

# **Access to Head Start Programs for Families with Disabled Parents**

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# ACCESS TO HEAD START FOR PARENTS WITH DISABILITIES

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# **ACCESS TO HEAD START FOR FAMILIES WITH PARENTS WITH DISABILITIES**

This paper summarizes the information gathered during a preliminary investigation conducted for the Research and Training Center on Families with Adults with Disabilities (RTC) at Through the Looking Glass. Funded by the National Institute on Disability and Rehabilitation Research, one of the major goals of the RTC is to conduct research that can improve services and public policy for families in which one or both parents has a disability. The purpose of this exploratory research project is to begin examining the degree to which parents with disabilities have access to the Head Start program for their children and how the expansion of Head Start in the Clinton Administration could be shaped to improve this access by:

- (1) ensuring that Head Start outreach activities target and reach parents with disabilities;
- (2) ensuring that the Head Start curriculum complements parents' abilities; and
- (3) ensuring that parents with disabilities are invited to participate in the same way that non-disabled parents are.

## **OBJECTIVES**

This project has been guided by several key objectives:

- (1) To review analysis of the policies governing Head Start, examining the ways in which the program does or does not take into account the needs of parents with disabilities;
- (2) To identify several local Head Start programs and interview program staff to understand what makes them successful or unsuccessful at involving parents with disabilities; and
- (3) To prepare a report summarizing this information that can be used by program operators, advocates, and policy makers in their efforts to enhance the ability of Head Start programs to meet the needs of families with disabled parents.

## **INTRODUCTION**

For the last thirty years, Head Start has served low-income children in the cities and rural areas of America by focusing on the whole child. In what is known as the Head Start “family involvement model,” teachers visit each child’s home and collaborate with a team of social service specialists to design an individualized plan for the child’s cognitive and social development. Family Advocates work with each child’s family, encouraging parents to act as the child’s primary teachers and often referring parents to social service and employment programs (Sissel, 1997).

Over the years, researchers and community members have alerted Head Start programs to the specific needs of many types of families, ranging from migrant workers following the crops to homeless families in urban settings. Head Start has responded to many of these needs by creating a variety of programs with varying hours and duration in order to accommodate different schedules and living conditions of families, and creating a home-based option designed for younger children (under three years old) and children in “special circumstances” (Roberts and Wasik, 1994). The Head Start Bureau has also created innovative programs designed to provide more comprehensive services to families, such as the Head Start Family Service Centers, day care facilities which also focus on issues such as substance abuse, unemployment, and illiteracy (Besharov, 1992).

Although Head Start has made considerable progress in accommodating families with a wide range of challenges, there are still a number of relatively common disadvantages that the program does not address in detail. One of the most important but least discussed of these disadvantages is the set of problems faced by families with disabled parents. The prevalence of such families is surprisingly high; according to 1993 census data, approximately seven million parents aged 18 to 64 have disabilities (Toms Barker and Maralani, 1997). These families are more likely to be lower income than the families of non-disabled parents. Children of disabled parents may also be more likely than children of non-disabled parents to have special needs that can be addressed through early intervention. Despite their widespread existence, however, Head Start has no specific policies designed to address the needs of these families.

Many families with disabled parents face the same problems that other Head Start and low-income families often confront: violence, crime, unemployment, underemployment, poor health care, poor nutrition, inadequate housing, and even homelessness. Parents with disabilities and their children also face a second set of challenges as well. They may have difficulty finding housing that is not only affordable but also accessible, and they may not be able to find or maintain employment. Many parents with disabilities face obstacles when trying to find and obtain the social services they need (Toms Barker and Maralani, 1997), and they may need extra assistance with household tasks as well. Children of parents with disabilities encounter their own challenges in the classroom as a result of their parents’ disabilities. For example, deaf parents may need help developing their children’s verbal and language skills, while children of parents with physical disabilities may require assistance to develop advanced motor skills through such activities as riding a bike or participating in team sports.

In this paper, we examine the extent to which the Head Start program and its family involvement model currently address the needs of children in families with one or more disabled parents. We explore what a few sample Head Start sites are doing to make the program available to parents with disabilities, and we begin to identify the factors that affect a site’s ability to deliver effective services to children of disabled parents. Following our examination of present efforts, we look ahead to see what effect emerging trends will have on the participation of parents with disabilities in the program. We conclude by noting that although Head Start does not currently focus on meeting the needs of families with disabled parents, it can easily adapt to accommodate these families, and we present some ideas on how to achieve this accommodation.

## I. HOW HEAD START HAS SERVED PARENTS WITH DISABILITIES AND THEIR CHILDREN

Head Start has served parents with disabilities and their children through its highly individualized programs. With the attention of teachers and social service staff focused on each family's individual circumstances and situation, the needs of children and family members are addressed as they arise on a one-by-one basis. This individualized attention has allowed parents with disabilities and their children to have their needs met in several areas, including admissions and outreach, classroom activities, and child and family social service availability.

### ADMISSIONS AND OUTREACH

Head Start was created with a mandate to serve children with disabilities and special needs and to conduct extensive outreach in order to reach those children who are most in need of the program's services. A full ten percent of Head Start students are required to be children with special needs. Once diagnosed as disabled, children with special needs receive a priority for entrance into the program and a waiver on the income requirement. The definition of special needs or disabilities is as follows:

*Children with disabilities means children with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairment or specific learning disabilities who, by reason thereof need special education and related services. The term "children with disabilities" for children aged 3 to 5 inclusive, may, at a State's discretion, include children experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, or adaptive development; and who by reason thereof, need special education and related services.*

(45 CFR Part 1305.2, (a))

There are two ways in which children of disabled parents can gain priority entrance to Head Start. First, children of disabled parents may have disabilities of their own. According to the recent RTC National Survey of Parents with Disabilities, almost 14% of parents with disabilities have disabled children, as compared to only 3% of non-disabled parents. Second, children of disabled parents may be classified as disabled if their parent's limitations have contributed to a significant delay in their own development; for instance, if children of deaf parents have delayed verbal abilities, they may be classified as disabled. This classification of children of disabled parents as themselves disabled allows Head Start to waive the income requirement if necessary and ensures the child a priority for enrollment. However, since parents with disabilities are disproportionately likely to be poor (Toms Barker and Maralani, 1997), the question of waiving the income requirement may rarely arise.

Children who do not qualify as disabled may, in some locations, gain priority for enrollment because of their parent's disability. A number of Head Start programs, including, the 55-site program in Santa Clara County,

California and the 11-site program in Fremont, California, assign priority to children whose applications demonstrate a social service need or a special need within the family. This designation offers a lesser degree of priority than that given to children with disabilities and seems to be applied on a case-by-case basis with careful consideration of each child's individual need. The case-by-case nature of many enrollment and admissions policies indicates a need for extensive awareness training, especially for teachers and social service specialists with little exposure to disabilities. In the provision of effective family support services, it is clearly important for an intake specialist to understand that parental disabilities may potentially affect a parent's need for services.

Head Start operates under a mandate to perform extensive outreach in order to ensure that the neediest children are served. Other agencies, particularly those that provide disability-related services, often refer parents with disabilities to Head Start. Outreach to parents with disabilities therefore consists in part of outreach efforts to these potential referring agencies. For example, Head Start staff members at the Santa Clara Head Start find that they are able to do much of this networking by attending conferences and seminars about different social service issues affecting children. They frequently connect directly with service providers and form personal relationships with them so that they and their agencies can then easily refer parents to Head Start. Reaching parents with disabilities who are not already affiliated in some way with a social service agency or advocacy organization would undoubtedly prove more difficult, and might require some form of coordinated effort with schools or other mainstream organizations on a regional or state level.

## **INSIDE THE CLASSROOM**

Because the Head Start model focuses on the individual needs of each child, the classroom instruction and Head Start curriculum are designed to provide each child with a highly individualized education. This individualized plan allows children to move at their own pace while also allowing teachers and Head Start staff to accommodate any child's special needs. With the required home visits that are a centerpiece of the Head Start model, social service specialists get a chance to learn about each child in the context of the family's situation. They can then offer each child the instruction and services that he or she needs, including extra help in areas such as behavior modification, language skills, and cognitive and social development. Home visits also allow teachers and social service specialists the opportunity to get to know family members and learn about disabilities or special needs that the parents or siblings of a Head Start child may have. Once the teacher and the social service specialists are aware of the parents' situation, they are able to adapt the child's individualized plan to address specific problems.

Because the Head Start curriculum is based on an individualized educational plan, it is not difficult for a teacher to request specific educational specialists to work with a child. For example, a Disability Coordinator at a Head Start program in Berkeley, California, related the experience of one teacher who worked with several children who had deaf mothers. Finding that the children were often uncommunicative, the teacher arranged for a speech therapist to see the children. Most Head Start sites have a social service staff member who specializes in working with children with disabilities. While this position is called "Disability Coordinator" at many sites, some programs,

including the Head Start program in Santa Clara County, have recently changed the position title to “Child Development Coordinator.” The change came about, in part, because staff members realized they were often working with children with relatively minor delays, including children who had delays stemming from their parent’s disability.

In some programs, the development of an individualized educational plan begins even before the child has entered a Head Start classroom. A Child Development Specialist at Santa Clara Head Start detailed the typical intervention process staff members engage in with each child by relating an anecdote. Aware that a child’s mother had a developmental disability and that the child might need some specific types of individual attention in the classroom, staff members from Head Start arranged a home visit during the summer before the Head Start session began. Although a teacher is generally present at a home visit in addition to the social service staff, one was not able to attend in this case because it was the summer. Instead, the Child Development Specialist and the Social Services Specialist conducted a home visit with the intention of reporting their findings back to a teacher at the beginning of the Head Start session. Also aware that the mother was being served by a local agency for people with developmental disabilities, the Head Start staff arranged for representatives from that agency to be present at the home visit in order to fully discuss the child’s family situation. After observing the child’s behavior at home and speaking with service providers from the agency for developmental disabilities, the Child Development Specialist and the Social Services Specialist concluded that the child’s problems, including behavior problems, were not severe enough to warrant immediate measures such as the assignment of a personal aide to the child. Instead, the child was observed closely and evaluated periodically. Again, as with enrollment policies, the fact that Head Start staff operate on a case-by-case basis as an interdisciplinary team requires that both social service and teaching staff be well trained and able to recognize children’s needs, including any that stem from their parents’ disabilities.

## **FAMILY INVOLVEMENT**

Another important aspect of the Head Start model is family involvement. This includes not only the participation of Head Start parents in the classroom, but also in the management and development of the Head Start program. Parents participate in the classroom and in workshops designed specifically for them in order to learn how to serve as their children’s primary teachers. To varying degrees at different sites, parents are also able to play a role in the direction of the program, either as teachers, staff, or advisory board members.

Because parental participation is such an integral part of Head Start, it is important that Head Start staff make the programs and activities accessible to all parents. While many Head Start sites provide sign language interpreters for deaf parents, not all parents with disabilities are able to fully participate in Head Start’s parent activities and programs. For instance, in an attempt to serve physically disabled parents who have difficulty reaching a Head Start site, the program may offer to provide home-based services. This, however, may not be a suitable alternative if the activity’s goals include social interaction and discussion with other Head Start parents. When

conducting home visits and evaluating a child's development, the Head Start social service staff must work with parents to identify ways to accommodate any special needs that arise from their disabilities.

Another important type of family involvement is the inclusion of Head Start parents as teachers and other staff in the Head Start program. This inclusion not only allows parents a degree of control within the Head Start site, but it also offers parents with low levels of education the ability to acquire experience in child development and strengthen their employability by earning degrees such as the Child Development Associate (CDA) degree. Precisely because this involvement in Head Start can lead to increased career opportunities and greater family stability, it is important that parents with disabilities have the opportunity to serve as teachers and staff if they wish.

## **SERVICES FOR CHILD AND FAMILY**

While Head Start does not provide social services directly, either to children enrolled in the program or to their family members, such services do play an important role in the Head Start model. As mandated,

*All grantees must identify, secure and use community resources in the provision of services to Head Start children and their families prior to using Head Start funds for these services.*

(45 CFR, Part 1306, Sec. 1306.30, Subpart C--Head Start Program Options, (d))

Head Start social services staff routinely make referrals for a variety of social services. Working under a case management system, Family Advocates are trained to find the services that best suit each family.

While the social service staff at most Head Start sites are extremely knowledgeable about public assistance, housing, literacy, job training, and addiction resources, they may not be as familiar with services for people with disabilities or aware of each service provider's level of accessibility and accommodation for disabled people. It is important that these staff receive disability awareness and community resource training so that they can effectively refer parents with disabilities to the appropriate services. Several Head Start programs report that parents with disabilities are usually already working with an agency and knowledgeable about such services. In fact, many of these parents come to Head Start through referral from an agency they already go to for services. It may be more important, then, for staff to be aware of the difficulties faced by disabled persons than to know about the services available to them.

## **II. FACTORS THAT AFFECT A PROGRAM'S ABILITY TO PROVIDE EFFECTIVE CARE FOR CHILDREN OF PARENTS WITH DISABILITIES**

In order to fully understand the factors that affect programs' effectiveness in serving disabled parents, it would be necessary to conduct much more extensive research than was feasible for this preliminary study. However, through our review of Head Start literature and interviews with program staff, we have identified several factors that appear to have a strong influence on the degree to which a site is able to accommodate parents with disabilities, including:

- (1) the extent to which the site or program staff have experience in serving disabled children;
- (2) the strength of the overall outreach effort; and
- (3) the degree to which staff are trained and aware of the needs of the disabled.

### **EXPERIENCE SERVING CHILDREN WITH DISABILITIES**

There are two important aspects of programs' experiences in serving children with disabilities that can carry over to how well they are able to serve families with disabled parents: (1) physical and programmatic access to Head Start services and facilities, (2) the development of referral networks of agencies providing disability-related services. In order to adequately serve children with disabilities, Head Start programs work to make their sites more accessible—both in terms of physical access and curriculum access. Improved physical access can include locating facilities at ground level, building ramps with gradual inclines, and providing elevators in multi-storey buildings. Enhanced curriculum access entails providing sign language interpreters or producing materials in alternative formats, strategies that allow children with disabilities to learn from the same curriculum that other children do. However, the improved physical and curriculum access that accommodates disabled children can be equally effective in accommodating disabled adults. Improved facility access and alternative material formats increase disabled parent participation in the classroom just as they do with disabled children. Thus, the degree of experience that a site has in serving children with disabilities affects its ability to serve parents with disabilities.

In addition to increased access, sites that serve disabled children also tend to have well developed referral networks. Developing such a network generally requires extensive knowledge of community resources available to disabled persons as well as close ties to the agencies that provide these resources. While this knowledge and these working relationships do not affect the program directly, they help to ensure that children with disabilities receive the full range of social services available to them. Likewise, parents with disabilities can also benefit from the program's referral services since they are served by many of the same agencies. We therefore expect that sites with experience

in referring disabled children are also skilled at referring disabled adults. Once parents receive aid for their disabilities, the impact of these disabilities on their children may diminish.

## **OUTREACH PRACTICES**

Although Head Start has no specific mandate to serve children of parents with disabilities, those children often fall among those that the program generally targets. The more extensive the outreach effort of each Head Start site, the greater the chance that the site will enroll children whose parents have disabilities. A varied outreach effort, targeted towards social service agencies and those who are not already receiving services, is important. The outreach effort for children with disabilities can also include outreach targeted at parents with disabilities as well. The Berkeley Head Start, for example, aims to serve both children and parents with disabilities by targeting area agencies such as the East Bay Regional Center. As the staff members at the Santa Clara Head Start have learned, staff training and development opportunities that take place outside the Head Start site can allow for networking with other social service providers and possibly increase the number and diversity of people referred to Head Start.

## **STAFF TRAINING**

Another factor that may be important to a program's ability to adapt to the needs of disabled parents is the educational background, training, and experience of the staff. Some programs emphasize hiring staff with advanced degrees, but most do not. As Roberts and Wasik point out,

*Consistent with their mission of being involved in the communities they serve and providing employment within those communities, 90% of [home-based] Head Start programs [have] minimum education requirements below the bachelor's level, including the High School Diploma, GED, Child Development Associate Certificate (CDA), and Associate of Arts degree* Roberts and Wasik, 1994

It is reasonable to expect that programs not based in the home might have slightly higher requirements for teaching positions, but these figures indicate a relatively low level of academic achievement across all Head Start programs. While employing parents and community members with lower levels of education may further Head Start's goals of community and parent involvement, researchers have charged that these teachers and staff members do not receive adequate training or provide the best services. In her analysis of parent involvement, Sissel writes that "at any one time...upwards of 40% of programs are substandard due to lack of competent staff" (Sissel, 1997).

A general background in child development is important for the delivery of effective services, especially for children who face special challenges as a result of their parents' disabilities. Since they will work with parents and children who have a wide variety of disabilities, it is also important that staff members have a broad base of knowledge about child development. Specifically, it is critical that staff members, even those who are trained and knowledgeable about children with disabilities, learn about the common obstacles that parents with disabilities face. Some programs emphasize in-service training for staff members, while other programs emphasize collaboration with different agencies as an approach to keeping up to date with community resources.

For example, like a number of Head Start programs, Fremont's 11-site program operates on a 4-day school schedule. On the fifth day, teachers and social service staff receive in-service training from a variety of specialists and outside consultants. This training covers a wide range of topics, but at least several sessions a year deal with issues regarding disability. A small Head Start program, run in Alameda, California by Xanthos, has reached out to local advocacy groups and universities in order to provide staff with disability awareness training.

### **III. CONTEXT AND FUTURE: HOW PARENTS WITH DISABILITIES MIGHT BE SERVED IN A CHANGING HEAD START**

When Head Start was first proposed in the mid-1960s, it was designed as a comprehensive early childhood education program for low income children with little access to pre-school education. This comprehensive aspect of the program meant that it not only aimed to provide disadvantaged children with increased social and cognitive development, but also with a wide range of health services: immunizations, check-ups, and preventive medicine. Another key component was the family involvement aspect of Head Start. Greater family involvement in the program, its founders reasoned, would translate into increased performance from the children.

As Head Start has developed over the years, however, the comprehensive nature of the program has come to mean that Head Start serves not only the children of low-income families, but the families themselves as well. The role of social services in the Head Start model has changed considerably in the years since the program first began. As parents in low-income families increasingly faced chronic problems such as an unemployment and drug abuse, Head Start Family Advocates and social service specialists found that a major component of their work included making referrals to other agencies for housing, educational, and employment services. As a result, Head Start has increased its focus on family needs, creating special programs designed to improve the health care of siblings or combat drug and alcohol addiction among parents (Besharov, 1992).

With the rise of visible national problems such as violence and drug abuse in poor communities, policy makers have looked to programs like Head Start to expand their focus from the child to the family as a whole. The model emerging now for Head Start is a comprehensive child care program that also incorporates greater family participation and increased coordination of services with other agencies and providers. Already, Head Start has developed several pilot programs with these goals, including a Head Start model known as the Family Service Center. Funds have been awarded to 66 Head Start grantees for the purpose of demonstrating ways that Head Start programs can work with other community agencies and organizations to effectively deal with problems of substance abuse, illiteracy, and unemployment among Head Start families. The projects will encourage families to participate in activities designed to accomplish three goals: reduce and prevent the incidence of substance abuse in Head Start families, improve the literacy of parents and other adults in Head Start families, and increase the employability of Head Start parents (Gage and Workman, 1994).

This new model for Head Start could be beneficial for parents with disabilities. With a greater emphasis on children's families and circumstances, Head Start staff members may become more aware of the needs of a Head Start child and his or her family that stem from a parent's disability. Head Start staff members could direct families to accessible agencies and help them obtain services that might have been difficult to find earlier.

On the other hand, the new model may also offer some challenges in serving parents with disabilities. For example, an emphasis on offsite services for families may make the Head Start programs themselves less likely to ensure that their own parental activities and opportunities within the site will be accessible.

## **SUMMARY AND IMPLICATIONS**

In reviewing the needs of disabled Head Start parents and their experiences with Head Start's family involvement model, it is our hope that each site's Family Advocates, Social Service Specialists, Child Development Specialists, and other social service staff become familiar with the services available to disabled adults and can refer the parents to the proper agencies. While our research suggests that at least some parents with disabilities are being accommodated on an individual basis due to the concerted efforts of Head Start staff, it is not clear that there are any systems in place to ensure that disabled parents participate extensively in Head Start or benefit fully from the social service aspects of the program. The apparent lack of written policies and regulations directly addressing parents with disabilities is particularly disturbing. Without such policies, there will almost certainly be some families with disabled parents who fall through the cracks.

Despite its current shortfalls, however, Head Start appears to have the potential to fully accommodate parents with disabilities. For example, the program's traditional flexibility and accommodation is well suited to meeting the needs of families with disabled parents. As our preliminary investigation revealed, Head Start already has many of the components necessary to serve disabled persons: outreach networks, access to educational specialists, individually tailored educational plans, and close ties to a range of social services. Head Start's inability to fully address the requirements of disabled parents therefore appears to stem not from the program's inherent structure but rather from a lack of awareness regarding the needs of parents with disabilities. Our interviews with Head Start administrators, for example, revealed that they were unaware of the fact that placing their offices on the upper floors of a building with no elevators can make them inaccessible to disabled parents. Unfortunately, our experience suggests that this lack of awareness may be the rule rather than the exception.

Current efforts and the underlying structure of the Head Start program help ensure that only evolutionary, rather than revolutionary, changes are necessary to accommodate disabled parents and their children. Through our observations of a small sample of programs, we suggest a number of implications that merit further consideration, investigation, or implementation:

- C Organizations responsible for evaluating the Head Start program should include in their evaluations measures of the degree to which grantees meet the needs of parents with disabilities. This step is necessary to determine both how much improvement is necessary and what changes would be the most effective.
- C A more thorough review of Head Start programs should be conducted to identify effective and promising practices that can provide a basis for system-wide improvement.

- C Like many other social service systems, Head Start may lack disability awareness or expertise. Written policies that explicitly mention families with disabled parents can help raise awareness and provide a consistent framework for accommodating these disabilities.
  
- C Staff and administrators of Head Start programs should receive training in the Americans with Disabilities Act and the program's associated responsibilities for accommodating individuals with disabilities. This training would give personnel increased sensitivity to disability issues as well as some of the knowledge needed to address these issues effectively.

While we cannot accurately predict the magnitude of the potential benefits of these recommendations, we believe that they provide a solid basis for moving forward with future research and program improvements.

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