

Perspectives of Students With Intellectual Disabilities About Their Experiences With Paraprofessional Support

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ABSTRACT: *Perspectives of students with disabilities are notably absent from research about special education paraprofessionals. This study begins filling that gap by interviewing 16 young adults with intellectual disabilities about their experiences attending general education classes with paraprofessional support. Findings describe the primacy and exclusivity that often exists between paraprofessionals and these students as characterized by four interrelated themes regarding consumer perspectives of paraprofessionals as: mother, friend, protector, and primary teacher. Although study participants provided both positive and negative perspectives on these four descriptors, each descriptor represents cause for concern. Implications for practice encourage schools to (a) consider the social validity of supports, (b) increase teacher involvement, (c) highlight the importance of listening to students with disabilities, and (d) include them in decisions about their own supports.*

More students with a wider range of disabilities, including those with low-incidence disabilities (e.g., intellectual disabilities, autism, multiple disabilities), are receiving part or all of their instruction in the same classrooms as their peers without disabilities (McGregor & Vogelsberg, 1998). The use of paraprofessionals in

public schools has become one of the primary mechanisms by which students with disabilities are being supported in general education classes (Giangreco, Edelman, Broer, & Doyle, 2001). Therefore, it is not surprising that there has been a substantial increase in the number of paraprofessionals hired to support students with disabilities (French, 2003). Correspondingly, there has been an increase in the amount of research de-

voted to paraprofessional issues. We identified 23 studies about special education paraprofessionals published between 1997 and 2004. Although these 23 studies focused on students in the United States, paraprofessional issues are being studied in other countries as well, such as Australia (Hall & Macvean, 1997); Sweden (Hemmingsson, Borell, & Gustavsson, 2003; Skar & Tamm, 2001); and the United Kingdom (Cremin, Thomas, & Vincett, 2003; Lacey, 2001).

Of the 23 U.S. studies, only 4 involved interventions with a combined total of 14 students (Causton-Theoharis & Malmgren, (2005); McDonnell, Johnson, Polychronis, & Risen, 2002; Werts, Zigmond, & Leeper, 2001; Young, Simpson, Myles, & Kamps, 1997). Two others were evaluation studies of a schoolwide planning process to improve paraprofessional supports (Giangreco, Broer, & Edelman, 2002a; Giangreco, Edelman, & Broer, 2003); and one was an evaluation of paraprofessional training materials (Giangreco, Backus, CichoskiKelly, Sherman, & Mavropoulos, 2003).

The remaining 16 studies were all descriptive investigations. Eight studies were qualitative (Downing, Ryndak, & Clark, 2000; French & Chopra, 1999; Giangreco, Broer, & Edelman, 2001; Giangreco, Edelman, & Broer, 2001; Giangreco, Edelman, Luiselli, & MacFarland, 1997; Marks, Schrader, & Levine, 1999; Morgan, Ashbaker, & Allred, 2000; Tillery, Werts, Roark, & Harris, 2003). Four studies were quantitative (French, 2001; Hadadian & Yssel, 1998; Minondo, Meyer, & Xin, 2001; Wallace, Shin, Bartholomay, & Stahl, 2001), and 4 relied on combining quantitative and qualitative methods (French, 1998; Giangreco, Broer, & Edelman, 2002b; Riggs, 2001; Riggs & Mueller, 2001). All 16 studies obtained the perspectives of various stakeholders (e.g., teachers, special educators, paraprofessionals) about a variety of paraprofessional issues (e.g., roles, training, supervision). Paraprofessionals were participants in nearly 90% of the investigations ($n = 14$); all other respondent groups were represented in no more than 44% of the studies ($n = 7$). Paraprofessionals represented nearly 70% of the total number of participants across these 16 studies. Approximately 25% of the respondents were direct service professionals

(e.g., teachers, special educators); 3% were administrators; and less than 1% were parents. None of the U.S. studies included the voices of students with disabilities about their own experiences receiving paraprofessional supports.

This study describes the perspectives of young adults with intellectual disabilities about their experiences receiving paraprofessional supports in general education classes and addresses a gap in the literature. No other studies to date have described the perspectives of the persons most affected by paraprofessional supports, individuals with intellectual disabilities themselves. Two studies conducted in Sweden have reported on the paraprofessional perspectives of children and adolescents with orthopedic disabilities. Skar and Tamm (2001) conducted semistructured interviews with 13 children, ages 8 to 19, with *restricted mobility*. They reported on students' perceptions about their relationships with paraprofessionals as mutual, nonmutual, ambivalent, and unequal. For example, some students felt it was nonmutual and unequal, that they had to disclose personal information about themselves to unfamiliar people (e.g., "They [the assistants] know everything about me, but I hardly know anything about them. They barge right into my life."; p. 922). Hemmingsson et al. (2003) interviewed and observed 7 students with physical disabilities, ages 7 to 15. They reported that assistants could both hinder and facilitate participation and concluded that being aware of the importance that students with disabilities placed on social participation was necessary to ensure effective supports.

Exploring perspectives of former students can yield important information about service delivery issues that can inform schools that are seeking to extend inclusive opportunities to greater numbers of students with disabilities. Examining paraprofessional support through the eyes of former students creates opportunities to (a) develop a better understanding of the impact paraprofessional supports have on students with disabilities, (b) compare priorities and concerns included in the professional literature with those identified by individuals with disabilities, and (c) explore new areas of inquiry to improve outcomes for students with disabilities.

METHOD

DESIGN

This descriptive study utilized a qualitative design involving semistructured interviews that explored the experiences and perspectives of participants who were receiving paraprofessional supports in general education classrooms.

PARTICIPANTS

Participants were identified with the assistance of two advocacy organizations in Vermont, Green Mountain Self-Advocates (GMSA) and Champlain ARC. The study included a purposeful sample of 16 young adults with intellectual disabilities. See Table 1 for demographic information (e.g., gender, age, disability, employment). All of the participants were verbal and had sufficient language abilities to respond to interview questions with descriptive responses (e.g., they could recall and describe events and perspectives). All participants received special education throughout their school years and paraprofessional support in general education classes. The extent to which study participants were enrolled in general education classes with support varied, ranging from full-time membership throughout their school years to a few high school classes (e.g., American History, Band, Biology, Choir, Computer, Earth Science, English, Health, Home Economics, Math, Outdoor Leadership, Photography, Physical Education).

All participants completed high school within the past 5 years with the exception of the youngest participant, who was in her last 2 months of school, and the oldest participant, age 29, who was included at the recommendation of GMSA because she had strong memories and perspectives on her school experiences that she wanted to share. We purposely sought respondents who had completed school to minimize the risk that participating in the study might compromise existing relationships with paraprofessionals and to increase the likelihood that these former students would speak freely about their experiences. We had been advised by GMSA that power relationships that sometimes exist between adults and students might cause some respondents to be less than forthcoming if they were still in school.

Participants attended a total of 11 different high schools in northern and central Vermont. Nine participants attended 9 different high schools. Four students attended a 10th high school with overlapping years of attendance that spanned 4 different completion years. Three others attended the 11th high school with overlapping years of attendance that spanned 2 different completion years. The paraprofessionals who supported these students while they were in high school were all different individuals with two exceptions. The school that included 4 participants had one paraprofessional who supported 3 of the students, though in different years. The school that included 3 participants had one paraprofessional who supported 2 of the students, though in different years.

PROCEDURES

When interviewing individuals with intellectual disabilities, an important consideration is their capacity to remember experiences, in this case from their school years. The three-person research team addressed these interviewing challenges by first identifying and reviewing literature about memory. In part, it indicated that there is wide variability of memory characteristics among individuals with intellectual disabilities (Hale & Borkowski, 1991; Turnure, 1991). However, some researchers have found stable aspects of memory across a range of age and cognitive variables (Krinsky-McHale, Devenny, Kittler, & Silverman, 2003).

Additionally, we studied general issues about interviewing individuals with intellectual disabilities such as problems associated with (a) understanding questions, (b) responding to open-ended questions, (c) repeatedly giving the same answer to different questions, (d) pleasing the interviewer by saying what they think the interviewer wants to hear, and (e) significant others influencing or filtering participant responses during interviews (Biklen & Moseley, 1988; Walker 1999). We met as a group three times prior to conducting any interviews to discuss the literature, heighten our awareness of the issues (e.g., acquiescence), and develop a plan to incorporate suggestions from the literature into our interview protocol (e.g., build rapport, repeat, rephrase, as-

TABLE 1
Participant Information

<i>Name (Pseudonym)</i>	<i>Gender</i>	<i>Age</i>	<i>Level of Intellectual Disability and/or Other Known Condition</i>	<i>Living Arrangement</i>	<i>Current Employment Status</i>	<i>Support Person at Interview</i>
Cindy	F	19	Mild/EBD	Nuclear Family	Unemployed	Mother
James	M	20	Mild-Moderate	Adult Family Care	Unemployed	Provider
Bart	M	21	Moderate/DS	Adult Family Care	Supported PT	None
Douglas	M	21	Mild-Moderate	Adult Family Care	Unemployed	Provider
Donald	M	22	Moderate	Small Group Home	Unemployed	Provider
Harriett	F	22	Moderate/EBD	Extended Family	Unemployed	Aunt
Bruce	M	23	Mild-Moderate	Nuclear Family	Supported PT	Mother
Caleb	M	23	Moderate/DS	Nuclear Family	Supported PT	Mother
Paul	M	23	Moderate/DS	Nuclear Family	Supported PT	Mother
Samuel	M	23	Mild/Prader-Willi	Nuclear Family	Supported PT	Mother
Carter	M	24	Moderate /DS	Supported Apartment	Supported PT	Mother
Diane	F	24	Moderate/ EBD	Apartment on Own	Unemployed	Friend
Samantha	F	24	Moderate/DS	Nuclear Family	Supported PT	Father
Patrick	M	26	Mild-Moderate	Apartment on Own	Competitive FT	Mother
Nancy	F	27	Moderate	Adult Family Care	Supported PT	Provider
Robin	F	29	Mild	Extended Family	Unemployed	Provider

Note. DS = Down syndrome; EBD = Emotional Behavioral Disorder; PT = Part-Time; FT = Full-Time

sure confidentiality, break questions into smaller parts, clarify role of support person).

We mailed prospective participants information about the study, a consent form to sign, and a one-page information form to be completed (e.g., name, age, date of high school completion, list of high school general education classes attended, names of paraprofessionals and teachers). Participants were also asked whether they preferred to be interviewed individually or have an advocate present. All materials were returned in a self-addressed, postage-paid envelope provided by the researchers.

We screened each submitted set of materials to ensure that the participants were recent graduates and had participated in general education classes with paraprofessional support to some extent. Then the first author spoke with prospective participants by telephone to verify their capacity to recall and communicate educational experiences. He used the questions from the one-page information form as the basis for a brief conversation to ascertain the individual's ability to be interviewed. For example, he asked questions like: "Where did you go to high school?" "What year did you finish?" "What classes did you take?" "Do you remember the names of your teachers?" "Do you remember people who helped the teachers? They might have been called assistants or by some other name like paraeducators." Based on responses to these types of questions, the first author decided whether or not to include the individual from the sample. One of the research team members contacted those who were selected to schedule an interview. Six potential study participants were not interviewed because the first author deemed that they were unable to sufficiently recall or communicate their high school experiences. These 6 individuals differed from the 16 who were interviewed only in regard to their memory and communication abilities; they did not differ in any other meaningful ways (e.g., level of involvement in general education, extent of paraprofessional support, employment, living arrangement).

The majority of participants (12) chose to be interviewed in their homes. Two were interviewed in agency offices near their homes and 2 were interviewed at the researcher's office. Fifteen participants requested the presence of a support

person during interviews (see Table 1). In these situations where a support person was present to assist with memory prompting or communication, he or she was reminded that his or her role was not to answer questions for participants or interpret their responses. All interviews were audiotaped with written permission of participants and/or their legal guardians.

A topical interview guide was developed based on existing literature regarding special education paraprofessionals (Giangreco, Edelman, Broer, & Doyle, 2001; Marks et al., 1999; Pickett & Gerlach, 2003). Each interview included four broad categories. First, each participant was oriented to the purpose of the interview and asked a few questions about themselves in an effort to build rapport (e.g., "Where do you live?" "Are you working?" "What are some of your favorite activities?"). The one-page information form collected prior to the interview was used during the interview as a way to orient participants to their educational experiences and jog their memory.

Second, participants were asked to describe their *experiences in school*, particularly those that related to paraprofessional supports (e.g., "What did the teacher assistant/aide do to help you?" "What was it like having an adult assigned specifically to help you in school?" "How did other people, like your classmates, react to you having an adult with you during class?"). Initial questions were based on existing topics and findings from the literature (e.g., roles of paraprofessionals, proximity, teacher roles, peer interactions).

Third, participants were asked for their *perspectives* about the supports they received (e.g., "What did you like or dislike about the supports you received?" "How did you feel about it?" "What did you find most and least helpful?" "Were there any times that you didn't need to have an assistant helping you?").

Fourth, participants were asked what *advice* they would offer to school personnel (e.g., "If you were back in school, how would you like things to be different?" "What would you like to tell your teachers and assistants about what it is like having a paraprofessional help you in class?"). Because the interviews were semistructured, follow-up questions differed based on participant responses. Researchers rephrased questions repeatedly in

order to increase the probability that responses from participants were accurately understood.

After each research team member completed one interview, the research team met to debrief and discuss findings of the initial interviews. As a result, minor adjustments were made to the protocol. For example, issues related to bullying were not part of the initial interview guide because it was not identified as an issue in the paraprofessional literature. Because it emerged in each of the initial interviews, it was probed in subsequent interviews.

DATA ANALYSIS

All interviews were audiotaped, transcribed verbatim, and reviewed by the research team. Transcripts were imported into a qualitative, text-sorting program, HyperQual3 (Padilla, 1999). The first author, who conducted the primary data analysis, established thorough familiarity with the data by (a) conducting half of the interviews, (b) listening to all interview tapes, and (c) reading all transcribed interviews. Data were analyzed inductively using categorical coding (Taylor & Bogdan, 1998). Transcripts were marked by hand using 60 initial codes (e.g., paraprofessional roles, instruction, friends) using terms descriptive of text content. Particularly descriptive passages were highlighted and notes were maintained on emerging themes. The interviews were then re-read and data were re-categorized or combined into 31 codes (e.g., bullying, dependence, frustration with academics, instruction by teacher, proximity, stigma). HyperQual3 was used to sort data into 31 code-specific reports. Inductive analysis was applied to the code-specific reports to assist in the identification of themes, which overlapped code categories. The research team reviewed themes to confirm that analyses were consistent with their interview experiences; then they collaboratively conceptualized and wrote the findings.

FINDINGS

The overarching finding of this study revealed the primacy, and sometimes exclusivity, of relationships between these former students and the paraprofessionals assigned to support them. This

finding was evidenced through four interrelated themes pertaining to consumer perspectives of paraprofessionals as (a) mother, (b) friend, (c) protector from bullying, and (d) primary teacher. Each theme provides insights into the relationships between students with disabilities and paraprofessionals, how those relationships affected the students' self-perceptions, as well as their interactions with their teachers and classmates without disabilities.

It is not surprising that within each of these themes, the study participants offered a range of perspectives that were intertwined with their affective recollections about the paraprofessionals. Although some spoke about paraprofessionals positively, (e.g., "They're very nice, they're great" "He was there for me"), others reported feeling mistreated, misunderstood, and not meshing well with the paraprofessional who was assigned to them (e.g., "She didn't really understand who I really was" "She was mean" "She used to put me down" "I don't like being yelled at" "Sometimes I thought they weren't patient enough . . . just trying to get it done and over with").

PARAPROFESSIONAL AS MOTHER

I was kind of getting embarrassed because I always had, like a mother right there. People were like looking at me and stuff, and saying, "Why do you always have this person with you who is twice as old as you?"

That is the way one young man described how he felt about some of the paraprofessionals assigned to support him. It was not surprising that several participants described paraprofessionals using the term *mother* because nearly all of the paraprofessionals described by the study participants were women. Although they ranged in age, many were old enough to be the parent of these former students.

Some participants were indifferent to age and gender issues, (e.g., "It's okay, I don't really care"). Others expressed a preference for younger and same gender paraprofessionals, "They [paraprofessionals] should be exactly your age." Explaining why younger paraprofessionals were considered preferable, another former student commented, "They were more fun to interact with and learn more from." A common reason for

preferring paraprofessionals of the same gender was described by a former student, who is male, this way, “I was more comfortable with men because sometimes I just feel more embarrassed if I was with a woman.” Participants made links between age, gender, and mother designations that were most closely associated with middle-aged or older women.

The designation of being like a mother carried mixed connotations for the respondents. Some study participants used that language to express their heartfelt admiration for paraprofessionals. As one participant stated, “I liked her a

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lot because she was like a mother to me for my whole life when I was in school.” Other participants attached negative connotations to mothering, identifying it as unwanted and out of place within the context of school, “I felt a little weird. It felt like I was having, like a mother.” Participants described how they perceived that the assignment of a paraprofessional interfered with their opportunities to develop friendships, “That’s why I didn’t have any best friends or a girlfriend in high school because I always had a mother on my back.”

PARAPROFESSIONAL AS FRIEND

To fully appreciate the study participants’ perceptions of paraprofessionals as *friends* requires an understanding of how they perceived their other social relationships and their self-image. First, many of the study participants expressed a deep sense of isolation from the regular life of the school. As one young woman described, “When I was in school I had, like, my own world; I was in my little world there.” A different woman explained, “I didn’t feel like I was with a group.... I feel like I was sitting on the outside.” One young man stated, “I could never sit in the way back with the other kids. I always had to sit down there

with the kids that didn’t belong.” A pervasive sentiment expressed by several study participants was, “I felt like I didn’t belong.”

Second, participants linked feelings of disenfranchisement with recognition of seeing themselves as “different.” As one participant explained, “I wasn’t like other people. I wasn’t with the other kids. I was hurt.” Another respondent said, “I want to be normal like the other kids are, but I’m not.” The desire to belong and fit in was captured by a study participant who stated, “I would have felt like I belonged if I got along with the kids and I could be like them.”

Third, although a small number of participants reported positive peer relationships in school (e.g., “Oh yeah, I had a lot of friends” “I’m a people person, I love people. I really do”), the majority described either a nonexistent, small, or restricted range of friendships limited primarily to paraprofessionals and other students with disabilities. As one young man explained, “I made some friends that would sit next to me [in the cafeteria] who were like my kind of people [students with disabilities].” Another participant referred to himself and his group of friends with disabilities as “nerds.” Several participants shared feelings of isolation and rejection (e.g., “[In class] they [peers without disabilities] didn’t really want to be my partner” “In the library I would be sitting alone too” “I would sit alone too in the lunch tables”).

Participants explained how paraprofessionals, who were often described as their “friend” or “best friend,” filled the companionship void. “I feel comfortable with [the paraprofessional] . . . because she’s a friend now, she has been for a long time.” One participant explained, “It [having paraprofessional support] is more like a companion kind of thing.” Paraprofessionals were perceived as friends because they were the people these former students spent much of their time with in school (e.g., “I spent most of the time with the IAs [instructional assistants] and they took me out of the class”). Some participants identified paraprofessionals as their primary social contact during times when students without disabilities typically interacted with one another. “I would sit with them [paraprofessionals] at lunch tables if they were there having lunch.”

Although several participants spoke positively about their friendships with paraprofessionals, others recognized that it interfered with peer relationships. As one participant explained, “When they [paraprofessionals] go by you, they cut into your conversation and stuff.” Another commented, “When I’m having a conversation with my friends, all of a sudden, there’s a break in [by a paraprofessional], and it breaks it off [my conversation with peers].” The desire to establish friendships often was tempered with frustration and sometimes astonishment (e.g., “I want to learn more about friends, like being a friend. But I can hardly do it if I have no friends” “I still can’t understand why they just didn’t want to have nothing to do with me”). For some, isolation and a restricted range of friendships continued into the postschool years.

PARAPROFESSIONAL AS PROTECTOR FROM BULLYING

Eleven of the 16 study participants reported experiencing various forms of bullying while they were students. The presence of a paraprofessional in close proximity to these students with disabilities served to shield them, temporarily and situationally, from mistreatment. Some of these former students endured name-calling (e.g., “They would say words like, ‘you’re stupid’ or ‘you’re no good.’ Some kids called me retarded”). Others reported

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loss of personal property (e.g., “They would steal my lunch money”) or physical abuse such as being pushed, hit, or having objects thrown at them. Two former students, who attended different schools, reported instances of being forced into lockers, and a third reported being forced into a trash can by other students. Bullying reportedly occurred most often when students were not accompanied by a paraprofessional and were outside the classroom (e.g., cafeteria, gym, hall-

ways, school bus). The emotional wounds of these experiences remained fresh for several of the study respondents as evidenced by the fact that the recounting of their stories of bullying brought many of them to tears.

Several study participants indicated their belief that the reasons they were picked on in school related to their perceived disability differences (e.g., “This kid picked on me because I was totally different from other kids. I [have] Down syndrome, mentally retarded”). They also speculated that some bullying stemmed from personal characteristics or circumstances that were not disability related (e.g., “how my teeth were crooked and how I was overweight” “My mom sent me to school after [we] got sprayed by a skunk and all of our clothes were smelly. That was an awful day to live with. She wouldn’t let me stay home and get rid of it [the smell]”).

At other times, in-class experiences led to mistreatment outside of the classroom. Sometimes stigma associated with paraprofessional support was perceived by respondents as the catalyst for being bullied, “People picked on me because I had an aide. The kids would pick on me because they didn’t need anybody and I did.” In reference to physical education class, a respondent stated, “I’d get picked on by how I’d played and stuff with the kids [in gym class].” When one student was embarrassed to read aloud in class because he was self-conscious about his limited reading skills, he explained, “When it was my turn [to read aloud in class], I refused, so I went out of the room crying, so I got picked on from there.”

Former students reported coping with incidents of bullying in a range of ways. Avoidance strategies were common (e.g., “I made up every excuse in the book” [to avoid the gym]). One former student reported, “I’d hide in the janitor’s closet.” Others reported confronting bullies, “I told them to stop that.” Students with disabilities also stood up for each other, especially for peers they perceived as more disabled than themselves. “They’d be mean to my friends who couldn’t talk and couldn’t communicate” “I used to stick up for them [peers with disabilities]. I used to tell them [students without disabilities], ‘They aren’t stupid and they’re good kids!’” Another student echoed a similar experience, “I helped my friend; he was in

the wheelchair—to stand up for his rights—to speak up for him, because he couldn't speak.”

When participants were asked about their perceptions of how adults responded to incidents of bullying, although a couple responded affirmatively, (e.g., “I got the support I needed where I could deal with it”), more commonly they reported their perception that adults were unaware of the extent of bullying experienced by students with disabilities and that they were ineffective in responding to it. “They [adults in school] didn't talk to the kids about how they were treating each other... the teachers would not deal with it and the principal wouldn't really do much about it.” In reference to bullying on the school bus, a study participant recalled, “He [the driver] didn't try to control the kids, you can hit kids, or you can throw stuff at them, or just sit there and pick on them.” Some of the study participants expressed resignation that bullying was inevitable (e.g., “I mean, you get picked on all your life anyways, so you can't really do much about it”).

Study participants who reported feeling supported when incidents of bullying occurred indicated that paraprofessionals served as a protective buffer. When informed of bullying incidents by students with disabilities, it was typically the paraprofessional who advocated on a student's behalf to the principal or teachers. Paraprofessionals also directly confronted students who perpetrated the bullying. As one former student related, “I usually tell and then she [the paraprofessional] goes and talks to the person [the bully].” Students subjected to bullying reported feeling safer when paraprofessionals were nearby, “When I was around her [the paraprofessional] I didn't care.... She was like my protector.”

PARAPROFESSIONAL AS PRIMARY TEACHER

The study participants reported that when they were in general education classes, most often, it was the paraprofessional, rather than the classroom teacher, who interacted with them and functioned as their primary teacher. Several of the study participants indicated feeling they were not important or deserving enough to warrant the teacher's time after having had this idea communicated to them by both teachers and paraprofessionals. As one person summarized, “They're

always telling me, ‘We got too many kids in the classroom; we can't just deal with you.’” Another shared, “They told me that I couldn't get the teacher to help me because they're busy with other things in the room.” A third explained the justification for lack of teacher involvement this way, “They [teachers] can't really spend a lot of time with one person [the student with a disability], because they have a class to teach.”

As a result of their limited interactions with teachers, several participants expressed the sentiment, “The classroom teacher, she didn't know me very well.” Participants were also very aware of instances when this limited interaction showed up as a lack of communication between teachers and paraprofessionals. “I would be told one thing [by classroom teacher] and [another by] the aide. That happened a lot in high school.”

Participants perceived having paraprofessionals function as their primary teacher in the general education classroom in a variety of ways. Some expressed appreciation for the support they received from paraprofessionals and its impact: “She taught me a lot” “They helped me to read and I don't like reading” “He helped me put money in the bank and stuff” “They helped me get a job.” Some spoke favorably about the approaches used by the paraprofessionals. “Her strategies worked pretty good.” “[The teachers] sometimes made no sense to me, but Barb [the paraprofessional] helped me understand what they're trying to say.”

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Some participants acknowledged their need for paraprofessional support during specific parts of their daily schedule, but not in all. “I feel like I need one [a paraprofessional] in history, but I don't think I need one in all my other classes.”

Others talked about recognizing the benefits of a paraprofessional for behavior support, "I get out of control; but when I had someone around me, it made me stop."

Some former students reported awareness of paraprofessionals fading their support, "He [the paraprofessional] knew when to back off." A small number of respondents experienced systematic fading of paraprofessional supports, "At first I had them [paraprofessionals] in every class and then it went down to only the hard classes." When fading of paraprofessional supports was successfully achieved, respondents spoke about the experience with excitement and pride in their voices, "At the end of the school year, when I was a senior, she like, let me go into my classroom by myself and didn't come with me at all!"

Yet a more common experience was study participants' frustration with the constancy of paraprofessional supports, "I want to be independent...in the halls, in the cafeteria." "Well, sometimes I get tired of being with someone [a paraprofessional] for a long time." These individuals expressed a dislike for the ways in which the paraprofessionals offered their support, and they sought to distance themselves from them. "It feels like I'm being babysat from class to class to class." "It [having a paraprofessional assigned to me] embarrasses me." Another individual commented, "I don't want all those [paraprofessionals] with me all, every day."

Several study participants commented that the work in their general education classes was too difficult for them, that they did not understand the teacher's large group instruction, and that it was a challenge to keep up in class. A rare exception was a former student who discussed his success and enjoyment of an elective high school course called "Outdoor Leadership." He attributed his success in this class to the personal attributes of the teacher (e.g., "He's a great guy") and to the teaching format, which consisted primarily of activity-based groups.

There were only a few instances in which the study participants described anything that might be considered a modification of curriculum or instruction to meet their individual learning needs. Although such accommodations likely occurred to some extent and were alluded to by

some of the respondents (e.g., "He would read and tell me what to write"), the participants' most common recollections included paraprofessionals intervening while the student was still attempting to complete their work (e.g., "They would tell me words when I'm trying to sound them out, and that bothered me"); or experiencing repetition, (e.g., "They just give you the same stuff all the time; it repeats"). The most common recollection across study participants was that of the paraprofessional actually doing the work for them. "I didn't even have to do anything. She pretty much did it all for me." Another respondent summarized the paraprofessionals' strategy for keeping up with class this way, "I guess I pretty much got the stuff [completed by the paraprofessional] and put my name on it."

STUDY LIMITATIONS

There are study limitations to be considered when reviewing the preceding themes. First, this study included a relatively small number of participants from one state and relied on a single data source (i.e., interviews at a single point in time). These data reflect the perspectives of a relatively homogeneous group of young adults in terms of their language, memory, and intellectual characteristics. The extent to which the findings might overlap the experiences of people with more severe intellectual disabilities, those without formal language systems, or those with other disability labels (e.g., sensory disabilities, autism, multiple disabilities) is unknown. We documented that all participants were included in general education classes and received paraprofessional support to varying extents. However, given the retrospective nature of the data collection, we cannot state with certainty (a) the specific number of years or amount of time each participant spent in general education classes, (b) the exact nature of the supports provided by the paraprofessionals, or (c) the school culture or other contextual variables and how they may have influenced participant responses. Despite its limitations, this study includes compelling consumer perspectives regarding the impact and effect of receiving paraprofessional supports, and it offers an initial contribution on a topic of importance where little other data from self-advocates currently exist.

DISCUSSION

Findings of this study present participants' positive, negative, and sometimes ambivalent perspectives about paraprofessionals as mother, friend, protector, and primary teacher. These interrelated themes highlight the primacy and complexity of the relationships that exist between these former students with intellectual disabilities and the paraprofessionals assigned to support them.

Though each of the four interrelated themes could be construed as being positive, especially in situations where they were perceived favorably (e.g., paraprofessional as a friend or protector), we suggest that each of the four themes actually presents cause for concern, regardless of whether they were perceived positively or negatively by the consumer. For example, school is one of the key social environments where children and adolescents establish relationships and an identity separate from their parents. When paraprofessionals function in ways that are perceived as *mothering*, students are denied typical opportunities to develop peer relationships and a sense of self that is so important for social-emotional maturation. This finding of the paraprofessional in a mothering role is consistent with the Swedish study that explored paraprofessional issues from the perspective of students with restricted mobility (Skar & Tamm, 2001).

When classmates notice paraprofessional support as mother-like, in essence they are telling us, in the language of Wolf (1978), that the support is not *socially valid*. Being perceived as needing or having a mother figure in school is likely to have exclusively negative implications for how classmates perceive and subsequently treat students with disabilities. It's hard to imagine many

shield students with disabilities from bullying may actually serve to delay attention to the root issue; namely, that bullying exists in our schools. As long as paraprofessionals spend part of their time shielding students and confronting bullies directly, teachers and administrators may be unaware of the extent to which their students with disabilities experience bullying or other mistreatment.

Finally, when paraprofessionals functioned as the primary teachers for students with disabilities, the concerns were numerous. First, the very nature of the service delivery is socially stigmatizing for at least some of the students, which can contribute to negative feelings of difference in the classroom. Second, it is hard to imagine any student being primed for learning when he or she feels disenfranchised by being separated from the life and routines of the classroom, especially from instructional interactions with the classroom teacher. Third, in some cases it is a concern whether students with intellectual disabilities who are placed in general education classes are receiving adequate instruction. For example, in some cases respondents indicated that paraprofessionals provided too much assistance (e.g., doing their work for them in an effort to keep pace with the class), whereas in other cases they stated that they did not receive enough support. This leads us to believe that the types of supports and accommodations provided by paraprofessionals require individualization and the teachers and special educators need to take on a greater role providing instruction to students with disabilities in general education classes.

IMPLICATIONS FOR PRACTICE

Overall, the extent to which consumers perceive paraprofessionals as mother, friend, protector, and primary teacher can serve as a gauge of the health of a school's general and special education service delivery. The more firmly embedded these perceptions, the more likely that schools will find their service delivery in need of adjustment and improvement. Given the range of student and school characteristics, any collection of actions considered by a school or individual student planning team should be individualized. The following list provides some initial implications for practice

that can be refined by school personnel based on such individualization.

1. Schools are encouraged to scrutinize their existing paraprofessional service delivery practices to ascertain if they are perceived by consumers as being unnecessarily motherly/parental. The findings may result in the need to consider both structural (e.g., rotating paraprofessionals) and attitudinal changes such as sensitizing paraprofessionals and teachers to the experiences and concerns raised by consumers (e.g., stigmatization). In general, we need to explore alternatives to our current utilization of paraprofessionals and develop more socially valid ways to provide students with needed supports in the general education classroom (e.g., general classroom paraprofessionals; peer supports).
2. Students with disabilities should be given age-appropriate input into decision making about their own supports (e.g., paraprofessional supports) and deliberately be taught self-advocacy skills so they can improve their own decision making.
3. Schools may need to actively address the friendship void that currently exists for many students with intellectual disabilities. Although we are not suggesting that schools have the power to create friendships, we feel that they do have the power to minimize barriers to friendships (e.g., physically separating students with and without disabilities, having paraprofessionals eat lunch with students) and have the ability to create fertile ground where friendships can take root and grow. Schools can create opportunities for shared learning experiences where students can display their attributes. These experiences can range from in-class activities, to more formalized peer-support programs, to participation in co-curricular activities. Furthermore, paraprofessionals can be trained to facilitate interactions between students with and without disabilities (Causton-Theoharis & Malmgren, 2005); though we suggest this role also involve teachers and special educators.
4. School leaders can initiate a school- or districtwide dialogue on teacher involvement with students with disabilities. At least part of this dialogue should address the changing role

of teachers in the education of students with a full range of disabilities that are placed in their classes. The outdated, but still prevalent, practice of hosting, rather than teaching students with disabilities, limits access to competent instruction and sends devaluing messages to and about students with disabilities (e.g., that some students are more or less worthy of teacher time than are others). If students with disabilities are ever to realize the promises of the IDEA, the practice of hosting must be confronted honestly and replaced by genuine individualized education. This will require fundamental changes in how some teachers and special educators approach the inclusion of students with disabilities in their classrooms, as well as the training and supports teachers receive. We do not mean to suggest that such a transition would be simple or easy, but we believe it is necessary if we want to improve outcomes for students with disabilities.

5. Perhaps most of all, we need to listen to students with disabilities about their experiences and perspectives. If students with disabilities were getting bullied in a school, it would not be surprising that other students were too. If students with disabilities were having difficulty understanding didactic, large-group lessons and keeping up in class, it would not be surprising that other students were too. Taking action to address the issues raised by the presence of students with disabilities will likely clear the path for nondisabled students who share similar experiences.

Future descriptive research is needed to address the limitations of this study. It would be enlightening to know more about a larger number of students with disabilities in different locations, based on more data sources (e.g., direct observation), and across disability categories. For example, in what ways are the experiences of students receiving paraprofessional supports the same or different if their disability is intellectual, orthopedic, sensory, or behavioral? As long as the risks could be minimized, it would be especially helpful to study the impact of paraprofessional supports across school levels (e.g., preschool, elementary, middle school, high school) at times when students are actively receiving those supports, thus creating opportunities for interven-

tions to be enacted that address areas of concern. Research should continue to explore ways for the perspectives of students with limited language skills (i.e., those who cannot be interviewed or surveyed in traditional ways) to be better understood because these students are likely to be ongoing recipients of paraprofessional supports.

Finally, models need to be explored and studied that actively involve students in contributing to decisions about their own supports, specifically paraprofessional supports and related services. Although a recent article presents a summary of encouraging data regarding student involvement in individualized education program meetings (e.g., goal selection; Test, Mason, Hughes, Konrad, Neale, & Wood, 2004), virtually no data exists in the professional literature in which students with disabilities have a substantial voice in making decisions about their paraprofessional supports.

CONCLUSION

Although a small number of respondents recalled their school experiences primarily with fondness, the vast majority expressed powerful messages of disenfranchisement, embarrassment, loneliness, rejection, fear, and stigmatization. What these students sought was so simple and yet foundational to quality education. They wanted to belong. They wanted to feel that they were worthy of the teacher's time. They wanted to have friends. They wanted to go about their school day without fear or embarrassment. They wanted to learn. In too many cases they did not experience these basics, despite the fact that they attended general education classes and had the support of paraprofessionals.

By raising these concerns we are not suggesting a return to segregated classes, nor are we suggesting that the responsibility for these problems be laid at the feet of the paraprofessionals. Rather, we are suggesting that, as a field, we need to be proactive in addressing our service delivery models and practices that, in essence, continue to communicate messages to students with disabilities that they don't belong. Inclusive schooling means more than merely placing students in general education classes and providing a paraprofes-

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sional for support. Interviewing the 16 young adults in this study reminded us that we must guard against complacency when the trappings of inclusive practice (e.g., general class placement) are in place, because in too many instances an insufficient amount of the substance is present (e.g., curricular and instructional accommodations). Most of all, it reminded us of how important it is to listen to the stories of people with disabilities.

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