in their own home), other physical places necessitated the need for more help. Respondents stressed they were careful to anticipate the physical contexts in which they would find themselves and would seek to minimize their needs. For example:

In an ideal world, I would like to not need help. I would like everything to be accessible . . . to be as independent as I can possibly be. I'd like to be a lot more independent than I am right now—door openers, lower shelves, and on and on. (#21:93)

#### Types of assistance needed

The specific type of assistance needed by these people with disabilities varied, depending on their specific disability type and the context. Most common was assistance with mobility or transportation, and manual dexterity. First, for most participants, mobility issues, such as transportation, propelling over curbs, steps, or ramps presented the greatest challenges.

Many of the participants were able to drive, although a few relied on family, friends, or public transportation to get around. Many of those who drove themselves discussed challenges associated with getting in and out of vehicles—folding and stowing wheelchairs, and assistance needed to pump gasoline for their vehicles. Several respondents discussed the importance of public handicapped parking spaces, indicating that the ability to park close to a building minimized other assistance they might need. However, when those spaces were not available or sufficiently spacious, then they were unable to function without assistance. For example, a 57-year-old wheelchair user shared:

I get into situations now and then where somebody has . . . parked to the side [of the van] where I get my lift out, therefore not leaving me enough room to get out the lift or even open it up for that matter. Then what I have to do is grab a stranger, so to speak, and ask that person to drive my van out of the parking space enough so that the lift is . . . free and clear to get out all the way and for me to get on it. (#15:39)

A related type of mobility assistance involved help navigating through crowded areas, for example in a mall or at a party.

Second, people with disabilities reported needing assistance involving hand strength or dexterity, for example, removing lids from jars, opening envelopes, balancing several items in their hands, or opening a heavy door. Again, advance planning enabled the person to avoid needing help. For example, if an item was moved from its usual place, this was likely to necessitate the need for assistance. As one woman described needing to ask a neighbor to put her phone back into its cradle (#9:46). Related, several wheelchair users discussed the difficulty of obtaining items out of their reach, such as retrieving a drink from a pop machine or reaching items on a high store shelf. One participant laughed and described, "A situation where this happens all the time is where I go grocery shopping. I always want something off the top shelf. It doesn't matter what I want, it is always on the top shelf" (#21:89).

#### Managing needed assistance

When we asked participants to talk about how they communicate and manage assistance that they needed, first, people with disabilities reported that they wanted to avoid being dependent on others for help and focused on anticipating and planning strategies to control the amount of assistance they need: "Well, I organize my life in a way that I can be as independent as possible. So usually when I need help it is in an unexpected situation that occurs" (#19:77). This planning effort was designed to minimize or eliminate their need for assistance, or to receive assistance in the desired way. For example, one respondent described how he and his friend, who is also a wheelchair user, obtained the assistance they needed to exit their van at the store:

Well, I have a mobile phone . . . I will call into the store and let the store manager or whoever know, "Hey, we're in a white minivan and if you look out your window, you can see us! We're two guys in wheelchairs, can you come out and help us get out of the van?" (#26:68)

The logistics of planning ahead was perceived to be helpful for the person with the disability as well as for nondisabled others: "I'll always mention the wheelchair when making dinner reservations.... If you put that right out there, I think everyone is a lot more comfortable" (#17:61).

Along with careful planning, a second strategy to manage needed assistance was to enlist the use of formal support services that are available, as this person described, "I am educated enough and perfectly capable of picking up my phone and saying, 'Hey, here's a problem and we need to take care of this. Here's an obstacle I need to overcome'" (#9:50). In fact, using formal support resources was often cited as a way to eliminate the need for assistance altogether, as this female student with degenerative arthritis illustrated, "I usually come here to the Disabled Student Resources . . . it was just more a case of asking for help in order to help myself rather than have someone else do for me" (#7:28).

#### Failure to help

From the interviews, it was clear that people with disabilities most often receive the assistance they need from nondisabled others. Assistance occurs when nondisabled people notice their need or when the person with the disability asks for help. Rarely did respondents mention incidents when they did not receive assistance when they needed it. This retired man who used crutches after having his leg amputated, described one of these rare events:

I slipped and fell. And there must have been twelve to fifteen people that walked by me as though I didn't even exist. . . . But when at least twelve people pass you by, like you're not even on this planet earth it gets to you. I felt, they would have more consideration for a dog that injured a foot than for a human being that was laying on the ground. (#10:62–63)

Failure to receive help was even more rare when the person with the disability requested assistance directly, although participants did reveal a few instances when help was not given.

When we asked who initiates assistance, the person with the disability or the nondisabled person, it becomes clear that these categories are not mutually exclusive. Most of the respondents reported they received assistance that was at times self-initiated and at other times initiated by nondisabled others. Both types of assistance will be discussed in the following sections.

#### Assistance Initiated by Persons with Disabilities

#### Asking for assistance

Most respondents indicated they would rather not have to be in the position to need assistance, but when they needed it, they preferred to be the initiator. When analyzing these data, we were careful to attend to the *strength* of this response. Most of the interviewees reported they would *prefer* to be the one to initiate assistance, while a smaller number were *adamant* that they initiate. Most of the participants indicated they would prefer to be the one asking for assistance, but most said they accepted help when a nondisabled person offered. Those who were adamant about being the initiator were those who would likely refuse help that was offered, often in more aggressive ways. The people we interviewed also indicated that they preferred to ask acquaintances for help rather than ask strangers.

Interviewees indicated that when they did need assistance they would ask strangers for help, rather than go without assistance. These requests most often came as simple requests of a bystander such as, "Would you please open this door for me?" to more aggressive solicitations, such as flagging people down or honking a car horn for assistance. One man's description was typical:

I'm the kind of person that if I want help, I want to be —I would always want to ask for it . . . generally I'd always like to be in a position to ask. . . . It's a control thing. You want to feel like you're in control of your day and if people give help without asking you feel like you're not in control. (#26:66)

#### Choosing whom to ask for assistance

Next, we categorized the types of individuals people with disabilities would ask for help. This choice was usually based on access and timing. Many participants said they would prepare to ask whoever happened to be the next person to come along:

I'd come out of school in the cold and I couldn't wear mittens or gloves because my hands were so deformed and so swollen that they'd cut off the circulation.... But I'd come out of school and stand on the parking lot until someone would come by and I'd ask them to open my door.... I never ever had anybody turn me down. (#7:34)

Before actually asking a stranger to help, the participants indicated they would first make a judgment about whether the potential helper had the time to help.

Many respondents indicated that they had become quite adept at reading the nonverbal cues of others. Respondents indicated that they could "just tell" who to ask. When the interviewer probed how they could "just tell," participants explained that they relied on nonverbal cues to tell them whom to ask. Many said they would look for a person who appeared not to be in a hurry and a person who was approachable. When we asked them to describe *how* they determined who was approachable, they responded they would look for someone who would make eye contact with them and/or someone who would smile at them. This interviewee's response was typical:

There's a lot of nonverbal communication that goes on. It's like, if somebody wants to help you, they've got that look in their eyes. If they don't have time or don't care, I don't want to be bothered with them either, so you know, I'll look at them and look away. I can tell pretty much . . . I can tell. (#28:28)

Additionally, respondents reported they would look for someone who had the physical capability to meet their need, for example, they might look for someone who appeared to possess greater physical strength if they needed something heavy lifted. Conversely, a few people with disabilities mentioned other situations when they might look for someone physically weaker, one who would pose little physical threat to them. One wheelchair user explained:

If I'm in a dangerous neighborhood and . . . I know I'm going to need help up a ramp or I know I'm going to need help with a certain thing . . . I kind of look for somebody who maybe is physically weaker because, because in those kinds of situations you're a little bit concerned for your safety and, for instance, and I don't mean to be sexist at all, if I ask a small woman to help me with something . . . then I feel safe because I know that physically she's probably not going to be able to do very much to me. If she tried, I could probably at least hold my own a little bit . . . you're gonna tend to not ask the biggest, strongest guy to help you do it because you're putting yourself at risk if he decides to steal your wallet and run away or attack you in some way. (#26:61)

People with disabilities also indicated that they would often ask someone whose role would dictate helpfulness, for example, a store manager or clerk.

#### Strategies people with disabilities use to initiate assistance

While carefully observing the nonverbal behavior of nondisabled others, people with disabilities also indicated the strategic use of nonverbal and verbal behavior in potential helping situations. Most frequently, interviewees described nonverbal strategies such as establishing eye contact with potential helpers. For example, one respondent described, "I'd make eye contact with a few people and see if anybody seems, you know, like they wanted to help . . . I rarely come out and ask anybody unless I've kinda judged them" (#28:28). Participants also explained they would initiate assistance by smiling at a potential helper. Others indicated they would pause and intentionally look frustrated, hoping the other person would notice their need and help them:

If I needed help in a situation that was obvious, such as a doorway, if I'm sitting in a doorway . . . and just sitting there, looking stupidly at the door, probably somebody could guess that I need help opening the door. (#15:44)

While people with disabilities initiated assistance situations nonverbally, the communication strategy used most was direct verbal communication. "Would you help me, I'm having a problem with this. Would you mind helping me?' and knowing that people would be courteous enough or whatever to do that" (#8:41). The majority of the interviewees stressed they were not afraid to ask for help and preferred to be the one to initiate asking for assistance.

#### Assistance Initiated by Nondisabled Persons

#### Strategies for offering assistance

All of the participants told us that they received offers of assistance from nondisabled people quite regularly. Most indicated they did not mind if the nondisabled persons initiated the helping interaction. However, successful offers of assistance (those that were accepted by people with disabilities) met certain conditions and parameters, which will be discussed below. For most of the interviewees, offers of assistance were acceptable or even welcome—especially when the need for help is obvious. One woman pointed out that an offer of assistance "takes the pressure of always being the one to say, 'Would you please, would you please, would you please'...so, I think the offer of assistance is not bad" (#21:93).

Participants explained that some nondisabled people ask if they may help first, while others go ahead and simply assist the person who is disabled. This man's response was typical:

More often than not, they'll say, "Can I give you a hand? If I can give you a hand, I'll be glad to help you." You know, if I drop something. And that happens a lot. That's a good question. If I drop something, chances are I don't even have to talk to people. If somebody's around, they'll pick it up. (#28:88)

Most respondents indicated that, while they preferred to be the one to initiate in a helping situation, it was acceptable for nondisabled persons to offer assistance if their need was obvious, for example, "When I've fallen out of my wheelchair, um, if I'm tipped over, I think that would be an appropriate time for somebody to come and say, 'Can I help you?'" (#27:80). Several respondents indicated that they would accept help in these situations because it is the practical thing to do. One man who had muscular dystrophy explained, "Like I said, my philosophy is, hey, if I get help doing something, that's energy saved that I can use to do more things for myself within the day" (#28:91).

While most of the respondents indicated it is acceptable for nondisabled people to initiate the helping situation, our analysis revealed five suggestions for nondisabled people to follow when they want to help. First, most of the interviewees said they preferred the request be very general, "May I help you?" or "Do you need anything?" rather than suggesting a specific action. For example one woman responded:

But make it very generic, and don't ask, "Can I tie your shoe?," "Can I walk you?," "Can I hold your hand?" Ask.

[Interviewer: "What is the difference between the two statements?"]

One, you are saying that you know what the person needs. And you may not. You may be saying, "Do you want me to hold your cane?" and the disabled person may say, "No, I want you to hold the door." *Don't* assume you know what the person needs. (#21:94–95)

Second, the offer of help should be natural and casual, like the assistance that would be given to any individual, disabled or not. One woman explained how she decided whether or not to accept assistance:

A lot of it comes from the way the person approaches you. I think if somebody is very doting then I'll say "no." If I think somebody is saying, "I'm going to get myself a drink anyway," then I will probably say "sure." . . . Someone who is very casual about it . . . I can see that is just a helpful hand as opposed to somebody that thinks I'm in need of that help. . . . Make it seem like a casual offer that you would offer to anybody else. (#21:91–92)

The third suggestion was that the nondisabled person should ask before acting, whenever possible. The majority of the participants were clear that the nondisabled person should always ask before physically assisting them and then wait for the person with the disability to assent before assisting. One participant described this as the "five second rule":

Use the five-second rule . . . if you're in a situation where you think somebody needs help, instead of leaping into the situation like superman, count five instead, inside the head, and if after the count of five if that person still looks like they need help, then go over and say, "Excuse me, can I give you a hand" or "Can I open that door?" . . . because normally, if you give somebody that five-second lag time, they will have either accomplished what they attempted to do, you know, happily on their way or they haven't . . . well then there's a chance to help them. But if they have, you have avoided a situation where somebody might have said to you, "No I can do it myself." And you've also given them the chance to let's say, feel more confident themselves. (#15:49)

A fourth suggestion was the nondisabled person may go ahead and offer help as long as they are willing to be turned down or take "no" for an answer. One respondent explained:

I guess ideally I'd like to have all able-bodied people in the world trained to ask the question. Not to rush up or not to rush in, but to ask, "Can I assist you or something?" I think offering assistance is fine as long as you don't get the feeling you are going to hurt their feelings if you say "no." . . . As long as it is not forced upon you. . . . Don't get personally invested in the request. It may be turned down, and it is not a personal affront to you. (#21:93–94) Many respondents expressed a great deal of concern about hurt feelings on the part of nondisabled people. Most importantly, they did not want another disabled person to be denied assistance in the future because they or someone else turned down the nondisabled persons' offer of assistance:

The other thing is that when you run into the occasional jerk [with a disability] that bites your head off when you try to open the door for them or something like that . . . don't think that everybody else is that way. I mean you may run into two or three in a row but you know . . . we're all not that way, and we all have good days and bad days too. So, it may not be that we're upset with you for opening the door, it's that we're upset with the person who slammed the door on us a little bit ago, so that may be part of it. (#1:5)

The fifth suggestion for the nondisabled person initiating help was willingness to follow the instructions of the person with the disability. While instructions may not be needed for simple tasks like retrieving a dropped object or opening a door, interviewees discussed more complicated tasks, such as folding and stowing a wheelchair in a car, or helping them get up if they have fallen. Interviewees stressed that, since nondisabled people will most likely not know how to help them in these situations, it is important that the nondisabled person attend carefully to the instructions given. One man said, "If you have no experience dealing with a wheelchair, you gotta listen to the instructions . . . some people listen better than others" (#28:86). Several interviewees told stories of nondisabled people who did not listen to their instructions. The outcomes of these situations ranged from wasting time, frustration for one or both parties, potential harm to the person who is disabled, to breaking specialized equipment. One wheelchair user provided this example:

One time though, I did have somebody come around the doors on the back [of the van], and I have an electronic switch to close the doors, and this guy manually broke the door when he closed it. . . . I was yelling, "Wait don't . . . don't push that door" and he physically pushed it and broke it. . . . But, he was just trying to be of assistance. . . . I think he was a little embarrassed. But, on the other hand he . . . was out of his water. He didn't realize what I needed or what I didn't need. [He] felt like he was doing the right thing and then he ended up breaking something. (#9:48)

#### Managing Unwanted Assistance

#### Reasons assistance is not wanted

In our analysis, we categorized six reasons that assistance would be considered unwanted by people who are disabled. First, respondents indicated that they will reject offers of assistance when they perceive the nondisabled person is patronizing them. One interviewee described rejecting the assistance when a nondisabled man tried to give him advice on how to get his wheelchair into an elevator. "He was giving me suggestions for how to turn my chair and stuff, when I've been in a chair for 16 years and [he] probably has seen a chair for . . . eight minutes of his life" (#28:89–90). Second, people with disabilities will reject the assistance if they perceive the nondisabled person is making "too big of a production" of giving assistance, which would cause discomfort or embarrassment. This included offering help too loudly, or rushing across the room in front of other people to offer help. One participant commented, "total strangers who don't know me as a student here on campus would go out of their way to make way for me on the stairs and hold the doors for me . . . and even though I appreciate the politeness, I didn't appreciate the fact that all of a sudden everybody was aware that I was handicapped" (#7:27).

Third, people with disabilities may reject the assistance if they have received too much help. Rejecting assistance might occur if a particular nondisabled person has offered or provided more assistance than the person who is disabled needs or is willing to accept. The person who is disabled might also reject assistance if they have received too much help in a given situation or on a given day, even if the assistance has come from other nondisabled people. One woman explained, "If it's the 59th time that day, the 'no' gets firmer" (#21:92).

Fourth, the person who is disabled may reject assistance if the nondisabled person provides help without being asked. One man characterized this situation:

They just start, they just start pushing [the wheelchair] sometimes. They'll come up, you know, and they'll just start pushing. . . . I don't think twice if someone offers help that I don't want. But it's the times when people come up behind you and start pushing the chair that makes you a little nervous. (#26:64)

Fifth, people with disabilities may reject unwanted assistance if they believe their safety is compromised. If assistance is not provided in the appropriate manner or directions for helping are not followed closely, physical harm to the disabled person can occur. One participant expressed these concerns, "The worst thing a person can do is actually, physically try to help me with something. . . . Especially if I'm standing trying to do something because that can throw me off balance. So it can be a real detriment" (#18:69).

A sixth reason for declining assistance is that assistance may actually make the situation more difficult than if the persons with the disability had performed the task themselves. Participants expressed this time and again:

Trying to put the wheelchair in the car and people run up to you, with the trunk open, and "here, here let me help," and you know that you have to get it in a certain way or it won't fit in the car. There's times when "yes I realize this person is trying to be nice, but it is going to end up being a lot more work than it really is good, because I'm going to have to try to pry this thing out of this trunk." I have told them "thank you, but no thank you," in a very quiet way. (#16:55–57)

### Strategies for managing unwanted assistance

While people with disabilities have differing needs for physical assistance, each of them talked about strategies for managing unwanted assistance. People with disabilities may try and perform the task themselves, before the nondisabled person can step in. One man

said he would try and pick up a dropped object, even though it was difficult for him, "Sometimes, like if I drop one thing, I can pick it up and a lot of times it is more important for me to pick it up myself and prove that I'm not a helpless gimp" (#28:88).

Participants described several different communication strategies used to manage unwanted assistance, ranging on a continuum from indirect to aggressive responses. The first strategy, representing the indirect end of the continuum, was to accept help even if it is unwanted. Most of the interviewees indicated there are times they would accept the unwanted assistance because they did not want to appear rude, or because it was simply easier to accept help rather than argue with the person, "A lot of times you have to just, if someone helps you, just shut up and let them do it because . . . you learn awful fast after being in a wheelchair that a lot of times it is better to shut up and say thank you. You know?" (#8:39). People with disabilities realized that helping often makes nondisabled people feel good about themselves, "Yeah . . . you know, and a lot of times I just shut up and let them help . . . they're more into being helpful and . . . I've been in that place too. It is nice to feel that you've helped somebody" (#17:60). Participants also rationalized accepting help as a way to conserve energy for things they would be doing later in the day when their energy would be depleted or when they might have less opportunity for assistance. A second indirect strategy would be to appear to ignore the offers of assistance:

Say, I'm in the cafeteria.... A lot of people just look at me and the chair and figure well, she needs help. Like a lady today, reaching way up high filling the pop container, "Oh, can I help you with that," and sometimes if you just ignore people they'll walk away, so it is easier to just pretend you didn't hear that. So I didn't do or say anything, so she kept standing there.... She looked at me and she was so put out and walked away. I thought, "Well, I'm terribly sorry I hurt your feelings, but you know, get out of my space." (#13:24)

A third strategy used to manage unwanted assistance was direct refusal of the offer for assistance. For example, simply saying "no" or "no thank you." Of all the strategies reported, the verbal refusal strategy was used most often. Participants stressed that they were conscious of communicating the message using a firm but pleasant tone of voice, especially at the first attempt. Interestingly, several participants pointed out that it would not be unusual to need to use this strategy multiple times. One woman explained, "Sometimes people are taken back a bit. Sometimes you have to be fairly persistent. They want to help no matter what . . . I don't generally end up with things I don't want" (#21:93).

A fourth strategy was more direct, as people with disabilities would refuse help and also explain why assistance is not needed. One interviewee said simply, "I would tell them that I could do that myself" (#27:79). Another disclosed, "Generally it's just a polite 'thank you' and I generally offer a reason why I don't need [the help]" (#21:92).

A fifth strategy was to use humor. This could be done indirectly or directly, depending on the situation and the type of humor used. Using humor as a strategy to manage unwanted assistance was discussed by most of the interviewees. Humor was often used as a more indirect way to refuse help in hopes of sparing the nondisabled person embarrassment or escalating into a confrontation. For example, when asked how to handle nondisabled persons who continually open doors, even though the doors had electronic button openers, a participant replied, "I might kid 'em and say, 'You like opening doors?'" (#15:42). Another woman described a more direct approach when a nondisabled person opened the door for her when she did not want help, "There are times when I will rush ahead of someone and say, 'Oh, allow *me*!' Make a joke about it and I think it points out to them that they don't always have to be doing this" (#21:93).

A sixth strategy ranged between an assertive and aggressive refusal. This included very direct refusal, "telling the person off," and/or nonverbally showing anger. One man described how he reacted when someone pushed his wheelchair without asking:

Generally when I push the chair, I don't move all that fast . . . people will see ya and they'll think that you're going, I don't know, too slow or whatever, and they'll come up and they'll push, you know. . . . I usually just glare back at 'em and say, "I *got* it. It's OK!" or whatever and they kind of get the message. (#26:64)

Most participants were quick to indicate that they would use an aggressive response only when they believed this was their sole recourse. Another man, who used a wheelchair, described how his communication moved from assertive to aggressive when his refusal of help went unheeded:

I'll be going . . . through the airport with my luggage. A lot of people always come up and ask can they push my wheelchair. And, I can perfectly do it with my hands myself. . . . And I thought like they were invading my space, concentration, doing what I wanted to do, which I enjoy doing; doing what I was *doing on my own*. . . . They say, "Can we help?" "Can I carry your luggage for you?" or "Can I push you?" And each time I said, "No, I'm doing fine." They just looked at me like I was strange—you know, crazy or something. One person started pushing . . . they said they have to "do something" and I said [in an angry tone], "Well, *you* don't have to touch the wheelchair." And then she just looked at me like I'd slapped her in the face. And, uh, I was polite about it, but I didn't need that. (#27:78)

We also noted that people who were disabled a shorter amount of time seemed more likely to use the more aggressive strategies. One man, who had polio as a teenager, reflected on how he often got into fights as a teenager when people offered to help him or when he perceived that they treated him different. Now that he was older, he had a much larger repertoire of strategies for coping with unwanted assistance.

One additional way of managing unwanted assistance is for a companion to "run interference" for the person with the disability. One man explained:

My wife is a terror when it comes to that. Because, when she has . . . sees me trying to get into a bus or a van, she tells people [he says loudly], *"Leave him alone!* 

Let *him* judge whether or not he can make it! And if he knows he can't make it, he will ask someone to help." (#10:64)

It was not clear whether these nondisabled people ran interference with the permission of the person with the disability or whether they acted on their own. Participants did not appear to object to these intercessions; at least they did not report it in the interviews.

#### Discussion

In this study we illustrated the issues surrounding the communicative management of instrumental social support by people with visible physical disabilities as they interact with nondisabled others in early phases of relationships. We described how these people with disabilities interact when they need physical assistance, when they initiate assistance interactions, when nondisabled persons initiate assistance, and how people with disabilities manage unwanted assistance. This work extends previous research on social support by focusing on how support providers and recipients communicate and manage support on an ongoing basis rather than in response to a temporary crisis. People with disabilities, especially those with visible disabilities, communicate and manage assistance on a daily basis, especially from strangers and people they are just getting to know, and they are well aware that assistance can be both rewarding and costly for them. While most of the literature links social support with physical and psychological health, looking at these data in the present study from an exchange perspective clearly highlights another side of supportive interactions, where support can be costly to the recipients. Through this finding we extend previous researchers' work indicating both costs, as well as rewards, for recipients of social support (Albrecht & Adelman, 1987; Braithwaite et al., 1999; Cutrona, 1996; Galaif, Nyamathi, & Stein, 1999; Goldsmith, 1994; Ray, 1992). It is clear from our data that dealing with help numerous times each day, especially unwanted help, can be a negative experience for persons with disabilities and managing these interactions requires a measure of patience and grace under pressure on their part.

#### **Implications for Persons with Disabilities**

Our findings support findings of previous researchers that people with disabilities need varying amounts of assistance depending on their specific disability (Braithwaite, 1987; McColl et al., 1995; Smith & Goodnow, 1999). Every disabled person we interviewed indicated that they receive much more assistance than they want or need. Not only do people with disabilities receive too much help, they often receive assistance that is not always helpful in terms of timing or delivery. While we were not surprised to hear that people with disabilities need to manage overhelping, we were impressed by how much their own advance planning could lessen or eliminate the need for assistance. When people with disabilities successfully plan to minimize their need for assistance, they reduce or avoid the social costs of these interactions in terms of personal embarrassment or having to confront a well-meaning nondisabled person and refuse assistance. Using advance planning would

be in line with the goals of the independent living movement that focuses on environmental and social adaptations that make it possible for people with disabilities to live as autonomously as possible (Crewe & Zola, 1983). One way people with disabilities can accomplish this independence goal is to take advantage of the latest technologies that assist with mobility and transportation, ranging from having surgery to increase grasping abilities in the hand in order to be able to drive an automobile, to using accessible vans with lifts, scooters, and other adaptations. Occupational therapists can introduce people with disabilities to the latest strategies and environmental control units (ECUs) to help them best perform the necessary tasks (Parrott, Stuart, & Cairns, 2000).

Interestingly, it is important to note that most of the planning strategies people with disabilities reported in the present study were less technologically-oriented. Rather, people with disabilities described how they function intentionally and proactively to be able to minimize help needed from others, with the goal of being as independent as reasonably possible. Minimizing the need for assistance most often involved easily enacted, but essential moves like making sure objects are placed within reach or calling ahead to a restaurant to make sure an accessible table is available. People with disabilities also indicated they arrange for formal services so they do not need to rely on strangers, for example, arranging in advance for a grocery store employee to meet them and help them shop or calling ahead to a hotel to line up any assistance that will be needed. Clearly, rehabilitation professionals and others working with people who become disabled can assist them in developing the skills necessary to minimize the need for assistance, especially from strangers in public contexts. Beyond this rehabilitative training, those familiar with communication and disability issues can be especially helpful in providing people with disabilities the communication tools to help them anticipate and communicatively manage unwanted assistance, while still obtaining the assistance they may need.

While people with disabilities indicated that they acted proactively to avoid the costs of needing to ask for or receive assistance, they are also quite pragmatic in managing the need for help when it does arise. People with disabilities we interviewed indicated they would accept help when it will save them time and energy and allow them to accomplish other things in their day. Finding ways to balance autonomy and connectedness will be an important task for people with disabilities as they relate to others, both strangers and those with whom they have relationships (Braithwaite & Harter, 2000; Lyons &Meade, 1995). Those who work in rehabilitation and occupational therapy need to provide training for people with disabilities to help them develop the necessary communicative skills to manage helping interactions and people with disabilities may also learn some of these strategies from disabled peers (Braithwaite, Waldron & Finn, 1999; Schopler & Galinsky, 1993).

Of course, the need for instrumental support of all kinds will depend largely on the type of disability an individual has, especially once the person's condition has stabilized, if that occurs (Braithwaite, 1990, 1996; Cunningham & Coombs, 1997; LeClere & Kowaleski, 1994; Pardek, 1998; Soule & Roloff, 2000). For example, once a person with a spinal cord injury completes hospitalization and rehabilitation, he or she should have the knowledge and skills to function as independently as possible. As time passes and experience managing these situations increases we note that most people with disabilities seem to develop a repertoire of physical and communication strategies to eliminate or minimize assistance

needs and to obtain necessary help in the best way, depending on their particular disability. In this way, persons with disabilities are maximizing the positive aspects of receiving assistance by minimizing its social costs.

We would note that there has been little research that has focused on giving and receiving support for people with disabilities that takes into account the type of disability, which influences what kinds of assistance is needed. In addition, researchers need to take into account what happens when a persons' disability is not visible, for example those who have emphysema or epilepsy (e.g., Matthews & Harrington, 2000), or those who have AIDS (e.g., Cline & McKenzie, 2000). While this will be a complex task, given the many different types of disabilities, researchers need to consider disability type more seriously so that rehabilitation professionals can best tailor their training to meet individual needs.

People with disabilities will be further challenged when dealing with helping situations when they have a disability that involves a changed or reduced capacity to communicate (which was not the case in this study). For example, how do people with disabilities who have limited vocal abilities (e.g., a person with cerebral palsy) or those who have reduced access to the nonverbal channel (e.g., a person who is blind or deaf), reduced ability to verbalize (e.g., people who have had a laryngectomy) communicatively manage instrumental support interactions with nondisabled people? Clearly, communication scholars need to address these issues to provide the most useful advice to help people with disabilities manage assistance and some of this work has begun (e.g., Romski & Sevcik, 2000; Weitzel 2000).

The issue of handling unsolicited assistance is a difficult one for people with disabilities. While Soule and Roloff (2000) argued that the two differing views of helping ("help the handicapped" vs. "encourage independence") create conflict between people with and without disabilities, our findings lead us to conclude that, although tension may be present when unsolicited assistance is offered from strangers or new acquaintances, overt conflict rarely occurs. People with disabilities seem to have developed ways of coping that will generally help them obtain the assistance they need in public in the least costly way and manage situations when they do not want it. From our data, we provide a different view of "overhelping" people with disabilities. Some researchers have argued that overhelping may be a way to control others' behavior, or create indebtedness and dependence (Gilbert & Silvera, 1996). However, people with disabilities who participated in our study most often viewed overhelping as the response by nondisabled people who misunderstand the needs of people with disabilities, or simply do not know the best ways to go about helping them (including doing nothing). The people with disabilities we interviewed demonstrated an ability to choose among possible courses of action to meet their physical needs and interaction goals, including accepting unwanted help they judge as offered with the appropriate motivation on the part of nondisabled strangers or acquaintances. This finding also supports a view of social support as interactive, rather than one-way (Goldsmith, 1992; McColl et al., 1995), looking at offering and receiving assistance as complementary. We believe that these results have import for people with disabilities and we would stress the importance for rehabilitation professionals to also be aware of the need to help their clients learn to communicate about assistance. Our results provide rehabilitation and occupational therapists with a starting place to arm people with disabilities with a repertoire of communicative and behavioral options for obtaining assistance in order to most effectively communicate to manage instrumental support.

#### **Implications for Nondisabled Persons**

There are important findings in this study for nondisabled people as well. Our experience working with communication and disability for many years is that most nondisabled people do wonder what to do when they believe a person with a disability might need or want help. While they appreciate the social rewards of providing instrumental support, most are not aware of how to offer and provide this support in ways that reduce the social costs for the people they are trying to help. This is one place where social support researchers can provide practical help when they take the perspective of social support recipients and discover what will work for them. While nondisabled people may find that many people with disabilities will accept their help when it is offered, it was clear from our data that people with disabilities strongly prefer to be the initiators and in control of interactions involving their own assistance whenever possible.

Thus, our results lead us to offer nondisabled people in potential helping situations three points of advice. First, the best course of action is to recognize the desire of people with disabilities to control their own actions throughout the day. Therefore, wait and see if the person who is disabled requests assistance before assuming knowledge of their needs. Second, when nondisabled people do offer to help, these offers should be general in nature to avoid assuming one knows what the person with the disability needs, if anything, and when. For example, one should ask, "Do you need anything?" or "Let me know if I can help you" rather than "Let me push your chair for you." This finding may be somewhat different than what we would see concerning social support in other short-term crisis situations, where the person needs help on a temporary basis. In a crisis, a person may be less aware of what they need or what assistance may be available to them. In this case, the person experiencing a short-term crisis might be more accepting or appreciative of a surprise visit, food delivered, or other assistance. In contrast, when needing to address the issue of support over the long-term, the potential recipient may have a much greater need for specific types of assistance and for control over how assistance is offered and delivered. Whether support is given in the long or short-term, however, we do need to be mindful that any support, no matter how well intended, may be perceived as a negative face-threat by the recipient (Goldsmith, 1994). The results of the present study certainly point to considering the perspective of the person one believes needs support before acting.

Third, these data help us highlight the important point that, no matter what the intentions of the support provider might be, it is important to *listen* to the potential recipient and *honor* his or her wishes in terms of when and how support is provided, if at all. Too often people with disabilities find themselves having to interact with a nondisabled person who will not take "no" for an answer or who is not providing help in a helpful way. Rather than leave these issues to chance, organizations should provide training opportunities for nondisabled people who will be interacting with people who are disabled to help them make choices that will maximize the rewards in these helping situations for both disabled and nondisabled interactants. This training can be part of the overall plan to respond to issues of diversity in the organization (Braithwaite & Labreque, 1994; Kreps, 2000).

#### **Implications for Support Providers**

Beyond the specific context of disability used in our study, support providers in other contexts may benefit from our findings. Support providers should engage in perspective-taking and attempt to understand and balance their own desire to meet personal social obligations to provide support against the potential embarrassment, inconvenience, or harm to recipients. The three general prescriptions suggested to nondisabled people above would seemingly apply to other situations as well, especially when assistance might be an ongoing issue, for example, when providing instrumental support to an elderly person, a single parent, or a person with a long-term illness. First, when feasible, give control to the potential support recipient and let them indicate when and how support is needed. Second, when support is offered, present the offer of assistance in a general way, rather than assuming what the support recipient needs. Last, listen carefully to what the support recipient says in order to provide assistance in the desired way, including a refusal of assistance. These prescriptions should help both support providers and recipients to maximize the rewards of instrumental support while minimizing costs for either provider or receiver.

#### **Strengths and Limitations**

The strengths of this study include the focus on the perspective of the recipients of instrumental support, and the rich descriptions provided by the participants representing a wide range of age, disability type, and length of disablement. This study provides a much more comprehensive picture of helping as a communication issue and how people with disabilities manage this issue. Our findings help us make a contribution to the support literature by looking at the recipient's perspective, looking beyond emotional and esteem support, and viewing support over the long-term, especially dealing with unwanted support, focusing on managing both rewards and costs for support recipients and providers. Limitations include working with a relatively small group of participants, and only studying these encounters from the perspective of a single interactant. Future researchers may benefit from interviewing dyads to gain the perspective of both parties in the helping interaction or perhaps using focus groups to bring persons with and without disabilities together to talk about how to interact in helping situations. In addition, we would like to suggest more observational studies, like the one by Thompson and Cusella (1988), where they observed public helping interactions between disabled and nondisabled people. Interestingly, they found surprisingly little talk in helping situations, which does not match the picture provided in our data.

As people with disabilities find themselves active in the community and workplace, the need for them and nondisabled others to manage issues of instrumental support will remain. Both nondisabled people and people with disabilities will find the results of this study useful in providing some guidance on how to communicate and behave in potential

helping situations. Finally, we believe that these findings will lend insight for understanding other people in other contexts who find themselves managing ongoing supportive interactions, either as support recipients or support providers.

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#### Notes

- 1. Quote is from a woman with a disability, interviewed in an earlier study (Braithwaite, 1987).
- 2. In the literature, the terms "help" and "assistance" are both used. When talking about instrumental social support, we use these terms interchangeably to talk about all of the various tasks associated with mobility and self-care provided by strangers or people in early stages of relationships (acquaintances).

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