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EDITORS' NOTE: The Forum section of the Journal of Positive Behavior Interventions is presented to encourage communication among readers and provide for an exchange of opinions, perspectives, ideas, and informative personal accounts. We welcome brief articles from family members, professionals, friends, advocates, administrators, researchers, and other individuals who are concerned

with behavioral support issues. The purpose of the Forum is to facilitate a constructive dialogue among many stakeholders regarding important issues in practice, research, training, program development, and policy. Submissions to the Forum undergo an expedited review.

Developing a Student Respite Provider System for Children With Autism



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Many parents of children with autism and other severe disabilities report heightened levels of stress due to the unique challenges their children present. Respite care is likely to alleviate some of the stress associated with caring for a child with a severe disability. However, it is often difficult for families to identify motivated and responsible individuals to provide respite care. This article delineates the steps for identifying potential respite providers through the development of a babysitter list of university undergraduates who show interest in babysitting children with autism. Families reported an improved quality of life after using the list to secure respite providers. In addition, the university students gained valuable hands-on experience working with children with special needs and their families, and many reported that they planned to go into careers working with children with disabilities.

The approach delineated here contributes to the wraparound process, one of three interrelated aspects of positive behavior support (PBS) that drive the implementation of a values-based perspective (Carr et al., 2002). Respite contributes to the wraparound process because of its emphasis on needs-based planning and its impact on the entire family system (Carr et al. 2002; Clark & Hieneman, 1999).

The babysitter list was implemented based on needs identified by parents attending a university-based center within the university's School of Education that specializes in services for individuals with special needs and their families. Families participate in a parent education program in which they are active participants in delivering intensive intervention to address the social, communication, and behavioral needs of their children. Parent education has been extremely successful with many families for reducing behavior problems and skill deficits for children with developmental disabilities (Diggle, McConachie, & Randle, 2002; Koegel, Koegel, & Dunlap, 1996; Marquis et al., 2000) and has become a standard part of the service system for families in many parts of the country (Singer et al., 2002).

The responsibilities of caring for a child with a disability are often associated with clinical levels of stress (Moes, 1995; Moes, Koegel, Schreibman, & Loos, 1992). To address high levels of stress, families are often provided with respite care. However, one challenge for families is

identifying individuals who are responsible and eager to work with children with autism.

Although many state agencies provide funding for respite, parents who received services through the School of Education frequently reported difficulties with finding respite providers. Often, respite providers have little experience working with children with severe disabilities. Additionally, the challenging behaviors some children with autism display are likely to decrease interest and enthusiasm to provide respite support on the part of potential providers. Thus, the purpose of the babysitter list was to provide parents with a resource for identifying respite providers who indicated interest in providing respite for children with autism. The primary mechanisms for identifying respite providers was the recruitment of students from large university courses, the development of a babysitter list of names and phone numbers, and the distribution of the list to families of children with autism.

Recruitment

DEVELOPING A RECRUITMENT FORM

To recruit potential respite providers, a simple form was developed that could be quickly and easily distributed, completed, and returned in large undergraduate university courses. The location and phone number of the center located in the School of Education—as well as the name and e-mail address of a contact person—were listed at the top of the form.

The recruitment forms requested the following information from students:

contact information (name, address, phone number, e-mail address) grade-point average (GPA) year of study and major related experience times available for the current quarter or semester access to transportation (car)

Also included in the recruitment form was a checklist that collected the following information:

- available multiple university semesters/quarters Y/N
- 2. willing to work occasional weekends Y/N
- 3. available to work during the summer Y/N
- 4. bilingual (what languages?)

RECRUITING ON CAMPUS

Most respite providers on the babysitter list were recruited from upper-division psychology, sociology, and education courses. Prior to students arriving in classes, professors were contacted and asked if they would be willing to provide us with a few minutes at the beginning of the class period to describe our project and pass out the recruitment forms.

In each class, students were informed that a babysitter list would be compiled and distributed to families living in surrounding areas each quarter as a resource for acquiring respite providers. Recruitment forms were then distributed to students who could either take a minute or two to fill out the form and return it at that time or to the School of Education at a later time.

In addition to recruiting in university undergraduate courses, we also found that many campus departments employ list-serves to notify undergraduates of upcoming events, deadlines, and/or opportunities via e-mail. E-mails included a brief message about the School of Education, ongoing projects, the opportunity to be added to the babysitter list, and an attachment of the recruitment form with specific directions for returning completed forms.

SCREENING FORMS AND DEVELOPING A LIST OF RESPITE PROVIDERS

Once students returned recruitment forms indicating an interest in providing respite for a child with a severe disability, we screened information provided on the recruitment forms to increase the likelihood that families were provided with motivated, responsible individuals. For example, students who maintained above a 3.0 GPA were included on the final list. Although a relationship between GPA and responsibility is not entirely clear, we thought that a high GPA increased the likelihood that respite providers would be dedicated and knowledgeable. Therefore, it was considered in the inclusion criteria. We also screened for bilingual students to address the needs of families with linguistically diverse backgrounds.

Once screening was completed, we developed an alphabetical list of names and phone numbers to distribute to families. At the top of the list was, "Students Interested in Providing Respite for Children With Disabilities" and the quarter (Fall, Winter, Spring, Summer) and year the list was developed. At the bottom, a disclaimer indicated how the list was generated:

The people on this list have expressed interest in providing caregiving/respite assistance. This list was created from an announcement made in an upper-division undergraduate class. It does *not* imply a recommendation from the [School of Education].

We indicated the languages in which students were fluent so that families with culturally diverse backgrounds could choose respite providers accordingly.

DISTRIBUTING THE LIST TO FAMILIES

The list was distributed to families of children who represented various ages and skill levels. The children ranged in

age from preschoolers through adolescents and ranged in social communication skills from nonverbal to competent social communicators. Because all of the children were in active PBS programs, none exhibited severe challenging behaviors such as self-injurious behavior or severe aggression. Once the list was compiled, graduate student clinicians distributed the list to interested families. Typically, the babysitter list included 20–30 names, which allowed families flexibility with scheduling and availability. Families were informed that the babysitter list had been compiled by recruiting undergraduates in university courses and that each student on the list had specifically indicated that he or she would like to provide respite for children with autism.

Once the list was distributed, families could use the babysitter list as they felt necessary, but without specific further assistance from the School of Education. Thus, we recommended that families interview students just as they would any new caretaker. In doing so, families were empowered to contact, meet with, and schedule babysitters of their choice. Periodically, the list was modified and updated to provide families with current information. Finally, all funding issues—private or through a funding agency—were worked out between the family and the respite provider.

Program Impressions

The purpose of the respite list was to develop a requested tool for families. Over the 10 years we have conducted this project, hundreds of lists have been distributed to families. Based on the positive feedback we have received from families and respite providers, the following impressions have been formed.

BENEFITS TO FAMILIES

Parents who have used the respite lists have reported many advantages. As mentioned previously, families with children with severe disabilities frequently experience high levels of stress associated with finding babysitters. For families who either had difficulty finding respite care providers or were unsuccessful after time-consuming searches, the respite list reduced family stress by providing a single source with many options of babysitters. In this regard, the respite list made it easy to access a number of people interested in babysitting children with autism spectrum disorders and related disabilities.

In addition, parents also reported collateral effects on their personal, social, and family lives by having access to respite care. Specifically, families mentioned that using respite care allowed them to devote time to other demands and other aspects of their lives. For instance, they had more quality time to address the needs of their jobs, spend time with spouses or significant others, care for other chil-

dren, and complete daily tasks. These positive changes were related to improvements in lifestyle change and quality of life that Carr et al. (2002) discuss as a critical feature of PBS. Furthermore, gaining time to devote to other demands could lead to improved *quality interactions with their own children with autism*. In terms of the *quality of services*, families reported *high levels of satisfaction* resulting from accessing the respite resource list. Many families mentioned that the student respite workers were responsible, motivated, and had high levels of energy. This was an especially important attribute because parents frequently reported the challenge of having enough energy to continuously engage their children when faced with other life demands.

Because the respite list was composed of individuals who expressed motivation to work with children with autism and related disabilities, the *respite providers were open to learning best practices*. Parents reported that they were able to teach the care providers specific techniques to work with the children (e.g., behavioral strategies, following through with routines, prompting communication). This demonstrates *parental empowerment* in teaching caregivers skills and also produces *consistency* for the children, two important issues for families and children with special needs (Bailey, 2001; Iacono et al., 1998).

In addition to the reported high quality of services, the *resources were cost effective*. Interventions for children with autism can be extremely costly for schools, funding agencies, and families. An unpredicted and extremely encouraging outcome was that several of the parents reported that the respite workers were able to follow through with the specific strategies that they had been implementing in their parent education programs. Thus, the respite providers learned to implement techniques into the naturally occurring activities and interactions. This provided a low-cost supplement to the ongoing intervention services that the children were receiving.

Flexible scheduling was mentioned as an additional advantage for families who utilized the respite list. Part of the challenge in identifying respite care includes scheduling difficulties. However, undergraduate students were often available during the daytime, evenings, and on weekends. Thus, respite providers and families could schedule respite time around the needs of the family. Additionally, some families interviewed and hired two or more respite providers in order to maximize the benefits of respite.

BENEFITS TO THE CHILDREN

Children with autism typically require intensive, individualized intervention in the areas of social and communication skills. Families often experience stress associated with meeting their children's needs while still addressing typical family issues. Competent respite care can address some of these needs. During the time that the respite workers are

caring for the children, the *children can be afforded many opportunities for social communication*. Likewise, opportunities to develop relationships with a variety of caregivers may assist with *generalization of skills* and can help to provide children with consistency across routines to enhance learning.

BENEFITS TO THE RESPITE PROVIDERS

Aside from benefiting the family members, the opportunity to provide respite appeared to be advantageous to the respite providers. First, respite opportunities *provided students with supplemental funding* while earning undergraduate degrees. The *flexible scheduling* was also beneficial for university students. Many students were employed and enrolled in courses simultaneously. Thus, students required a work schedule that was compatible with their class schedule. Providing services to families, then, allowed students to easily schedule employment hours around the demands of coursework and studying.

By providing respite for children with severe disabilities, students also benefited from gaining *hands-on experience* in a field that was related to their career interests. As discussed earlier, students were recruited from courses related to their majors in sociology, psychology, and education. Therefore, working with families with children with autism provided students with an excellent opportunity to gain applied experience and to develop skills that often related to career goals.

Further, it appeared that some of the students who provided respite for the families decided to pursue careers in the field on the basis of their respite experience. Several of the students who began providing respite services to families through this process also assisted with research projects through the School of Education, and others ended up applying to graduate programs in teaching, special education, clinical psychology, and pediatric medicine. With the growing number of children diagnosed with autism and the extreme shortage of well-trained and highly qualified professionals to serve these families, developing a babysitter list could be a potentially valuable way to recruit additional professionals into special education and related fields.

Conclusion

As discussed, the development and distribution of a respite care list provided a useful resource that was fairly simple to create and provided benefits to families with children with autism and the undergraduate student caregivers. This article describes the steps in developing a resource for families and the potential benefits for both families and undergraduate respite providers. We encourage other colleges, schools, departments of education, and universities to develop similar resources to support families living in their

local communities and surrounding areas. As a next step, future projects could more systematically assess the benefits of using such a tool as a resource for families of children with autism and other severe disabilities.

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AUTHORS' NOTES

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