

## Towards an Understanding of the Impact of Welfare Reform on Children with Disabilities and Their Families: Setting a Research and Policy Agenda

Elisa A. Rosman, Hirokazu Yoshikawa, and Jane Knitzer

Summary

Increasing attention is being paid to the question of how special populations are affected by welfare reform. One subgroup that has been largely ignored in research concerning the effects of welfare reform on children and families is that of children with disabilities and their families. In order to address this gap in both policy and research, this paper aims to develop a research agenda that will inform both the policy and research worlds by developing policy-relevant data, spurring those in welfare and policy fields to consider individuals with disabilities and their families when designing research and creating policies, and spurring those in disability-related fields to consider the effects of poverty and its attendant policies. This paper discusses these central questions:

- 1. What do we already know about families who are on welfare and have children with disabilities?
- 2. What are the developmental processes through which we expect the challenges of welfare reform to affect these children?
- 3. What changes in current policy and practice are feasible and would work towards increased self-sufficiency and increased quality of life for these families?

The paper concludes with research questions and preliminary policy recommendations to stimulate active consideration of a population that is too often ignored in consideration of welfare and anti-poverty policy.

## Social Policy Report

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# From the Editor

It is a pleasure to present the third Social Policy Report in a series on welfare reform, children and families. The first, by Reichman and Mclanahan, examined effects of welfare reform experiments that were precursors to the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA). The second, by Morris, summarized the findings from the experiments following the PRWORA, in terms of child well-being. The third, by Rosman, Yoshikawa, and Knitzer, focuses on a specific group of families-those who have a child with a disability. The authors' premise is that such families are likely to find it difficult to manage work and family issues, given the health and schooling demands of their children. Hebbeler, in a brief comment, urges policy scholars to take advantage of three relatively new data sets to address the issues raised by Rosman et al. Lonnie Sherrod and I hope that this SPR will garner support for policies and practices targeting lowincome parents who have children with disabilities.

Jeanne Brooks-Gunn, Ph.D., Associate Editor Virginia and Leonard Marx Professor Child Development and Education Teachers College, Columbia University Towards an Understanding of the Impact of Welfare Reform on Children with Disabilities and Their Families: Setting a Research and Policy Agenda

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As welfare rolls fell drastically in the late 1990's following passage of federal welfare reform legislation, concerns grew about those who remained on welfare, and/or faced serious barriers to employment (Danziger et al., 2000; Rosman, McCarthy, & Woolverton, 2001; Yoshikawa, Magnuson, Bos, & Hsueh, 2002; Zedlewski, 1999). One barrier that has been identified but not well-explored in either the research or policy communities is having a child with a disability. In discussions about those who remain on welfare due to barriers—a group variously referred to as the hard to employ, those with multiple barriers, and floundering families (Berlin, 2001; Danziger et al., 2000; Haskins, Sawhill & Weaver, 2001)—having a child with a disability is usually included in the laundry list of barriers. However, the specific and unique implications for families of having a child a disability are almost never considered. This population is one about which we know very little, despite recognition that the law could have serious implications for these families (Harbin, 1998; Janko-Summers, 1998, Ohlson, 1998). In fact, little is known about families living in poverty who have children with disabilities in general (Park, Turnbull & Turnbull, 2002). Further exploration of the unique challenges this population faces, as well as a better understanding of the mechanisms through which the law may affect these children and families, is necessary in order to begin to make policy recommendations

This paper aims to develop a research and policy agenda that will address the needs of families who are poor and have children with disabilities. In order to develop this agenda, it poses the following questions:

- 1. What do we already know about families who are on welfare and have children with disabilities?
- 2. What are the developmental processes through which we expect the challenges of welfare reform to affect these children?
- 3. What changes in current policy and practice are feasible and would work towards increased self-sufficiency and increased quality of life for these families?

What do we already know about families who are on welfare and have children with disabilities?

#### **Definitions**

One difficulty in assessing policy impacts on children with disabilities is that of developing a definition of what constitutes childhood disability (McNeil, 1997). The Individuals with Disabilities Education Act (IDEA), most recently amended in 1997 (P.L. 105-117), presents the following definitions. Under Part C of the law, which establishes services for infants and toddlers with disabilities, an infant or toddler is considered to have a disability if: 1) he/she is experiencing developmental delays in one or more of the areas of cognitive, physical, communication, social/ emotional, or adaptive development (criteria defined more specifically by the individual states); 2) he/she has a diagnosed physical or mental condition that has a "high probability" of resulting in developmental delay; or 3) he/ she is considered to be at-risk (states can chose whether or not to serve this last group of children and define the criteria). (P.L. 105-117; §632 (5)). For children over the age of three, Part B of the law defines thirteen categories of disability under which children can qualify for services: autism, deafness, deaf-blindness, hearing impairments, mental retardation, multiple disabilities, orthopedic impairment, other health impairment (e.g. AIDS, asthma, diabetes), serious emotional disturbance, specific learning disability, speech/language impairment, traumatic brain injury, and visual impairment. In research studies, definitions vary greatly. National studies such as the Survey of Income and Program Participation (SIPP), the National Health Interview Survey (NHIS), and the National Longitudinal Survey of Youth (NLSY) use a variety of terms, including impairment, condition, limitations, and disability, all of which are defined slightly differently (Loprest & Acs, 1996). Thus, in examining literature related to disabilities, it is important to pay close attention to the definitions employed.

#### Prevalence Rates

Childhood disability is over-represented among families in poverty and families on welfare. Newacheck, Jameson and Halfon (1994) found that "poor children experience a disproportionate number of health problems" (1994, p. 232); using data from the NHIS, they found that children from families with incomes below \$10,000 were more than twice as likely to report limitations in activities as their peers in families with incomes at or above \$35,000. Furthermore, parents of children in low-income families reported 38% more behavioral problems in their children than did parents of children in higher-income families. Researchers have documented a significant increase in the rates of childhood disability over the past fourteen years (from 3.94 million children aged 3 to 21 in 1983 to 4.99 million in 1996), which seems to be concentrated among "constituencies defined by poverty and single-parent headed families" (Fujiura & Yamaki, 2000, p. 194).

Some studies have explored the prevalence of disability among children whose families receive welfare. These studies are pre-Temporary Assistance to Needy Families

(TANF) and focus on children in families receiving Aid to Families with Dependent Children (AFDC). Ohlson (1998) cites studies finding that anywhere from 8 to 21% of families on welfare had a child with a disability. Using data from the SIPP, the NHIS, and the NLSY, Loprest and Acs (1996) found that almost 16% of the families in their sample had a child

with some type of functional limitation. In a sample of AFDC recipients in California, Meyers, Lukemeyer and Smeeding (1996) found that 21% of the women reported having at least one child with a disability or chronic health problem. There is difficulty in comparing across studies due to the varying definitions of disability and to the possibility of underdiagnosis, but these figures suggest that this is a sizeable population that neither researchers nor policy makers should ignore.

Experiences of having a child with a disability in the family system

Family systems theory recognizes that parents and children can affect each other in complex ways. While research in the past decade has emphasized the strengths and competencies of families who have children with disabilities, there is still the recognition that raising a child with a disability can be a difficult endeavor, bringing with it

unique challenges. Raising a child with a disability carries both psychological and economic costs. Among psychological costs, parents have to deal with concern about the child's future, extra caregiving tasks, and the realization that a child expected to be "normal" is not. Economic costs include out-of-pocket (i.e. not reimbursed) medical expenses, transportation to and from appointments, baby-sitting for other siblings while attending treatments for the child, special clothing, special food for children on specialized diets, and specialized day care (Meyers, Brady & Seto, 2000).

Recognizing the above demands, research has found increased levels of parenting stress and negative affect among mothers who have children with disabilities (Beckman, 1983; Boyce, Behl, Mortensen & Akers, 1991; Dyson, 1993; Friedich & Friedrich, 1981). This fact is especially relevant for the families being considered here, since research also shows increased levels of depression among mothers in poverty (for a review, see Rosman et al., 2001). Parenting stress has been associated with lower levels of parenting satisfaction, higher levels of symptoms and abusive behavior,

and insecure child attachment (for a review, see Smith, Oliver & Innocenti, 2001). Furthermore, both parenting stress and depression have been linked to more negative parenting styles and, in turn, to more negative child outcomes (Alpern & Lyons-Ruth, 1993; Downey & Coyne, 1990; Huston, McLoyd, & Garcia Coll, 1994; Kalil & Eccles, 1998; McLoyd, 1990).

It is also important to note that, even within the subgroup of families receiving welfare who have children with disabilities, there are important differences relating to type and severity of disability, as well as age of child. As Seligman and Darling (1989) stress in their discussion of the impact of having a child with a disability on the family system, some disabling conditions have greater impact on family functioning than others. Specific characteristics of a child's disability, such as the child's level of functioning or degree of impairment, may predict parenting stress and depression (Scorgie, Wilgosh & McDonald, 1998). characteristics as a child's social responsiveness, caregiving demands, temperament, communication skills, and level of behavior problems have been found to predict parenting stress (Beckman, 1983; Frey, Greenberg, & Fewell, 1989; Hauser-Cram, Warfield, Shonkoff, & Kruass, 2001). The age of the child will also help determine the impact on the

Childhood disability is over-represented among families in poverty and families on welfare.

family. For example, a schoolage child will be in school several hours a day, leaving the parent available to meet work requirements. However, early intervention services provided to families of infants with disability are primarily home-based. Having to be home for the child to receive services effectively precludes a parent's ability to participate in work requirements.

The cornerstone of PRWORA is its "work first" philosophy. However, research shows that it is particularly difficult for women who are caring for children with disabilities to maintain employment.

Components of PRWORA that may affect families with children with disabilities

The cornerstone of PRWORA is its "work first" philosophy, which explicitly links welfare receipt with work participation (for a review of work requirements, see Relave, 1999). However, research shows that it is more difficult for women who are caring for children with disabilities to maintain employment. This may be due to difficulties in finding appropriate child care, to a mother's belief that she is best able to care for her child, or to the simple inability to hold down a job due to such factors as frequent doctor's visits, early intervention appointments, suspension from school due to behavior, or therapy sessions.

For example, consider a mother whose newborn has just been diagnosed with Down syndrome. She must cope with numerous doctor's visits surrounding the medical complications that often accompany Down syndrome, try to establish an early intervention plan, and face the emotional issues associated with having a child with a disability. And she may also be in a state that requires the primary caregiver to return immediately to work, creating a set of conflicting demands. The conflict that arises when a mother has a sick child and has to conform with welfare requirements was poignantly expressed by a participant in a focus group of welfare recipients in New Jersey. She spoke of the experience of having to go to a job search center right after her one-month-old was released from the hospital, where he had had surgery for pyloric stenosis: "...I had to go right down to job search, as soon as my son got out of the hospital. Mind you, I had him in February, he went to the hospital in March. At the end of March I was in class. That's ridiculous" (Rosman & Yoshikawa, 2000). The effect of maternal employment, especially mandated employment, on children with disabilities themselves, has not been well-researched.

In the area of time limits, these families may be more likely to reach time limits or, before reaching time limits, to be sanctioned for non-compliance with work requirements, due to difficulties in finding and/or maintaining employment. PRWORA does allow states do exempt up to 20% of their current caseload from time limits. However, as the caseloads fall precipitously, that percentage

doesn't cover as many families as it did in 1996. Even for states that offer exemptions and extensions for families caring for a household member with a disability, there is a great deal of uncertainty as to how consistently these categories are defined and, in turn, how well these exemptions and extensions are actually implemented (Rosman et al., 2001).

We also know that, while finding appropriate and affordable child care is an issue for almost all families receiving welfare (Children's Defense Fund, 2000; Miller et al., 2000), it may be especially problematic for families who have children with disabilities<sup>2</sup>. In a focus group study of women in Michigan who received welfare and had children with disabilities, LeRoy (2000) found that 72% of her sample cited availability of care, cost of care, quality of care, and knowledge and skills of the provider as barriers to their finding employment. Recent research shows that, although take-up of child care subsidies is remarkably low, the child care needs of welfare reform have been accommodated, except for care for infants, children with special needs, and during nonstandard work hours (Besharov & Samari, 2001). This may be due to a multitude of factors:

- 1. a dearth of specialized child care slots for children with special needs, particularly for children who are the most medically involved or have serious behavior problems (Ohlson, 1998)
- 2. difficulties in finding informal care, since it is more difficult to rely on family and friends or to "trade" child care favors when a child has special needs (Shearn & Todd, 2000)
- 3. child care subsidies that do not reflect market rates for children with special needs; in Michigan, the average hourly rate for specialized care is \$4.80/hour, and the state-allotted subsidy is only \$2.95/hour (LeRoy, 2000).

Finally, we also know that the changes PRWORA made to the Supplemental Security Income (SSI) program by tightening the definition of disability for children (see Karoly, Klerman & Rogowski, 2001) resulted in fairly significant declines in SSI receipt. This loss of benefits can have severe financial impacts for families. SSI has been found to make the difference between living above or below the poverty line and to noticeably improve economic circumstances for families (Kearney, Gundmann, & Gallicchio, 1994; Meyers et al., 1996). According to Karoly et al., "To make up for the lost income [from SSI], families have turned to other sources of support, including public and private transfers and work. Whether these sources can be sustained, especially in a less robust economy, remains to be seen" (2001, p. 490).

A second consequence of loss of SSI benefits is that many children are also erroneously losing their Medicaid benefits. Though states are required to continue Medicaid coverage for children who have lost SSI due to redeterminations, many state Medicaid agencies have not yet implemented a process for ensuring that these children maintain their benefits (Bazelon Center for Mental Health Law, 2000; Family Voices, 1998).

What are the developmental processes through which we expect the challenges of welfare reform to affect these children?

The above section highlighted what we already know

about families who have children with special needs and receive welfare. Because PRWORA is aimed at parents, the changes described above specifically affected parents. However, they have significant implications for children, as well. How might we expect the policy-level changes of

Flexible work requirements can take into account unique constellations of stresses and strengths among families with children with disabilities.

PRWORA to affect children's development? This section proposes some possible mediational models, in which family-level mechanisms link TANF policy changes to developmental outcomes. The two mechanisms considered here involve family-level processes that may be most proximally related to child development: changes in family resources and changes in family routines.

Family Resources

As a result of TANF, levels of available family-level resources have declined across multiple domains (Yoshikawa & Hsueh, 2001), including time, money and supports. For example, mothers who had not previously worked and are forced to do so as a result of work requirements and time limits have found themselves with less time to spend with their children, as well as less time to spend on daily chores, such as laundry, cooking, and grocery shopping (London, Scott, Edin, & Hunter, 2000). Individuals may reach their time limits for welfare receipt without a job that will provide adequate income to support them and their families. The loss of SSI benefits may also mean the difference between living in or out of poverty (Kearney et al., 1994; Meyers et al., 1996). Since 1996, there have been large decreases in both Medicaid and Food Stamp receipt, even among families who remain eligible (Fix & Passel, 2002; Weil & Holahan, 2001; Zedlewski and Brauner; 1999a, 1999b). Such declines in family resources o be associated with more negative psychological outcomes and parenting styles among parents, which in turn can lead to more negative outcomes for children (Alpern & Lyons-Ruth, 1993; Downey & Coyne, 1990; Elder, Liker, & Cross, 1984; Elder, Ngyuen, & Caspi, 1985; Huston, McLoyd, & Garcia Coll, 1994; Kalil & Eccles, 1998; McLoyd & Wilson, 1991)3.

Families who have children with special needs may be particularly vulnerable to declines in family resources. Even before taking levels of resources into account, parents raising a child with a disability may be at increased risk for higher

levels of parenting stress and negative affect (Boyce et al., 1991; Bradley, Rock, Whiteside, Caldwell, & Brisby, 1991; Margalit & Ankonina, 1991). These families must cope with the emotional issues of coming to terms with having a child with a disability, which involve shifting the family's "cultural model" of what to

expect in infancy and early childhood (Weisner, Matheson, & Bernheimer, 1996), as well as accepting that a child assumed to be normal actually is not (Seligman & Darling, 1989). They must also navigate the time demands of doctors' visits, early intervention programs, and finding a child care setting that will accept a child with special needs. These stresses and sadnesses are often chronic: not only is

#### Research in progress on poverty and childhood disability

The findings presented in this article are drawn from disparate sources, and no one study (with the exception of the LeRoy study, which is a small, focus group study) presents a coherent picture of the lives of families who are poor and have children with disabilities. However, we do know that there are several research studies examining these families that will report findings in the near future. These include:

## **❖** "The Impact of Welfare Reform on Families with Members with Disabilities," a component of "Welfare, Children, & Families: A Three City Study"

This study is a four-year, ethnographic research project, embedded in a larger quantitative and ethnographic study. It consists of in-depth interviews with forty families who receive TANF benefits and also have a child under age eight who has a disability. The principal investigator is Debra Skinner at the Frank Porter Graham Child Development Center of the University of North Carolina at Chapel Hill. For further information, see: http://www.fpg.unc.edu/activities/Projectsdatabase/a Detail.cfm?ID=141.

#### **♦** "Urban Change"

This is a multidisciplinary study of how the revolutionary changes in welfare policy embodied in the federal welfare reform legislation of 1996 are playing out in four of the nation's largest urban counties. A portion of the ethnographic component of the study focuses on the challenges faced by families who have children with disabilities. For further information, see: http://www.mdrc.org/WelfareReform/UrbanChangepage.htm.

## \* "A Mother's Work is Never Done: A Critical Analysis of Low-income Women's Roles as Financial Provider and Caretaker of Children with Special Needs"

This dissertation is a qualitative study of families who are receiving welfare and have a child with a disability. The goal is to understand how mothers make the choice between working and caring for their children, as well as identifying support systems and work environments that enable the successful transition from welfare to work. For further information contact Chrishana Lloyd at clloyd@UDel.edu.

# \* "At the Crossroads of Poverty and Disability: An Ecological Approach to Predicting Maternal Outcomes in Families who are Poor and Have Young Children with Disabilities"

This study will examine stress and depression outcomes among low-income mothers who have a child receiving early intervention services. The study will employ an ecological model that looks beyond the immediate family to the impact of the family's involvement with three systems: disability- and poverty-related services and programs, maternal employment, and child care. For further information contact Elisa Rosman at ear222@nyu.edu.

there stress at the time of discovery of the disability, but parents of children with disabilities often experience stress and feelings of grief at many points throughout the child's life, as milestones are delayed or missed completely (Stoneman & Manders, 1998). The cumulative impact of these stressful events, especially if combined with the losses in family resources just discussed, may increase mental health problems for parents in poverty, and ultimately lead to more negative child outcomes.

From a policy perspective, it is also important to consider the role of increased resources. Can maintaining or raising levels of resources within the context of welfare reform ameliorate risk and lead to more positive developmental outcomes? Two recent welfare-to-work experiments provide examples of what these positive effects might look like by "making work pay", either through an earnings supplement (New Hope; Bos et al., 1999; Huston et al., 2001), or an earnings disregard (Minnesota Family Investment Program, MFIP; Gennetian & Miller, 2000; Knox, Miller, & Gennetian, 2000). Both programs demonstrated positive effects on a variety of parent and child outcomes, including school performance and behavior problems (Bos et al. 1999; Gennetian & Miller, 2000; Huston et al., 2001). The effect these programs may have had on families with children with disabilities is unclear.

#### **Family Routines**

PRWORA's policy changes may not only change availability of family-level resources, but also necessitate that families reorganize or restructure their daily lives. Researchers have examined the importance of family routines or "life management strategies," suggesting that the ability to maintain structures and routines is conducive to positive development for all family members (Gallimore, Bernheimer, & Weisner, 1999; Scorgie, Wilgosh & McDonald, 1996). The changing time constraints mentioned above mean that carefully constructed routines may have to be altered. A mother who had created with her child a nighttime routine of a bath and a story before bedtime may no longer have the time or energy to maintain that routine if required to work full-time or in the evening. Similarly, a mother who established a pattern of going to three or four different grocery stores a week in order to capitalize on sales and make the most of her Food Stamps may simply no longer have that kind of time and may find that her Food Stamps (if she still receives them) do not stretch as far as they once did (Rosman & Yoshikawa, 2000).

As with the family resource model, the effects of policydriven changes in family routines on children may be especially prominent in families that include a child with special needs. Having a child with a disability and reacting to changes brought about by PRWORA are both situations that require restructuring if the family is to sustain a daily routine. For example, work requirements under PRWORA or loss of SSI benefits may result in the following scenario: A mother who was able to stay home with her children and, therefore, had time to communicate with the child's teacher, attend Individualized Education Plan meetings, and take care of the neighbor's children in exchange for occasional use of the neighbor's car, now needs to disrupt this routine in order to attend work. In order to work, the mother may arrange for a relative to bring the child to and from school, leaving her unable to communicate daily with the teacher about her child's progress. These changes affect every family member, as well as the balance that the family has established and been able to maintain.

Thus, the balancing of caregiving, work, and family roles that low-income families who have children with disabilities construct are often precarious and easily disrupted (perhaps even more so than among families in poverty; Edin & Lein, 1997). These disruptions have implications for every aspect of the family's day, as eloquently described here by a mother of a child with a disability:

Where is that fifteen minutes [to carry out the intervention plan] going to come from? What am I supposed to give up? Taking the kids to the park? Reading a bedtime story to my eldest? Washing the breakfast dishes? Sorting the laundry? Grading students' papers? Because there is no time in my life that hasn't been spoken for, and for every fifteen-minute activity that is added, one has to be taken away. (Featherstone, 1981, p. 78)

What are the implications of the above for welfare policy? What changes are feasible and would work towards increased self-sufficiency and increased quality of life for these families?

Clearly, more research is necessary on families in or near poverty who have children with disabilities. "Raising a child with a disability" can no longer simply be listed as part of a laundry list of barriers to employment. Welfare and poverty research must begin to include a focus on these families, as well as on developmental mediators. The studies

#### Where Policies Intersect: Children with Disabilities, PRWORA and IDEA Kathleen Hebbeler, SRI International

Numerous federal policies impact children with disabilities and their families. Some of the impacts are major and well recognized; others are major but less widely recognized. The Individuals with Disabilities Education Act (IDEA) is an example of the former. As the discussion in these pages makes clear, the Personal Responsibility and Work Opportunity Act (PRWORA) is an example of the latter. Both pieces of legislation are being reauthorized in the near future which presents an opportunity to craft coordinated policies that address the multiple challenges faced by poor families who have one or more children with a disability.

One approach to increasing what is known about the impact of welfare reform on the lives of families of children with disabilities and on the developmental outcomes of children is to design studies focused on welfare reform that look specifically at the subgroup of families with children with disabilities. A complementary approach is to look at children with disabilities and focus on the sub-group of families who are low income. There are three large scale studies underway that will allow for this second approach and that can inform the upcoming reauthorizations and future policy-making.

The Office of Special Education Programs in the U.S. Department of Education has funded a series of longitudinal studies that are looking at three age groups of children and youth with disabilities. The studies are the National Early Intervention Longitudinal Study (NEILS) which is following a sample of over 3300 infants and toddlers who received services provided through Part C of IDEA; the Special Education Elementary Longitudinal Study (SEELS) which is following a sample of 13,000 children who received special education in elementary school; and the second National Longitudinal Transition Study (NLTS2) which is following a sample of 12,000 adolescents who received special education in secondary school. All the studies involve a nationally representative sample of children with disabilities. SEELS and NLTS2 involve sufficient samples of each of the IDEA disability categories so that results for can be examined separately for children and youth with different disabilities. Each study is following its sample for several years. NEILS is following infants and toddlers into kindergarten; SEELS is following elementary students into secondary school, and NLTS2 is following secondary students into young adulthood.

NEILS is the oldest of the three studies and therefore in the best position at the present time to provide data related to welfare reform. Accommodating welfare reform within the context of early intervention services is especially important because Pt. C services have a stronger focus on the family than services for school age children with disabilities and because the majority of early intervention services are provided in the home. NEILS data have not yet been analyzed to look specifically at issues related to family poverty and welfare reform but some preliminary findings underscore the points being made by Rosman, Yoshikawa and Knitzer. From NEILS, we know that 26% of families of infants and toddlers receiving early intervention have annual household incomes of less than \$15,000 a year. Another 16% have annual incomes of less than \$25,000. One in four families receiving early intervention had received welfare in the past year. Limited income and a baby with a disability were not the only stressors in the lives of families with household incomes of less than \$15,000 a year. Thirty percent of the mothers in these families were employed; 22% had one or more other children with special needs; and 39% had only one adult in the household. These statistics apply to the families who actually began early intervention services. We have no data on how many low income families never even accessed services for which their child was eligible.

More research is needed to understand the complex interplay of policy, family issues and child development, but with regard to children and youth with disabilities in low income families, we already know we have a group of children at high risk for poor developmental outcomes. As policy-makers approach the reauthorization of PRWORA and IDEA, the choices they make will either increase or decrease those risks.

For more information about NEILS, SEELS and NLTS2, see http://www.sri.com/neils/, http://www.seels.net/index.html, and http://www.sri.com/nlts2/.

highlighted above are beginning to do this. Other important research directions include:

- 1. Research on the prevalence of childhood disability among families who receive welfare.
- 2. Research on the impact of systems outside of the family on the development of children with disabilities within the context of PRWORA. What is the impact of maternal employment, especially if it is mandated and not voluntary? What is the impact of child care, particularly low quality child care?
- 3. Research on the ways in which the developmental mechanisms outlined here actually operate for families. What demands do families face, and what resources are available to meet those demands? How do families construct and sustain workable routines, and what components of those routines do families value the most? How do these two mediators specifically relate to child development, especially for children with special needs?

Finally, although more research is necessary to craft appropriate policies, preliminary policy recommendations are presented here. They recognize the unique needs and situations of families who are in poverty and have children with disabilities, and they involve changes in the federal law, as well as changes in practice in local TANF offices.

1. Implement screening and assessment strategies to include childhood disability as well as family strengths.

There is growing recognition of the importance of effective screening and assessment of TANF recipients, in order to identify both needs and strengths that are relevant to an individual's ability to maintain employment (National Center for Children in Poverty, 2001; Rosman et al., 2001; Thompson & Mikelson, 2001). However, there is very little information available about whether or not states are screening for childhood disability and, if so, what types of tools they are using. For many families, this is a very delicate subject, and the results of a screening can be biased by language/cultural barriers, by the belief parents have that they will be considered "bad parents" if they reveal that their child has behavior problems or a disability, or fear of being referred to child protective services (Harry, 1992; O'Connor, 1999; Rosman et al., 2001).

However, it is vital to get an accurate picture of childhood disability. Assessments could incorporate information on developmental needs of children, the demands placed on the family by such needs, and the family's capacities to respond. This is currently being done in Iowa, where individuals identify personal and family strengths and needs

Families must be educated about what services they are, in fact eligible for. This may require a change on the ground level of implementation—in welfare offices.

and then bring those to their discussions with caseworkers (Rosman et al., 2001). Just as "families on welfare" would not be considered a monolithic group, so "families who have children with disabilities" would not, either, and there would be recognition that some families, due to their child's demands, have a greater need for flexibility and accommodation than others. This would allow for the creation of individual plans that would allow the family to better balance the demands of work and disability-related caregiving.

2. Create broader definitions of what qualifies as work

Changes in definitions of work are being widely suggested by advocates for many different groups that are considered hard to serve (Derr, Hill & Pavetti, 2000; Rosman et al., 2001). Flexible work requirements can take into account families' unique constellations of stresses and strengths, as well as they way that families organize their lives, creating solutions that decrease families' levels of stress and increase families' coping and abilities to maintain balance and routine. Some states offer "model" programs that we can draw from in this area. For example, in Washington State, if a WorkFirst participant is unable to find or keep employment because of a child with special needs, a referral is made to the local Public Health Department. A Public Health Nurse conducts an assessment geared toward the impact of the child's special needs on the parent's ability to participate in Work First. The Nurse then works with the individual's case manager to identify creative and workable activities for the parent. These could include taking a child to therapy appointments (Rosman et al., 2001).

Changes in work definitions may require TANF agencies to identify and partner with agencies that have experience serving individuals and families with barriers to work (Pavetti et al., 2001; Rosman et al., 2001, Zedlewski & Loprest, 2001). An example cited by Zedlewski and Loprest (2001) and Rosman and Knitzer (2001) is Project Match, a

program that uses the concept of an incremental ladder of economic independence to meet women "where they are," providing them with attainable goals and a clear course to follow (Herr, Halpern, & Majeske, 1995). In Nashville, TN, Project Match's case management tool, Pathways, is used to create definitions of work that include such activities as going to medical appointments, taking children to extracurricular activities, and serving on tenant management boards. If this type of model were applied to families who have children with disabilities, activities that could be added would include: attending an Individualized Family Service Plan (IFSP); feeding a child with a feeding tube (which can take an hour every three hours); or training a child care provider about a child's disability.

3. Revisit implementation of time limits and exemption policies

Should families with children with disabilities be subject to time limits for welfare receipt? Currently, there is some discussion of abandoning time limits, or at least expanding the current 20% exemption option, so that states would have more time to help families work towards independence, providing them the supports necessary for working towards self-sufficiency (Bernstein & Greenberg, 2001; Haskins & Blank, 2001).

When exemptions are in place, it is vital that they be more clearly defined and implemented. There is mounting evidence that exemption policies, stated in the law, are not necessarily implemented on the "front-lines" in welfare offices. In Massachusetts, although parents caring for children with disabilities are exempted from time limits, work requirements, and sanctions, a recent study found that this was almost never implemented. Individuals who might qualify were not being identified, and local offices were taking the exemption to mean that a parent had to be caring for the child 24 hours each day (Family Economic Initiative & Massachusetts Law Reform Institute Time Limit Documentation Project, 1999).

Attempting to solve this problem requires clearer definitions of exemptions and extensions. In addition, special efforts may be needed to insure that TANF case workers are not only well informed about the policies, but also "buy in" to them, so that they can begin to more effectively identify families who have children with disabilities. This might entail special training sessions for caseworkers or holding town hall-style meetings, in which welfare recipients who have children with disabilities are invited to share their stories and their life situations with groups of caseworkers. It also

requires better screening and assessment practices, as described above.

4. Increase affordable, good quality child care for children with disabilities

There are several mechanisms that have been suggested (see, for example, Rosman et al., 2001). First, creative and flexible approaches to funding (Whitney, Groginsky, & Poppe, 1999) can be implemented, such that money is pulled from multiple sources to build states' capacities for serving children with special needs. This entails making funding streams "less categorical and less rigid" (Besharov & Samari, 2001). Second, child care subsidies for families with children with disabilities could reflect market rates for children with special needs (LeRoy, 2000). Finally, increasing resources for training child care providers about the needs of children with disabilities would give providers access to experts in the disability field, so that more children can be served in inclusive settings (Sweeney et al., 2000). 5. Work to insure that families receive the supports for which they are eligible. For children with disabilities and their families, SSI is especially relevant, although, as for all families, Medicaid, Food Stamps, and the Earned Income Tax Credit are also highly relevant.

The first action required to meet this goal is maintaining funding for these programs and not converting Food Stamps to a block grant, as was widely debated during the drafting of PRWORA (Greenstein & Guyer, 2001). Beyond that, families must be educated about what services they are, in fact eligible for. Again, this requires a change on the ground level—in welfare offices. Other systems which come in contact with families in poverty could also be educated about these supports. For example, early intervention or special education caseworkers and service coordinators should be aware of poverty-related services so that they can help families access the supports for which they are eligible (Knitzer, 2000). Conversely, PRWORA caseworkers could help make sure that children with disabilities in low income families are identified and get the services for which they are eligible. Part C of IDEA specifically calls for identifying, evaluating, and meeting the needs of underrepresented populations, particularly "minority, low-income, inner-city, and rural populations" (P.L. 105-117; §631 (b)). Focused screening and assessments concerning child disability and family response, paired with increased training for casesworkers regarding pertinent issues, would be an excellent mechanism for meeting that mandate.

6. Increase inter-agency coordination among agencies serving the same families.

There is an increasing call for recognizing that families, particularly poor families, are often receiving services from multiple agencies. These agencies often bring with them multiple and, at times, competing demands (Rosman et al., 2001; Woolverton, McCarthy, Schibanoff, & Schulzinger, 2000). If these agencies were to collaborate in a more formal way, that could result in increased efficiency, decreased duplication of services, as well as the creation of strategies that, by recognizing all of the demands on a family, are more likely to result in a family's success in achieving independence (Sussman, 2000). Strategies that have been documented or suggested for achieving higher levels of coordination and collaboration include; a) co-locating Child Find workers or disability experts in welfare offices, as well as sharing records between welfare offices and early intervention/special education systems (with parental consent) (Rosman & Knitzer, 2001; Rosman et al., 2001); b) setting up systems so that representatives of the multiple agencies that serve families on TANF communicate on a regular basis (Derr, Hill & Pavetti, 2000); and c) allowing families to have one family service plan that would incorporate goals from multiple systems, so that families are treated in a more holistic fashion and are not subjected to demands that compete with or work at cross-purposes with each other (Rosman et al., 2001; Woolverton et al., 2000).

Through increased coordination between welfare, early intervention, and special education systems, families with children with disabilities might no longer fall through the cracks between the welfare and early intervention systems. It would be clear to both systems, for example, that a mother who needs to be home for morning home-based early intervention services cannot report to a work placement at 9 AM. This type of coordination would discourage the imposition of demands that cannot reasonably be met.

#### Conclusions

As attention turns to reauthorization and beyond, more attention must be paid to the question of how special populations are affected by welfare and anti-poverty policies. One such population that has been largely ignored is that of families who receive welfare have children with disabilities. The evidence marshalled in this paper suggests that they are likely to be affected by welfare reform in ways that differ importantly from those of other welfare recipients. The implications concern not only potential changes in the

structuring of incentives in welfare policy, such as exemptions, but changes in implementation, most crucially in areas of assessment, training, and service delivery. We aimed to outline the scope of the challenge to researchers and policy makers, in order to improve the nation's response to a population that has been overlooked for too long in welfare and anti-poverty policy debates.

#### **Footnotes**

- <sup>1</sup> For more detailed information about each of these categories, see the National Information Center for Children and Youth with Disabilities (NICHCY) publication entitled Disabilities that qualify children and youth for special education services under the Individuals with Disabilities Education Act (IDEA). This is available by calling (800) 695-0285 or on their website: http://www.nichcy.org.
- <sup>2</sup> Though states may not penalize a parent for not working if the parent has a child under six and cannot receive needed care, there is concern that this section of the law is ill-defined and is not being applied consistently by caseworkers (Gong et al., 1999).
- <sup>3</sup> When examining parenting and its effects in families in poverty, it is important to bear in mind recent criticisms which suggest that mainstream notions of nurturant parenting are typically based on studies of White, middle-class populations and may not be appropriate for all populations, particularly populations experiencing the demands of poverty (Halpern, 1990).
- <sup>4</sup> For more information concerning Project Match and the Pathways System, including examples of successful implementation, see Project Match's website: http://www.pmatch.org.

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