Head Start provides comprehensive education and family support to over 15 million children living in impoverished environments in the United States. Surveys and canvass calls were used to ascertain the extent and nature of contact that Head Start staff have with parents with disabilities. Responses from Head Start programs in a six-state region indicated that 85 percent of programs serve parents with disabilities. Program staff reported that working with parents with emotional disabilities as being the most difficult. Making referrals, adapting information, and providing social support were the main strategies used when working with parents with disabilities. The majority of programs did not have any written policies to guide their work with such parents. Larger programs, usually located in urban areas, made significantly more referrals to leisure/recreation, social support, self-help and substance abuse services. The findings pose implications for programmatic changes in Head Start.
Running Head: Parents with Disabilities

Relationships with parents with disabilities:
Perceptions and training needs of Head Start staff

Yash Bhagwanji
Dawn Thomas
Tess Bennett
Marge Stillwell
Anita Allison

University of Illinois at Urbana-Champaign

Note: At the time this data was collected, the project was named GLRAP (Great Lakes Resource Access Project). The project is newly funded for five years and named GLQIC-D (Great Lakes Quality Improvement Center for Disabilities). Funding is through the Head Start Bureau, Department of Health and Human Services.
Abstract

Head Start (HS) provides comprehensive education and family support to over 15 million children living in impoverished environments in the United States (U. S. DHHS, 1997). A multimethod process was used to ascertain the extent and nature of contact HS staff had with parents with disabilities. Eighty-five percent of HS programs in a six-state region reported serving parents with disabilities. Program staff reported working with parents with emotional disabilities as being the most difficult. Program staff indicated making referrals, adapting information, and providing social support as the main strategies when working with parents with disabilities. The majority of the programs did not have any written policies to guide their work with parents with disabilities. Larger programs, usually located in urban areas, made significantly more referrals to leisure/recreation, social support, self-help, and substance abuse services. Implications for programmatic changes in HS are emphasized.
Relationships with parents with disabilities:
Perceptions and training needs of Head Start staff

Head Start (HS) is the largest provider of early childhood education in the United States. HS is a multifaceted program providing child care, preschool education, health and social services, disability services for children, and parent involvement opportunities to low-income families. Because of the national trends of normalization and community care, more individuals with disabilities are exercising their right to become parents. Therefore, young children in HS programs may have parents with emotional, cognitive, physical, or sensory disabilities. Many of these parents who have disabilities have incomes below the poverty level.

Because of the unique and complex needs of parents with disabilities, the purpose of this study was to explore and address the ways HS staff supported the involvement of parents with disabilities in HS programs.

The issue of parent involvement in children’s development and education is a national concern (National Education Goals Panel, 1995). Although parent involvement has been endorsed as a means to benefit both parents’ competence in caregiving and children’s social and educational outcomes (Bhagwanji & McCollum, 1998), the involvement of parents with disabilities has received very little attention in the literature. Educational institutions have been called upon to serve as critical links to increase parent involvement and parents’ participation in enhancing children’s social, emotional, and academic experiences (National Education Goals Panel, 1995). Parents with disabilities present special challenges in this regard.

HS staff have consistent, frequent contact with families with disabilities and may be influential in providing social support, referrals, information, and modeling appropriate interaction styles with children. There is no single predictor of parenting ability. The mediating variables of poverty, unemployment, poor
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parental models, lack of normal life experiences, isolation from extended family and lack of social support may often accompany disability. Feldman (1994) reported that natural social support networks are the key to supporting families with disabilities. For many families, the HS program may be the only link to parent education, friendship and support, understanding of child development, developing positive interaction styles, problem-solving, discipline and help in managing challenging behaviors.

To increase the quality of services provided to families served in HS programs, guidelines were provided in the Revised Performance Standards (Federal Register, November, 1996). The new guidelines strongly emphasize the development of partnership agreements with parents. By requiring the development and implementation of Family Partnership Agreements, strong parent involvement is expected to be achieved through the building of trusting and empowering relationships between parents and staff. Based on the family’s readiness and willingness, the agreements should specify goals, responsibilities, and timetables for family involvement. In addition, the guidelines also emphasized that preference for employment in HS should be given to current or former parents served by HS. These new standards create important implications for HS staff and administrators as they plan for the inclusion of parents with disabilities who have children in HS programs.

While addressing issues related to the Revised Performance Standards, program must adhere to federal regulations assuring non-discrimination on the basis of a disability. In serving children with disabilities, HS programs already comply with regulations stipulated in the Americans with Disabilities Act of 1990 by providing accessibility, special accommodations and services, and transportation. However, program administrators and staff may not have extended the same considerations to parents with disabilities who have children in HS. HS must strive
to provide equal opportunities in involvement and employment to all parents, including parents with disabilities. The next section explores issues that HS may face in establishing relationships and parent involvement.

Mental Health concerns

One in four American families is affected by mental illness. Depression is the most common form of mental illness affecting 10% of all Americans. More likely to strike women than men, maternal depression has important implications for children’s development because mothers usually hold primary caregiving roles in the early years of children (Seifer & Dickstein, 1993). Associated with mental illness are other risk factors such as poverty, substance abuse, unemployment, and lack of social support. These risk factors may contribute to difficulties in children’s development. Children whose parents have mental illness (a) have an increased risk for mental health problems, (b) live in environments that are less nurturing and therefore may develop more negative interaction styles, and (c) may have insecure attachment patterns, may be more impulsive, and have difficulty in peer relationships (Seifer & Dickstein, 1993). Parents experiencing mental illness need strong natural support networks. HS staff can play a critical role in offering friendship and support, information, and parenting skills instruction to these families.

Child Maltreatment

Parents with cognitive limitations are overrepresented in child maltreatment cases. Their children are at risk for neglect, developmental delay, psychosocial delay, mental retardation, and behavior disorders (Feldman, 1994; Pomerantz, Pomerantz, & Colca, 1990). Young children need a safe, healthy, nurturing and stimulating environment for optimal development. Although parents with mental retardation have the ability to love and care for their children, they may have problems in the following areas: a) making decisions; b) providing for the child’s nutritional health
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and safety needs; and c) providing a stimulating environment for the child. Lack of cognitive, language and social stimulation, and misunderstanding of developmentally appropriate expectations increase the risk of physical abuse, learning problems, and social maladjustment (Feldman, 1994). HS staff can play a critical role in enabling parents with cognitive disabilities to nurture and care for their children in the most effective ways.

Stigma

A stigma associated with disabilities is that persons with disabilities are not capable of being good parents. For example, persons with sensory impairments or physical disabilities may be considered unable to properly care for their children. Zelman (1997) hypothesized that a possible reason may be because “people are afraid our children will also be disabled and will add to the burden we already place on society” (p. 2). Erasing attitudinal barriers is a key first step in dispelling myths about parents with disabilities. Head Start staff can play critical roles as advocates for parents in their caretaking roles by (a) supporting parents as the primary spokespersons for themselves, (b) providing child development and parent education classes, (c) reinforcing parenting skills already learned, (d) linking the parents to pertinent services such as assistive technology, and (e) providing adaptive equipment that facilitates and eases caretaking of children (Michigan State Developmental Disabilities Council, 1997; Through The Looking Glass, 1997). Using an empowering approach, HS staff can establish strong involvement of parents with sensory or physical disabilities by continuously soliciting their input about their needs and supporting their goals for their children.

Other Mitigating Factors

As with all parenting, there are individual differences in outcome depending on parent demographic variables, skill level of the parents, social support, understanding of child development, and characteristics of the child (Belsky, 1984;
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Bhagwanji & McCollum, 1998). Social isolation and poverty may be the greatest risk factors. The social isolation often experienced by these families has been shown to be significantly related to child behavior disorders (Feldman & Walton-Allen, 1993). Increasing natural social support networks and friendships may significantly enhance modeling and effectiveness of parenting.

HS staff are in a strategic position to have consistent opportunities to interact with families around issues of child development and provide needed social support and information. To promote parent involvement in programs, the Head Start Bureau (1996, p. ix) articulated the following three goals for staff to incorporate in daily activities:

- Support parents as primary educators, nurturers, and advocates for their children
- Provide every parent with opportunities for a significant experience in HS
- Ensure that parents are involved in making policy and program decisions

The issues families face are complex in nature. Since it is likely that many HS programs serve parents with disabilities, the purpose of this paper was to investigate the extent to which HS staff or program: a) worked with parents with disabilities; b) used different or innovative strategies with these families; c) were confident/competent when interacting with families; and d) had written policies about working with and involving parents with disabilities in the HS program. The next section discusses the method.

Method

Subjects

Survey subjects. A total of 412 surveys were sent to all Disability Service Coordinators (DSCs) in a six-state region. Respondents to the survey included 269 DSCs from Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. This represented a 67% response rate. Indiana had a 100% response rate (n=47). Other states which had at least a two-thirds return rate were Wisconsin (84%; n=37), Ohio
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(83%; n=66), and Minnesota (68%; n=28). Illinois’ return rate was 60%, while Michigan’s response rate was 54%.

**Canvass call subjects.** DSCs in the states of Illinois, Indiana, and Ohio responded to canvass calls. These three states were selected because the Program Support Specialist (PSS) for each of those states were available to assist in the collection of information. Thirty-six DSCs from the state of Illinois participated in the canvass calls, with 31 DSCs participating from Indiana, and 33 DSCs from the state of Ohio. Both Illinois and Indiana PSSs, who conducted the telephone interviews, were housed in the same office as the Region V RAP Director and the RAP evaluator, all of whom were integral members of the research team. The Ohio PSS, based at the subcontract office in Dayton, collected information from the DSCs in Ohio.

**Instruments**

**Survey.** The survey was developed over a period of four months by the Great Lakes Resource Access Project (GLRAP) staff based in Champaign, Illinois. The staff met once a week to discuss and refine the survey. Based on information received from HS staff through personal contacts, previous needs assessments, and identification of national issues, the staff identified three critical areas to survey. The areas were: a) screening and developmental assessment of children; b) developing working relationships with parents with disabilities served in HS programs; and c) the impact of Welfare Reform on HS services. In addition to the core areas, program demographic information, utilization of GLRAP services, and satisfaction with service provided by GLRAP were surveyed. There were eight questions pertaining to working with parents with disabilities on the survey constituting 22% of total questions asked. The questions are listed in Table 1. In addition, a question for statistical analysis was developed based on the inductive reasoning that the size of programs may impact referrals made to community
agencies on behalf of parents with special needs. The question was: Is there a relationship between the size of the program and referrals made to community services for parents with special needs? Extensive program demographic questions also were asked on the survey.

Three Portage CESA #5 subcontract staff, the Regional RAP Project Officer, and two DSCs in the field served as validators by reviewing the survey. The survey was edited and revised several times utilizing the input of these reviewers.

**Canvass Call Questions.** The Indiana PSS developed interview questions with input from the GLRAP evaluator. These interview questions were designed to gain supplementary information to the survey data. The interview protocol was then submitted to the Illinois PSS and the Infant/Toddler Specialist to review and provide comments. Final review and approval was provided by the GLRAP Director. A semi-structured interview format was chosen by the team in order to organize the questions so they elicited similar information to the Needs Assessment Survey, while providing opportunities for participants to elaborate upon their responses. In this way, the canvass calls served to validate as well as supplement the needs assessment data. A standard protocol, two pages in length, was used by the PSS for Indiana, Illinois and Ohio. Questions about parents with disabilities focused on two issues: a) the nature of contact with parents with disabilities within the last year; and b) the availability and nature of written policies related to parents with disabilities. A copy of the canvass call protocol can be obtained by contacting the authors.

**Procedures**

**Survey.** The GLRAP office in Champaign, Illinois, and the CESA #5 subcontract office in Portage, Wisconsin, mailed the surveys. The GLRAP mailed surveys to DSCs in Illinois, Indiana, and Ohio, and CESA #5 sent surveys to DSCs in
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Michigan, Minnesota, and Wisconsin. Reminders were sent to DSCs who had not responded by March, 1997.

**Canvass calls.** Canvass calls were conducted in February and March of 1997. Brief responses were written verbatim on a blank protocol form and longer responses were summarized in writing by the interviewer and verbally reflected to the respondent in order to ensure accuracy. This type of verbal reflection is a form of informal member checking (Lincoln & Guba, 1985) which serves to increase the credibility of the data. Each interview took 20 to 40 minutes to complete. These phone interviews were conducted by the PSSs for their respective states.

**Analysis**

**Survey.** Quantitative analysis was conducted in three steps. First, descriptive analysis was performed to describe the characteristics of programs responding to the survey. Second, analysis of variance (ANOVA) was conducted to investigate associations between the program size (as represented by the number of families served in the program) and responses to survey questions. Program size was divided into five groups. Subgroup 1 represented programs serving 100 or less families; Subgroup 2 programs served between 100 and 201 families; Subgroup 3 between 200 and 301 families; Subgroup 4 between 300 and 401 families; and Subgroup 5 programs served more than 400 families. Third, post-hoc comparisons using the Bonferroni method were performed to determine which specific subgroups significantly differed from each other. The dependent variables were coded in binary terms; hence the comparisons were conducted to test for differences in the percentages of programs responding affirmatively to the dependent variable.

**Canvass calls.** Responses to each open-ended question (e.g., to the question “How are you serving parents with disabilities?”) were tallied for each state. A list of all responses was constructed and responses that were similar in content were grouped under category headings. The number of responses under each category
were tallied. The tallied numbers were divided by the total number of DSCs responding to the questions (i.e., Illinois, n=36; Indiana, n=31; Ohio, n=33) in order to calculate the percent of DSCs who responded in a particular manner to the interview items. In this way, the data was more easily compared to the data collected from the Needs Assessment Survey. Frequent meetings with the research team including GLRAP Director, Coordinator, Evaluator, and the PSS for Illinois and Indiana were held to discuss analysis and findings during the summer of 1997.

**Credibility and Dependability.** This was a complex research project utilizing two sources of data collected via two different methods. The qualitative data included information from the surveys and canvass calls. Several means were used to assure rigor of the qualitative data analysis. These methods included a) investigator triangulation, b) group debriefings, c) methodological triangulation, and d) data triangulation (Denzin, 1989; Lincoln & Guba, 1985; Smith, 1984; Stainback & Stainback, 1988; Taylor & Bogdan, 1984).

**Investigator triangulation** (Denzin, 1989) was accomplished by using multiple investigators and coders to code the open-ended questions on the survey and canvass call. Five members of the staff were involved in the coding activities. They were the Illinois PSS, Indiana PSS, Infant/Toddler Specialist (who was also the Project Coordinator), Project Evaluator, and Project Director. These five members made up the core of the research team. The Project Evaluator took the lead in organizing and coding for themes from Ohio. The Ohio PSS was not involved in any further research activity because of the difficulty in attending regular face-to-face meetings at the Champaign, Illinois, office due to distance. **Group debriefings** (Lincoln & Guba, 1985) were held weekly by the research team to discuss emerging themes from the survey question and compare these to the results of canvass calls. An additional purpose of these meetings was to develop a coherent framework incorporating the results in the contexts of training and technical assistance needed.
and the Revised Performance Standards. Minutes were kept of these meetings. Methodological triangulation (Denzin, 1989) was accomplished by utilizing two or more research strategies to study a topic. In this study, two methods were used (i.e., survey, canvass call telephone interviews). Data triangulation (Denzin, 1989) was performed using data from two sources, which enabled the investigators to combine methods and ask questions about a topic at different times and in different settings (e.g., some of the DSCs individually filled out a survey and participated in a one-on-one telephone interview).

In addition, a two hour summary group debriefing was held in September, 1997, in which all the findings from the two sources of data were compared and a framework for understanding results was developed. This meeting was led by the GLRAP director. All of the data fell into four categories: a) making adaptations/accommodations; b) individualizing services; c) making referrals; and d) policy and procedural issues. Assurance that the data and findings are credible and dependable are supported with the methods and processes described. The next section will discuss results and findings.

Results/Findings

Survey

At least 50% of programs in Indiana, Minnesota, and Wisconsin served in service areas of less than 50,000 people. The majority of programs in Illinois (61%), Ohio (63%), and Michigan (70%) served areas with at least 50,000 people. Extensive demographic information was collected but impossible to report here because of page limitations. For example, the average number of children in classroom-based programs ranged from 220 (Indiana) to 617 children per program (Ohio). The average number of classroom-based teachers ranged from 11 (Indiana and Minnesota) to 24 in Ohio. The average number of families served per program ranged from 214 (Indiana) to 653 (Ohio). The average number of children served in
the home-based option ranged from 22 per program (Indiana) to 73 per program (Minnesota). The number of home-based teachers ranged from two in Indiana to six in Ohio, Minnesota, and Wisconsin. A report summarizing state and regional results of the GLRAP Needs Assessment is available (Bhagwanji & Bennett, 1997).

Descriptive analysis revealed that 85% of DSCS in the six-state region indicated having contact or served parents with disabilities in the past one year. Fifty-eight percent (58%) indicated serving parents with emotional disabilities, 55% indicated serving parents with cognitive disabilities, 48% with parents with physical disabilities, and 45% with parents with sensory impairments.

HS programs in Ohio reported having most the contact with parents with disabilities (92%). At least 80% of programs in each state reported having contact with parents with disabilities: IL (90%), MI (86%), WI (86%), MN (85%), and IN (83%).

The percentage of programs which served parents with sensory impairments ranged from 36% in IL to 57% in MN. The percent of programs which served parents with physical disabilities ranged from 39% in IL to 58% in MI. For parents with cognitive disabilities, the range was 47% in MI to 70% in WI. For parents with emotional disabilities, the range was 53% in MI to 70% in WI.

The majority of programs indicated having good to excellent working relationships with parents with disabilities. However, in terms of specific disabilities, 23% of programs indicated working relationships with parents with emotional disabilities were difficult. Thirteen percent (13%) reported working with parents with cognitive disabilities as difficult. Eleven percent (11%) indicated difficulty working with parents with sensory impairments, and 8% noted working with parents with physical disabilities was difficult.

At least two-thirds of the programs utilized the following strategies when working with parents with disabilities: a) provided or made referrals to community
agencies (85%); b) provided educational information in different ways (78%); and c) provided social support (76%). Forty-eight percent (48%) of programs adapted materials, and 18% used other strategies (e.g., increased access to classroom; used interpreters). More than one-half of the programs referred parents with disabilities to: a) social support services (76%); b) mental health services (72%); and c) self-help skills assistance (53%). Other referrals were made for (a) suspected abuse/negligence (47%), (b) substance abuse services (43%), and (c) leisure/recreation activities (31%).

In response to the questions related to mental health competencies, 24% of programs indicated needing staff training in recognizing symptoms that may indicate a need for further evaluation. Nineteen percent (19%) of programs indicated needing training in interacting with mental health agencies. On the other hand, approximately four-fifths of programs indicated the competence of their staff in the two areas above as good to excellent.

The majority of programs did not have written policies for the involvement of parents of disabilities. Only 12% of programs had written policies for involving parents with emotional disabilities; 12% for parents with physical disabilities; 11% for parents with cognitive disabilities; and 10% for parents with sensory impairments.

The means and standard deviations for referrals made by each subgroup are shown in Table 2. The means, or the percent of programs indicating making referrals, appear to increase as the program size increased in the majority of the referral areas. Indeed, as verified by ANOVA results, referrals made differed by size of program in recreation and leisure services, self-help programs, social services, and substance abuse services (see Table 3). Bonferroni's post-hoc comparisons, however, indicated very few mean differences which were statistically significant at the .05 level. Although trends in the mean differences between many subgroups suggested programs with more families were more likely to make referrals to the
majority of the different community services, there was not enough power to produce statistically significant results.

**Canvass calls**

Analysis of the telephone interview data showed 87% of programs in Indiana served parents with disabilities within the last year. Illinois and Ohio DCSs reported contact with parents with disabilities in 70% of programs in each of their respective states.

In terms of strategies used in serving parents with disabilities, the DSCs reported their staff: a) provided individualized services such as interpreters, companions for person with visual impairment, transportation, home visit, or advocacy (61%); b) made referrals (40%); c) made adaptations in materials, physical environment, or language (35%); d) provided education and training (24%); and e) provided social support (11%). See Table 4 for comparisons among the states.

The interview data validated the written policy data gathered on the survey. None of the 31 DSCs from Indiana reported having involvement policy for parents with disabilities. A high percentage of DSCs from both Illinois (85%) and Ohio (94%) reported having no written policy for parents with disabilities to be involved in their programs.

**Data consolidation**

The consolidation of data from the survey and canvass call telephone interviews fell into four broad categories: a) adaptations staff made; b) referrals staff made; c) individualized support staff provided; and d) issues relating to policies and procedures for the involvement of parents with disabilities.

In the survey data, about one-half of all programs in the six-state region made adaptations when serving parents with disabilities. The interview data corroborated with data found on the survey. The telephone interview results indicated an average of 61% of the programs in Illinois, Indiana, and Ohio made adaptations and
provided accommodations such as wheelchair accessibility, communication systems for parents with hearing impairments, materials in braille, more time for parents to respond, and following up through telephone or home visits.

Eighty-five percent (85%) of programs in the survey indicated making referrals to a variety of community services, especially mental health services (72%) and social support services (76%). In the telephone interviews, an average of 40% of the DSCs confirmed making the most referrals to (a) mental health counseling, (b) social support services, and (c) parent education and literacy classes.

Services were individualized by program staff in a variety of ways. In the survey data, 78% of programs reported that information was relayed to parents in many different ways to ensure understanding. An average of 61% of programs interviewed over the telephone indicated individualizing services. For example, an average of 20% of programs in IL, IN, and OH provided interpreter services at meetings with parents with hearing impairments. Transportation, child care, and frequent visits to homes were other ways individualized services were provided for parents with disabilities. Helping access services and being advocates for parents with disabilities were also roles that staff reported in all three states during the telephone interviews.

Data from both the survey and canvass calls confirmed a critical gap in the availability of written policy for the involvement of parents with disabilities in a great majority of the programs. Of those few programs having written policies, the policies addressed aspects of involvement. For example, the only program in Ohio which indicated involving parents with disabilities in any formalized way reported that the parents' involvement was "addressed in a plan" which described how their needs were to be met. In Illinois, three programs indicated the involvement of parents with disabilities were part of "parent involvement policy and procedures by
components." No programs in Indiana indicated having written policies about involvement of parents with disabilities during the telephone interviews.

Discussion and Implications

Parents play an integral role in HS, from serving on the Policy Council, forming parent committees, volunteering in classrooms, to taking part in education or parenting classes. Given the importance of involving mothers and fathers in programming, it is imperative that HS programs consider the needs, as well as rights, of parents with disabilities. Inclusion extends, not only to children with special needs, but adults who may require assistance, modifications, or sign language interpretation to accommodate their involvement in program activities. Parents with disabilities are protected under ADA.

The findings from the current study indicate that programs serve parents with disabilities in a variety of ways. These may range from simple referrals to community health or public aid, counseling services, to providing materials in braille or sign language interpretation. With these actions come certain implications for every program, regardless of the activities and services rendered for parents with special needs. These implications can be summarized into four general areas: a) relationships; b) adaptations and modifications; c) policies and procedures; and d) staff training issues.

Relationships with parents with disabilities

Over 80% of HS programs indicated serving parents with disabilities through the referral system to their mental health agencies, public health departments, adult education programs, or similar community resources. Defining contact as a brief encounter and working relationships as a more complex and prolonged series of interactions, HS programs provide parents with various types of activities designed to build relationships. These activities range from support groups for parents of similar needs and abilities to consistent invitations to staff trainings on various
Welfare reform and the new federal work mandates for parents on public assistance, however, may make relationship building difficult due to the amount of time and resources that parents with disabilities may have available to them (Bennett, et al, 1998). Cuts in assistance will likely impact the quality of life of parents with disabilities and their children. It is unclear at this time how the states will determine exemptions as well as access to needed services by families facing multiple challenges. On the other hand, with the advent of the Americans with Disabilities Act (U.S. Department of Justice, 1990) and its employment protections, parents with different abilities may feel more comfortable working and volunteering in programs where staff with disabilities are employed. Federal regulations assure non-discrimination on the basis of a disability. HS programs already adhere to the regulations stipulated in the ADA as they apply to programming for children with disabilities by providing accessibility, special accommodations and services, and transportation. Program directors are cognizant of the requirements indicating that accommodations or adaptations, within reason, must be made for children. However, they may not have thought about the need for similar considerations for parents with disabilities. When parents with special needs have children enrolled in HS programs, a new dimension is added to the considerations directors must give to the inclusion of adults in the wide range of activities provided in HS and to the employment of staff in the program.

It would be of no surprise to find that parents with disabilities feel more comfortable in a program with such a premise toward its hiring and planning procedures for adults involved in the program, whether staff or parents. HS has always emphasized the importance of family influence on child development in the
home and in preschool and infant/toddler programs. The Revised Program Performance Standards (U.S. DHHS, 1996) reiterate the strong parent involvement focus of HS programs and magnifies the relationship to be established with parents. There must be a collaborative partnership-building with parents based on the family’s readiness and willingness to develop a Family Partnership Agreement specifying goals, responsibilities, and timetables. In addition, current and former HS parents are to be given preference for employment when there are vacancies for which they are qualified. These standards create important implications for HS administrators and staff as they plan for inclusion of parents with disabilities who have children in programs.

Consideration of special accommodations for parents with special needs may include budget implications. Programs need to plan in advance for the economic ramifications of purchasing resources for family resource centers, resource libraries, or classroom adaptations. Some of the resources may include: materials in Braille, books delineating issues relating to disabilities for children and adults, or educational materials and adaptations for working with children with disabilities. Some parents volunteering in programs may require modifications in the actual environment, such as ramps in the entryways, wider floor space for wheelchairs between centers in classrooms, or interpreters for the deaf or hard of hearing for those attending meetings or needing to communicate with staff or children. All of these examples impact the budget, and must be planned for in advance.

It was no surprise that a large percentage of programs indicated having no written policies or procedures in place about dealing with parents with disabilities, particularly those with emotional or cognitive needs. The ADA has raised the awareness of many administrators to the needs of persons with sensory (e.g., hearing or vision) or orthopedic impairments pertaining to interpreters for the deaf or physical accommodations. Parents with emotional or cognitive difficulties,
however, face a much stronger battle in educating staff and other adults to their needs.

**Adaptations and modifications**

It is imperative to the operation of any quality program that special consideration be given to the uniqueness of a family member with a disability. The modifications which are necessary in daily family life and the home physical environment also must be applied to enabling parent involvement in their children's program. The results indicated that having parents with disabilities attend school functions or participate in program activities require advanced planning and a certain sensitivity which goes beyond what typical parents need in order to fully participate. Adjusting program schedules or allowing for extra time or space in the classroom environment permits the parents to become more fully involved and integrated into the program itself. The advantages that generalize to all children being around individuals with disabilities are enormous in their scope as well.

**Policies and procedures**

Individuals with diagnoses reflecting emotional issues face stigma in many communities. In part due to misunderstanding about depression or mental illness or prejudice, many program staff find themselves being challenged with issues and meeting the unique needs of parents with disabilities. Simply acknowledging parents' condition is not enough to ensure parent involvement and more optimal outcomes for children. Changing preconceived attitudes of staff about parenting or involvement based on disability is the first of many steps to ensure stronger collaborative relationships with parents, especially families experiencing mental illness.

Parents with cognitive impairments face similar prejudices in communities, in that their mental capacities are judged to be predetermined, and thus are not
provided with the encouragement or motivation to pursue developmental or educational activities with their children. It is imperative that staff use scaffolding teaching techniques with parents diagnosed as having cognitive disabilities. Scaffolding techniques can motivate and challenge parents by providing successful experiences in the caretaking of their children. Specific examples of scaffolding techniques include (a) helping parents regulate difficult feelings or experiences, (b) providing parents varying and multiple contexts to practice higher-order thinking skills, and (c) increasing responsibility and independence in caretaking.

Having strong collaborative partnerships with parents is key to maintaining quality programs. All parents, including parents with differing abilities and capacities, have a right to belong and be integrated into the total program, ranging from attending children's functions and events to making decisions about program policy. Staff must enable parents with disabilities to feel comfortable in getting involved.

By having an established and written policy concerning parent welfare, involvement, issues relating to parents with specific disabilities, and procedures for staff on handling these issues, programs can make a strong statement about their commitment to parent involvement. The policies need to be developed thoughtfully, incorporating multiple perspectives, and implemented fully in order to have the total investment of both staff and families. Parent involvement is likely to be more invested when parents with disabilities play an active role in setting policies.

HS programs already have a strong concentrated focus on parent involvement. While the recent federal welfare-to-work mandate may make it more difficult for many parents to be involved (Bennett, Bhagwanji, Thomas, & Allison, 1998), HS programs must continue to create and provide opportunities for parents to be intricately involved in their children's development. In addition to specifying
opportunities and flexibility that can be offered, written policies must also address issues relating to the prevention of misunderstandings and conflicts because of its possible long-term effects on children, families, and staff. Flexible and individualized relationships, and making adaptations and modifications, have critical implications for staff development.

Training

HS programs have a strong history of providing training opportunities for staff development. Training needed may be delivered through the National Training and Technical Assistance (T/TA) network of Quality Improvement Centers (QICs), other collaborative training entities specific to states, or the utilization of National Training Guides. Programs must incorporate professional development plans for entire programs as well as individual staff members. Issues addressed in this study relating to relationships with parents with disabilities, adaptations and modifications, and policies and procedures provide a strong impetus for the type of staff development needed in programs serving children and families.

The national Head Start network is committed to bringing a sense of excellence in training and preparing HS personnel for working closely with families (U.S. DHHS, 1996). The QIC network, including Quality Improvement Centers for Disabilities, are specifically charged with the role of assisting programs and staff develop strong ties with families. This will be administered through opportunities for on-site training with consultants, on-site technical assistance relating to individual program need, continuing education for management staff, credits for Child Development Associate (CDA) degrees, and training for teachers and home-visitors.
Conclusion

This article summarized the results of a multimethod process to ascertain the extent HS staff (a) had contact with parents with disabilities, (b) used innovative strategies with this population, (c) felt confident or competent in interacting with families, and (d) had written policies to guide the involvement of parents with disabilities.

Results of this study indicated that over 80% of HS programs served parents with disabilities. HS programs made modifications and adaptations when serving parents with disabilities. Few programs, however, had written policies and procedures for involving parents with disabilities in HS activities. Key areas for improvement include increasing resources and employability of parents with disabilities. Future endeavors in HS training should include (a) assisting HS programs develop and implement involvement policies specific to parents with disabilities, and (b) teaching about effective practices when working with parents with disabilities.
Table 1. Survey questions about parents with disabilities.

1. Did your program have any contact\(^1\) or serve parents with disabilities within the last year? (This contact could be minimal.)

2. How would you describe your staff's working relationship\(^2\) with parents with disabilities? (Working relationship means consistent and continuous interaction.)

3. What strategies have been used to work with parents with disabilities?

4. How would you rate your staff's confidence/competence level in interacting with parents with disabilities?

5. How would you rate your staff's confidence/competence level in identifying symptoms that may indicate a need for mental health evaluation of parents?

6. How would you rate your staff's confidence/competence level in interacting with mental health agencies?

7. In what areas were referrals sometimes made for parents with disabilities?

8. Do you have written policies concerning involvement of parents with disabilities?

---

\(^1\) Contact is defined as at least one interaction, formal or informal, direct or indirect, with a parent.

\(^2\) Working relationship is defined as the quality of interactions and opportunities for building closer ties with parents.
Table 2. Means and Standard Deviations for Each Subgroup

<table>
<thead>
<tr>
<th>Variable</th>
<th>Subgroup 1 (programs serving 100 or less families)</th>
<th>Subgroup 2 (programs serving between 101 and 200 families)</th>
<th>Subgroup 3 (programs serving between 201 and 300 families)</th>
<th>Subgroup 4 (programs serving between 301 and 400 families)</th>
<th>Subgroup 5 (programs serving more than 400 families)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to Child Abuse &amp; Neglect Agencies</td>
<td>M1 (SD1) n=43</td>
<td>M2 (SD2) n=42</td>
<td>M3 (SD3) n=40</td>
<td>M4 (SD4) n=27</td>
<td>M5 (SD5) n=66</td>
</tr>
<tr>
<td></td>
<td>.419 (.499)</td>
<td>.429 (.501)</td>
<td>.626 (.506)</td>
<td>.593 (.501)</td>
<td>.545 (.502)</td>
</tr>
<tr>
<td>Referral to Recreation &amp; Leisure Services</td>
<td>.233 (.427)</td>
<td>.214 (.415)</td>
<td>.350 (.483)</td>
<td>.519 (.509)</td>
<td>.424 (.498)</td>
</tr>
<tr>
<td>Referral to Mental Health Services</td>
<td>.762 (.431)</td>
<td>.625 (.490)</td>
<td>.842 (.370)</td>
<td>.815 (.396)</td>
<td>.828 (.381)</td>
</tr>
<tr>
<td>Referral to Self-Help Programs</td>
<td>.442 (.502)</td>
<td>.429 (.501)</td>
<td>.575 (.501)</td>
<td>.630 (.492)</td>
<td>.712 (.456)</td>
</tr>
<tr>
<td>Referral to Social Services</td>
<td>.651 (.482)</td>
<td>.590 (.468)</td>
<td>.825 (.385)</td>
<td>.926 (.267)</td>
<td>.803 (.401)</td>
</tr>
<tr>
<td>Referral to Substance Abuse Programs</td>
<td>.326 (.474)</td>
<td>.286 (.457)</td>
<td>.500 (.506)</td>
<td>.593 (.501)</td>
<td>.515 (.504)</td>
</tr>
</tbody>
</table>
Table 3.
F-Test Results for Between Groups.

<table>
<thead>
<tr>
<th>Variable</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to Child Abuse &amp; Neglect Agencies</td>
<td>.886</td>
<td>.473</td>
</tr>
<tr>
<td>Referral to Recreation &amp; Leisure Services</td>
<td>2.838</td>
<td>.025*</td>
</tr>
<tr>
<td>Referral to Mental Health Services</td>
<td>1.863</td>
<td>.118</td>
</tr>
<tr>
<td>Referral to Self-Help Programs</td>
<td>3.138</td>
<td>.016*</td>
</tr>
<tr>
<td>Referral to Social Services</td>
<td>2.491</td>
<td>.044*</td>
</tr>
<tr>
<td>Referral to Substance Abuse Programs</td>
<td>2.827</td>
<td>.026*</td>
</tr>
</tbody>
</table>

*p > .05
Table 4
Strategies used by DSCs when serving parents with disabilities (telephone interview).

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Illinois (n=36)</th>
<th>Indiana (n=31)</th>
<th>Ohio (n=33)</th>
<th>Total (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provided individualized services such as interpreters, companions for persons with visual impairments, transportation, home visit, or advocacy</td>
<td>22 (61%)</td>
<td>27 (87%)</td>
<td>12 (36%)</td>
<td>61 (61%)</td>
</tr>
<tr>
<td>Made referrals</td>
<td>10 (28%)</td>
<td>16 (52%)</td>
<td>14 (42%)</td>
<td>40 (40%)</td>
</tr>
<tr>
<td>Made adaptations in materials, physical environment, or language</td>
<td>14 (39%)</td>
<td>11 (36%)</td>
<td>10 (30%)</td>
<td>35 (35%)</td>
</tr>
<tr>
<td>Provided education and training</td>
<td>6 (17%)</td>
<td>10 (32%)</td>
<td>8 (24%)</td>
<td>24 (24%)</td>
</tr>
<tr>
<td>Provided social support</td>
<td>2 (6%)</td>
<td>4 (13%)</td>
<td>5 (15%)</td>
<td>11 (11%)</td>
</tr>
</tbody>
</table>
References


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