

Policy Research Brief

RESEARCH AND
TRAINING CENTER
ON COMMUNITY LIVING
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A Qualitative Study of the Experiences of Transition-Age Youth with Disabilities in Relation to SSI Redetermination

This Policy Research Brief presents selected findings from a study and literature review describing the experiences of Supplemental Security Income (SSI) recipients and nonrecipients and their families in relation to the age 18 redetermination process, and in relation to their efforts to achieve postschool employment, independent living, and related community participation outcomes. The study was conducted at the Institute on Community Integration, University of Minnesota, and the authors of this brief are David R. Johnson, Director; Mary McEathron, Graduate Research Assistant; Jane Fields, Research Associate; and Katharine Hill, Project Coordinator. For further information, please contact Dr. Johnson at johns006@umn.edu or 612/624-1062. The study was funded by grant #H133G000201 from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education.

■ Introduction

Many children and youth with disabilities receiving special education services also receive Supplemental Security Income (SSI). Primary SSI benefits, such as Medical Assistance or work incentives, support youth with disabilities in the transition from secondary school to employment, independent living, and participation in the community. SSI beneficiaries receive general income support, medical coverage, and opportunities to use a range of work incentives including the Plan for Achieving Self-Support (PASS), the Student Earned Income Exclusion (SEIE), the Blind Work Expense (BWE), and the Impairment Related Work Expenses (IRWE) to achieve employment goals.

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996, more commonly known as the Welfare Reform Act, requires all individuals who received SSI as children (17 years of age and younger) to undergo

a redetermination, or re-examination, of their disability status upon reaching age 18 (Social Security Administration [SSA], 2000). To qualify for SSI benefits as an adult, an 18-year-old must demonstrate an inability to engage in substantial gainful activity (i.e., paid employment) due to a medically-determined physical and/or mental impairment. Information from the Social Security Administration (SSA) indicates that approximately half of the initial redeterminations that have occurred since the inception of the Welfare Reform Act have resulted in recommendations for cessation of benefits (SSA, 2000). The number of age 18 redeterminations jumped from 71 in 1995 to 48,834 in 1997. Almost half of the individuals who underwent redetermination in 1997 and 1998 lost their SSI benefits (SSA, 2000). Of those who lost their benefits, almost three-quarters had some form of mental impairment or intellectual disability (Halloran & Auxter, 1998). The trend has continued – with slight mitigation – through 2002, with more than 40% of those required to undergo redetermination losing their benefits each year (SSA, 2003). Little is known, however, about the impact of continuing or discontinuing SSI benefits for individuals with disabilities after age 18. The research described in this brief seeks to fill that knowledge gap, and provide information that may be useful in influencing and improving current and future SSA redetermination policies and transition planning practices by public schools and rehabilitation agencies.

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota.

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■ Purpose and Method of Study

The purpose of this study was to describe the experiences of SSI recipients and nonrecipients and their families in relation to the age 18 redetermination process, and in relation to their efforts to achieve postschool employment, independent living, and related community participation outcomes. The research questions were the following:

- What is the nature and quality of individual and family experiences in relation to SSI redetermination policies and practices, as described by transition-aged youth, family members, and service providers?
- What are the experiences of SSI recipients and nonrecipients and their families in relation to achieving employment, independent living, and community participation outcomes, as described by transition-aged youth, family members, and service providers?

The study was conducted in communities in four states: Colorado, Florida, Massachusetts, and Minnesota. States were selected to represent different geographic regions of the country, as well as locations where sufficient levels of support existed to identify participants for the study. Data were collected at the local level in each of these states through interviews with transition-aged youth with disabilities, family members, and school and community service personnel. The interviews were conducted between fall 2002 and winter 2005; thus, it was too early in the implementation of the various work incentives and other programs offered through the Ticket to Work and Work Incentives Improvement Act of 1999 for the provisions of this Act to have had an impact on the interviewees.

Key components of the study's methodology follow under "Data Collection Methods" and "Description of Study Participants." A more detailed discussion of the study's methodology appears in Johnson, Fields, Hill, McEathron, Mikhailova, and Lemieux (2005).

Data Collection Methods

Researchers interviewed transition-aged youth with disabilities and their families, and also conducted focus groups or one-on-one interviews with service delivery personnel, such as representatives from special education programs, vocational rehabilitation personnel, and disability advocates. A semi-structured interview protocol was used in the interviews of young adults and families to elicit information associated with the individual's and family's participation in the SSI redetermination process and about the attainment of key adult life outcomes (employment, independent living, and community involvement). The focus groups with service providers were guided by a semi-structured focus group protocol designed to obtain additional contextual informa-

tion about SSI and the redetermination process, as well as service providers' perceptions of outcomes for transition-aged youth with disabilities.

Description of Study Participants

The research team identified young adult study participants with the assistance of several local- and state-level sources. These included professionals in organizations that serve people who were likely to receive SSI benefits, such as high school transition programs, vocational rehabilitation centers, disability law centers, state departments of education, parent centers, community-based organizations, and other social service agencies. Researchers interviewed 29 young adults and 26 parents or guardians. Researchers have information on 34 transition-aged youth with disabilities because, in some cases, they gathered data on a young adult from an interview with a parent (typically only one parent was present for the parent interviews) or only from an interview with the young adult. Among the 34 young adults from whom researchers obtained information:

- 20 received SSI benefits before age 18 and went through the age 18 redetermination process.
- 17 of the 20 were redetermined as eligible for SSI, and 3 were redetermined as ineligible.
- Of those three, two were appealing the redetermination at the time of the interviews, and one was not.
- 9 of the 34 young adults started receiving SSI after age 18 and thus had not experienced redetermination at age 18.
- For 5 of the 34, other circumstances were discovered during the interview: two young adults were not receiving SSI, but instead were receiving another type of benefit, such as Social Security Disability Income (SSDI); one young adult thought he was receiving SSI, but did not know when he started to receive benefits or if he had gone through the redetermination process; one young adult did not know if he received benefits; and one young adult had received benefits as a child, lost them due to family income, reapplied at age 18, and then was found ineligible.
- 18 were female and 16 were male.
- They ranged from 18 to 23 years of age; six of the respondents were 18 years old, twelve were 19 years old, seven were 20 years old, six were 21 years old, and three were older than 21.
- 30 of the young adults were Caucasian; 2 were Chicano/Latino; 1 was African-American; and 1 was "unknown/other."

The eligibility criteria for study participants were presented in informational materials, and specified as follows:

- Young adults between the ages of 18 and 23 with disabilities, such as mental retardation, mental illness, learning disabilities, developmental disabilities, or emotional or behavioral disabilities;
- Young adults who received SSI benefits before their 18th birthdays; and
- Young adults who went through the redetermination process at age 18 (whether redetermined as eligible or ineligible to receive benefits).

Although the eligibility criteria were explicit, several individuals who were interviewed did not meet them (as noted above). When this was determined, generally near the beginning of an interview, researchers decided to continue the interview because they believed the information gathered from all the interviews adds to the larger picture of people's experiences with the SSI program and postschool outcomes for transition-aged youth. Thus, all interview data is included in the analysis and findings.

In addition to the interviews with youth and families, researchers conducted focus groups and interviews with service providers. They obtained information from 37 service providers, including 24 teachers, 3 transition coordinators, 3 vocational rehabilitation counselors, 3 school social workers, 2 state social workers, a work experience coordinator, and a disability advocate. Note that providers were asked about their experience, in general, with the SSI program (and not about specific young adults). Also, the service providers were often not recruited from the same sites as the young adults interviewed in this study.

■ Results: Nature of Experience with SSI

The interview and focus group data analysis, in relation to the first research question examining the nature and quality of individual and family experiences with SSI, revealed a limited understanding of SSI, SSI redetermination, and related benefits among young adults, their families, and transition service providers. Specific facets of that misunderstanding are described below.

Participants Possess a Limited Understanding of Benefits and Redetermination

Many of the people interviewed had, at best, an incomplete or limited understanding of SSI and the web of associated benefits and programs. This was true for both the respondents who were eligible for SSI as children and for those who became eligible for SSI when they turned 18. Young adults and families often did not understand the terminology used (such as what "redetermination" means), did not realize they received a different kind of support (e.g., they received SSDI rather than SSI), or were not sure what, if

anything, they received or when they began receiving it (i.e., whether they started receiving SSI benefits as a child or when they turned 18). For example, one mother stated that her daughter went through a redetermination process at age 16 after she received a letter about children's benefits under Social Security. This case suggests some confusion about the difference between redetermination at age 18 and continuing disability reviews (CDRs). CDRs occur sporadically to evaluate an individual's impairment and determine whether the person still has a disability and is eligible for SSI benefits, whereas redetermination at age 18 is mandatory for all and includes a shift from childhood eligibility criteria to adult criteria.

Researchers asked participants who had been on SSI as children and had gone through the age 18 redetermination process to describe the redetermination process. Researchers found that many of the people interviewed had a limited understanding of SSI and the age 18 redetermination process. One mother explained, "I just got a letter saying that because she was 18 then she had to apply because she was an adult then, and they had to make sure that she was still able to have it." Most indicated that they had received a letter in the mail, filled out the paperwork, and sent it back. Others noted that they completed a telephone interview as part of the redetermination process. After that, they waited to hear whether they were still eligible for SSI. They were not sure whether medical records or school records were accessed. One parent said, "They wanted to know everything [about my child during the SSI application procedure].... But it was just so much paperwork. I just remember being very confused, and I have a college degree."

For those who were redetermined as eligible, it may not matter that they did not clearly understand the age 18 redetermination process. However, for those redetermined as ineligible, it might have made a difference in the outcome of redetermination if they had better understood the process. For example, for one family, not understanding a request from SSA resulted in a loss of benefits: "They [SSA] sent me a letter and I wasn't able to read it, so I didn't know what it was and then she didn't get her check one day... So I appealed it. While we're waiting on court, they sent me bunches of pamphlets. She's on SSI for her learning disability. How is she going to be able to read that stuff to get it?"

In several cases, both young adults and their parents seemed unsure which government benefits they received. This complicated the search for study participants. Researchers often thought they had correctly identified a study participant, only to learn during the interview that he or she did not actually fit the study criteria. As mentioned above, 14 of the 34 young adults did not meet the explicit eligibility criteria established for this study (9 of the 34 young adults had not started to receive SSI until after age 18, and 5 did not receive SSI benefits at all, but instead received some other type of support from SSA or no support). In many cases, this was not discovered until the interview was

underway, despite careful screening before the interview began. This indicated the possibility that people were either confused about which benefits they received or did not differentiate among the various benefit programs (e.g., individuals may not differentiate SSI from SSDI). The confusion in recruiting study participants may be an additional indicator of participants' lack of understanding about the various benefit programs.

Participants Misunderstand the Link Between SSI Benefits and Health Benefits

Researchers asked study participants, "Do you receive any other benefits from the government in addition to SSI?" In many interviews, respondents initially answered "no," but when the interviewer probed and asked them directly whether they received health care benefits, they would then say "yes, as part of SSI." In their minds, it seemed, receiving SSI was synonymous with receiving health care benefits. The confusion was understandable given that in some states the SSI application is also the Medicaid application, and Medicaid eligibility starts the same month as SSI eligibility. This was true for the participants who lived in Massachusetts, Florida, and Colorado. However, Medicaid is a separate program, jointly funded by federal and state budgets. Some states, including Minnesota (where the remaining participants were drawn from), have their own eligibility rules for Medicaid, which are different than the eligibility rules for SSA, and applicants must fill out a separate form. Participants were also unaware of the protections SSA had put into place to ensure that people who became employed could, in many cases, still qualify for Medicaid.

The interviews with the service providers echoed this assumed connection between SSI and health benefits. One service provider explained that health benefits are a key reason for applying for SSI, and parents believe there is a direct connection between receiving SSI benefits and receiving health care benefits. Service providers also noted that families are nervous about losing benefits: "Parents have the perception that if the student makes any money at all that it will come off the SSI. And most of them aren't too concerned with that, but they have a real fear that that's going to stop them from getting Medicaid. So they're all kind of real frightened.... 'no, don't get my kid a job, he's going to lose his Medicaid.'"

Service Providers' Confusion and Uncertainty

In focus groups and one-on-one interviews, service providers reported feeling uncomfortable helping or advising students about the SSI program. One school-based professional said, "I've been asked for help a couple of times, but there was really not a whole lot that I could contribute at all. I'm not knowledgeable enough, I'm not comfortable enough, trying to give them information, and so that's when

I will refer them to [a contact at SSA]." Another teacher explained, "I think we have just enough information to make us almost frustrated. There's blanks that we need filled in. Just to get through the system, to get hold of somebody and to know what the paperwork is, is incredibly long." A teacher explained that she would like to know more about the process so that when parents come to her with questions she could be more helpful. She said, "a lot of times, some of these parents don't know what to do. And they come to us because they are so used to us helping them through everything and I'm like, 'I don't know what to tell you. The most I can tell you is you have to go down there and sit and take your number and wait to talk to somebody.'" Other service providers had no experience with the age 18 redetermination process, and one transition service provider explained that she is "not familiar with the redetermination process at all." Service providers often did not know whether the young adults they worked with received SSI benefits. One school-based service provider who had experience with various SSA benefit programs explained that it can be difficult to help a parent because, "It can be hard to get specific case information from SSA because of confidentiality concerns. You need to have the parent there when you make the call to give permission..."

■ Results: SSI Experience in Relation to Outcomes

The second research question asked, "What are the experiences of SSI recipients and nonrecipients and their families in relation to achieving employment, independent living, and community participation outcomes?" Most young adults in the study were, at the time of the interviews, in transition programs available to them through their secondary school. This may have affected the outcomes around employment, independent living, and community participation. Because many of these young adults were still attending school each day, most lived with their families and were not working part- or full-time. As part of the interviews, we asked participants specifically about the following postschool outcomes: employment, independent living, and community participation. The findings within each of these specific postschool outcome areas are discussed below.

Employment

At the time of the interviews, none of the 34 young adults was working full-time, 16 were not working at all, 13 were working part-time in a setting arranged through their transition program or by another organization (e.g., Goodwill) that supports employment opportunities for people with disabilities, and 5 were working in part-time jobs in the community. Since most of these young adults were in their secondary school transition programs, it is not surprising

that many would not be working. Researchers were unable to obtain information on wages for most of the young adults; however, the few young adults who reported wages to us were earning from less than minimum wage to \$8.50 per hour (wage information was only reported for seven young adults).

Three themes regarding employment were identified through the interviews:

- Young adults and/or their families expressed concern about losing SSI benefits if they worked;
- Young adults reported limited work experience; and
- Young adults reported difficulties holding a job.

These are addressed in detail in the following sections.

Fear of Losing SSI Benefits

Because there are many different rules and formulas for determining SSI benefits and how much money an individual receives per month (based on family income, amount of time spent working, and amount earned), many of the young adults and their families were nervous about having the young person enter the workforce. They were not sure whether it was possible for SSI recipients to work and continue to receive benefits. Many of the respondents could not find work that paid enough to supplant the SSI income. In addition, available jobs usually did not include health benefits. And, as was noted earlier, study participants did not understand the rules governing protection of Medicaid benefits for those who work. One parent said, “There is no way [she] can get a job and hold it. At least not a good paying job that would take care of her medical, pay her rent, make sure she has clothes and food. No, there is no job for her that can do that.”

The service providers reported hearing similar stories from many of the people they had worked with in recent years. One service provider commented that “Medicaid is so important that getting close to that amount that says you’re able to be self-supporting, but it’s really not enough that you can live on and then you really wouldn’t have health benefits, that is a stumbling block for people [to working full-time].” Another service provider said, “we have had families say ‘we don’t want him to work because we don’t want him to lose his SSI.’” Thus, the prospect of working seemed too precarious a venture for some to undertake. This was especially true for young adults who had been redetermined as ineligible and were appealing the decision. One service provider explained, “so often my experience has been, we’re going to reapply so they [the young adult] step back and they do absolutely nothing until they know from SSI what is going to happen. And so they have months that they’re just sitting there doing nothing.”

Special education teachers expressed frustration because they thought some young adults had potential to work, but the young adults and family members resisted any

efforts to help them find a job due to their fear of losing benefits. A service provider explained that “some of the parents don’t want them [the young adult] working because if they work they’re afraid it’s going to affect their SSI.”

The service providers reported that they felt unsure of their understanding of SSI programs such as Ticket to Work, PASS, and other work incentives, and how these programs did or did not impact benefits. Thus, they were often unable to counter families’ concerns about how working would affect SSI benefits. One service provider commented that “there are PASS plans and other incentives and other programs to help people bridge to get into the workforce, but there’s the reality out there that some people will never be able to work a full-time job; they can work but [they don’t have] the stamina for a full-time job.” Another explained that if teachers had more knowledge about SSI and the related incentive programs, they might be able to counter the fears of young adults and their families. “If we could know some of the information, we could educate the parents on it. We could say, ‘well, you know, you’re gonna get this money, but you have to remember that if this happens, it’s gonna get reduced...’ So if we knew some of that information, we could help to educate parents, because SSI certainly doesn’t.”

Limited Work Experience

Of the young adults who had worked or who were working at the time of the interviews, many had not held any job other than the work experiences arranged for them as part of their secondary education and/or transition program. One young adult explained, “I had a job where I’d go for an hour or two after school or during school. I didn’t work every day, though.” In school-sponsored work experiences, the young adults often worked at a different job every few weeks, working no more than one or two hours per day or just a few hours per week. Sometimes the young adults were paid a small amount of money per hour for these work experiences (e.g., a few said they were paid \$2.00 per hour). One parent said, “There is no future in [flipping burgers]; she will be struggling all her life from the time she is born till the time she dies. I mean, SSI does not give you that much even to live off anyway. Five hundred and fifty-two dollars – is that going to pay somebody’s rent? No, I doubt it.” Another parent explained that she was not sure her daughter would ever be able to obtain paid, competitive employment, even though part of her transition program included providing her with a variety of work experiences. This parent said, “There’s a part of her that wants to work. She was doing dishes all last year at the little cafeteria [at her transition program], but to find an actual job for a few hours a day, I don’t know. They do try to find them jobs when they turn 21 and leave transition, but I don’t know if there are jobs out there.”

Difficulties Holding a Job

Many of the young adults experienced difficulties in holding a job, such as:

- They could not pay attention.
- They were told they did things too slowly.
- They were given too many directions at once and could not process them.
- They did not show up when they were scheduled.
- They were teased by other workers or customers.

One young adult explained that, “working the cash register was really hard; I had to ask the manager a thousand times on how to do this and that. It was too busy and it got too hard.” Respondents felt they did not have the needed skills and/or the needed support to succeed in these jobs. Generally, employers lacked knowledge on how to provide help or accommodations, and many of the young adults did not seem able to describe and explain the accommodations they would need. One mother said, “I don’t think they took into consideration her special needs.” Another mother explained that her son, “was taken out of job training last year... In order to work, he would need a full-time, one-on-one job coach, which is not available to him.”

Often the jobs held by these young adults were positions with typically high-turnover rates, so employers were not motivated to spend extra time in training and/or accommodations. When we asked one young adult whether she received much training for a position that she left after the third day, she said, “before I really started working, she let me use the cash register for about 30 minutes and then right after that I started, so I didn’t have that long to train.” Some of these young adults, as part of their transition program, had a job coach who supervised their work. Once they left the transition program, however, the job coach was no longer available. For many of these young adults, having a job coach is the only way they can successfully work. One mother said, “She needs a job coach with her all the time to keep her on task.” Most of these young adults and their parents believed that even if they were to work, they would not be able to hold down a full-time job. This was usually due to a concern related to their disability, but some seemed concerned about working too many hours and losing their SSI benefits.

Independent Living

Two themes regarding independent living were identified and are discussed further below:

- Most of the young adults in the study lived either in the home of a relative or guardian (i.e., with a parent, sibling, or other relative) or in a group home; and

- Family members, as well as some of the young adults, expressed a lack of confidence in the ability of the young adult to live independently.

Living Arrangements

For the most part, the young adults in this study were living at home with their parents or, in a few cases, with other family members, which is not surprising since most study participants were 18-23 years old and were attending transition programs. When the interviews were conducted, 27 of the 34 young adults were living at home (or with a family member); 5 were living in group homes; 1 was living in college housing; and 1 was living in a foster home.

The young adults living with their parents or guardians generally expressed satisfaction with their living arrangements. A small number of the young adults in this study were living in group homes, and several others indicated that they were planning to move into supported living situations or group homes in the near future (within the next year or so). However, several of the parents of young adults still living at home expressed concerns about both the quality of the group homes available in their communities and the likelihood that their child would be able to get into “a good one.”

Several of the respondents who lived in group homes perceived their living situation as very positive compared to living with their parents. They spent more time with friends, improved their independent living skills, and felt more autonomous in their daily lives. In one case, a young man was able to move into a group home with a long-time family friend, making the transition to independent living relatively easy for him. Another group home resident explained, “These places are very hard to find. I like it a lot. They treat me well there...we eat out, go to a movie, party. We get to pick out our own cereals, pop, meals, and snacks. We eat together, share chores.” One parent noted that moving into a group home was an important step forward in developing her child’s social skills as well as independence.

However, some of the young adults were not happy living in a group home arrangement. They reported feeling disconnected from the other residents; others wished that they were still able to live at home. One young adult described his group home situation as follows: “About 13 or 14 people live there. Everybody just sits and smokes. That’s all they do.”

Confidence in Ability to Live Independently

Many of the young adults, as well as their parents, expressed serious doubts about their ability to live on their own. Many of them reported studying “life skills” in school, which covered topics such as paying bills, cooking, cleaning, and other kinds of self-care. One parent noted that [in her child’s transition program], “They are doing some cooking and

that kind of stuff. And that's one of the things I stressed in the IEP [Individualized Education Plan] meeting... so now she's going to work three days a week and they're going to focus on apartment living and that kind of stuff. I just think, you know, the education line is coming to an end, and I want as much education as we can get." At the time of the interviews, almost all of the young adults depended on parents, other family members, or group home staff to assist them with life skills.

Most of the young adults who lived with their parents took a fairly passive role in the day-to-day management of the household; that is, they were not responsible for preparing their own meals or paying bills. Again, this finding may not be unusual for 18-23 year olds living at home in general, but it is consistent with comments made by several respondents who expressed doubts about the ability of these young adults to ever live completely independently. One parent explained that in order for her son to live on his own, he would need help with cooking, budgeting, and other life skills. "I would like him to be independent, to have a job someday, get married.... I don't want to get my hopes up, but... he's not really talking about it right now." Another parent said, "I think about her moving out to a group home or something like that, but it's something I'd never do unless she truly wanted to... there's a big part of me that wishes she would spring from the nest... sometimes there's a part of me that wishes I didn't have to worry about it [leaving her home alone]."

Community Involvement

Two themes regarding community involvement were identified through the interviews:

- Young adults reported few friendships or close relationships outside of those with family members; and
- Young adults reported limited involvement in community activities, except those that were arranged by their transition program.

These findings are further described below.

Family and Friends

In general, the young adults interviewed had strong relationships with family members, and they spent most of their free time at home with their families or alone. One mother described how her son goes bowling twice a week, and he goes to the gym and movies with her. She described him as a "home-body." Another parent said, "Lots of the kids that she was friends with when they were younger are older now and have kind of gone their way. She doesn't have too many social friends around..." One young adult said he "hangs out with [his] daddy" for fun. Many of the young adults had few social connections other than their families. One young adult said, "Other people say that I sound depressed when I

talk. I'm lonely." Another young adult said that he is "usually alone." Another said, "I don't really have any friends, I never really have."

Many of the young adults spent much of their free time in their bedrooms watching television or movies or playing electronic games (e.g., PlayStation). Some of the young adults interviewed specifically mentioned spending time with friends (rather than family or in addition to family): "I have one friend that comes over once in a while. I've known her since we were little kids." Generally, the young adults made friends through a structured activity or program, such as their transition program, a bowling league, or a community agency, rather than meeting people through a less-structured environment, such as in their neighborhood or at work. They reported spending time with these friends during the shared activity only (e.g., at school or at bowling), but not outside of the shared activity. A few mentioned talking with friends on the telephone occasionally.

Community Activities

If the young adults did participate in leisure activities outside the home, the activities were generally organized through their transition programs. For many of these young adults, these transition programs served as the primary social outlet and provided access, sometimes the only access, to extracurricular activities.

The most frequently mentioned extracurricular activity, by far, was participation in bowling leagues. Some young adults also mentioned participating in Special Olympics, church groups, or other organized activities. Being able to use the SSI check to pay for these activities was crucial for some families. One mother said, "She couldn't do it [participate in a variety of activities] if she didn't have SSI. I couldn't pay for all those programs, you know, and I'm glad I can get her into as many programs as I can. Because otherwise she would be sitting around and watching movies. She's really a movie buff, 8 hours a day, which is really unhealthy, so this money helps her get out and do things and be more healthy and growing."

■ Results: Other Findings

In the course of analyzing the interview data, three overarching themes not specifically addressed by the interview questions emerged as having the potential to affect the employment, independent living, and/or community participation outcomes for these young adults:

- How families use the SSI income benefit;
- Fears about going to work and living independently; and
- Limited access to safe, reliable transportation.

Details of these findings follow.

Family Use of SSI Income

How respondents and their families used the income received from SSI depended largely on the age of the young adult at the time benefits began and the economic status of the family at that time. Those who received benefits before age 18 were, by the requirements of the program, from families with a low socioeconomic status (eligibility for those under 18 depends on family income). In these cases, given that the family income was quite low, the family often depended on the individual's SSI check to pay for day-to-day expenses, such as rent, food, clothing, and utilities for the entire family, rather than just the individual. When asked what would happen if they no longer received their SSI benefits, the young adults in this category made comments such as: "We would probably be homeless," "My family would be doing worse than we're doing now or we might be out on the street," and "It would be really bad; we'd probably lose our house." One mother said that the family uses her daughter's SSI check for "...rent, because I'm a single mom.... I make \$9.15 an hour, which is actually more than I've ever made in my entire life, being 44 years old, but it's still hard to make ends meet, so her SSI pays the rent. She doesn't really comprehend money. She knows she has money, but she doesn't know how much money. I buy her whatever she needs." In some cases, family dependence on SSI income could make it less likely that parents and other family members will encourage the young adult to get a job or move out.

Some parents whose family income was too high for their children to receive SSI benefits as children reported feeling frustrated by having to wait until their children reached 18 and/or were considered independent. One parent said, "I was told we were not eligible because of my salary. When he turned 18, he became his own person. I don't know what we'd have done without it [receiving SSI for her son at age 18]. We were at our wits' end. He could not live at home; he wasn't progressing in any of his programs or his psychiatry. He'd be in jail right now without it. With SSI he's able to live in a group home. He's a different person." Another parent explained how her daughter, who has several chronic disabilities, first started receiving SSI benefits at two years of age. Then, "our income went up gradually and that was probably the most horrible time. They would send us the check at the beginning of the month and then when we would submit the paycheck stuff at the end, they [SSA] would say, 'Well, now you owe us half that back.' You are still not in a position where you can really make it on your own and yet they are penalizing you." Her daughter became eligible again for SSI benefits when she moved to a group home and was considered independent.

Some of the young adults did not receive SSI benefits before age 18. For those young adults who began to receive SSI benefits at age 18 and who continued to live at home, the SSI benefit was often used to pay for extracurricular

activities, club memberships, or other community activities or independent living supports, in addition to contributing to household expenses. Families of these young adults reported using a portion of the SSI benefit to subsidize family expenses (including necessities for the young adult such as personal hygiene items or clothing) or to pay for opportunities for the young adult to engage in recreational and leisure activities (such as bowling, going out to eat, movies, and so forth). One young adult described how the SSI money, "goes to me, but my mom uses it to help pay for the bills and food, but she gives me money whenever I need it." A parent said, "If she wasn't getting the SSI, definitely she wouldn't be in a lot of the classes that she likes and enjoys to do, bowling, you know, those kinds of things..." Another parent explained that they use the SSI benefit money for, "taking him places... the doctor's bills, there's some nights when we go out to eat, rather than cooking, stuff like that." A parent stated that after paying rent to the family, the rest of her child's SSI benefit money is spent on clothes and social activities. "I think it is a big thing with her, and a big thing I use the money for is places to take her out, because I can't afford to do that otherwise." Finally, another parent said, "I think some people who have children that have disabilities just stay home all the time and they need to go out. [She] is a very social person, and she can use some of her SSI to get out and be healthy in the community and learn of life."

Generally, if the young person was no longer living at home, the SSI check was spent almost entirely to cover the recipient's day-to-day expenses. One young adult explained, "My SSI check is about \$368 and my rent is \$350 a month." In several cases, the check was directly deposited into a group home account, and the young adult's expenses were paid out of that. One young adult said, "Yes, it [the group home] gets most of it [the SSI benefit] for rent." Researchers asked one parent, "If your daughter didn't receive SSI, would she not be able to live in that group home?" The parent replied, "That's a good question... her room and board is \$1,000 a month. Yes, it's possible she might not be able to be there."

Fears about Going to Work and Living Independently

Safety concerns affected employment choices for some participants. These participants and their families reported being nervous about the dangers of the "world of work," such as harassment and teasing. In speaking about her daughter, one parent said, "She works through the workshop at school. I mean she can work if she has to, has to, has to. I would never let her work though; I'm worried she'd be taken advantage of."

A concern for safety, and even perceived risk, played a role in many of the young adults' ability to interact with friends and to participate in the community. For example,

several respondents mentioned that they did not feel safe taking public transportation by themselves or leaving their homes by themselves. This fear was often reinforced by their parents, as well as outside events. One young woman explained, “I have friends that come over to the house, but I’m not much of a going-out person. I like going outside and playing games or something. Sometimes I’ll go out there if there’s a big group, but I don’t even like going to the store by myself and that’s not even four blocks up.” When the interviewer asked this young adult whether she ever goes to the store on her own, she responded, “No, [I live in a] bad neighborhood. I don’t think I’ve ever gone by myself. Someone got killed on Sunday, two houses up.” One of the parents reported that she would not let her daughter take public transportation, and her daughter did not want to because, “there are too many scary people.” Some parents, particularly the parents of young women, felt that they needed to closely monitor their children’s activities so that they would be safe. Other parents felt strongly that their children needed to be accompanied to all activities, including the interviews that were part of this study.

Access to Transportation

A major barrier to employment and building strong connections outside their homes for all the young adults interviewed was a lack of access to reliable transportation. One young adult said, “all my friends live too far to just go see them, and none of them drive,” so he doesn’t see them that often. None of the 34 young adults for whom researchers obtained information reported having a driver’s license. A few had learner’s permits, but were not actively working to pass the driving test. Additionally, several of the young adults said they could not afford to drive, due to the costs of maintaining a car, such as insurance, license, registration, and fuel.

Some of the transition programs have students practice taking public transportation as part of their programming, but very few of the young adults reported taking public transportation on their own. One young adult said that she would take the city bus, “if I have someone to go with me.” The majority of respondents relied on parents, family members, and (in a few cases) friends for most of their transportation. One family explained that they transport their daughter so she can participate in programs, which can be difficult. “But we don’t want her to ever just sit at home. It’s not good for her.”

Thus, not having access to reliable transportation posed a barrier to employment, independent living, and community participation outcomes for many of these young adults. How families used SSI income and safety concerns of these young adults also affected these outcomes.

Discussion and Recommendations

The discussion and recommendations presented below are based on researchers’ interviews with the transition-aged youth, family members, and transition service providers, as well as the researchers’ literature review of the impact on young adults of changes in SSI policy regarding the age 18 redetermination process after the Welfare Reform Act of 1996. Two of the most compelling observations are: (1) the interdependency of the various themes described above, and (2) the contextual obstacles that are beyond the control of families, persons with disabilities, and the agencies that serve them. That said, two additional findings deserve further discussion:

- The lack of knowledge about benefits programs and the lack of coordination among agencies, particularly schools and the SSA; and
- The significant obstacles, residing in both the workplace and in the individuals with disabilities, that act as barriers to achieving successful postschool employment, independent living, and community participation outcomes.

Lack of Knowledge and Coordination

First, the vast majority of people interviewed for this study had, at best, an incomplete understanding of SSI and the web of associated benefits and programs. This led to difficulties for the young adults and their families in accessing the full array of available services, as well as complicating the attempts of service providers to assist the transition-aged youth in planning for a successful transition.

In the focus groups with service providers and in the informal conversations with other professionals during subject identification, researchers repeatedly heard that these professionals often do not know the status of a particular student or client relative to SSI benefits. Teachers, vocational rehabilitation counselors, and other service providers expressed doubts about the quality and depth of their knowledge of the SSI program and its regulations, including the connection between receiving SSI benefits, receipt of Medicaid, and employment earnings. For example, most of the teachers were not involved with SSA; others indicated that their only involvement with SSA was filling out required paperwork specific to the student’s educational performance. Teachers and other service providers did not feel able to provide insight or advice to young adults and their families about how to work with SSI, specifically regarding regulations and requirements for receiving SSI. There seems to be a lack of personnel who are knowledgeable about SSI and the array of services and supports and who are available to counsel and work with parents and transition-aged youth to explain ways to safeguard against benefit loss due to employment.

Because many families see special education teachers as a primary information source on accessing services, it would be beneficial for school personnel to receive current information about SSI policies, such as changes in eligibility criteria. Whether this is realistic in view of the many responsibilities already placed on special education personnel is a major question, however. Nonetheless, it is clear from this study that transition-aged youth and their families would benefit from better information sharing between SSA and the education system.

Data from the National Longitudinal Transition Study 2 (NLTS2), consulted in the literature review, indicate that SSA representatives do not typically attend IEP meetings (Cameto, 2003); thus, information on SSI eligibility, the redetermination process, and available work incentives are not incorporated into student IEPs. Those most often present at IEP transition meetings include special and general education teachers, school psychologists, and school counselors. Vocational rehabilitation counselors were present at 14% of the IEP meetings reported in the NLTS2 survey; SSA and other agency representatives attended less than 2% of the IEP meetings (Cameto, 2003). Consequently, the student's IEP team members often do not fully understand the issues associated with a student's participation in SSI, such as eligibility status, the 18-year-old redetermination process, and the potential for using work incentives to achieve future employment goals. Additionally, although schools offer one consistent access point for information, transition-aged youth with disabilities not attending schools may not be able to easily access this information.

Given the continuing emphasis on work experiences as part of a student's transition process, a student's benefit status can be directly linked with their educational plan and discussions about their postschool employment and related outcomes. Further, a student's or family's eligibility for SSI benefits is directly tied to family income, which is, obviously, impacted by a student's employment status. Without an explicit facilitator or coordinator exclusively focused on the transition process and the array of services and supports available to students who are SSI recipients, opportunities to help transition-aged youth and their families are missed, which may result in diminished outcomes. The primary issue to be resolved is who explicitly should fill this role.

Recommendations for Improving Knowledge and Coordination

Given that the vast majority of people interviewed for this study had a limited understanding of SSI and the web of associated benefits and programs, and that currently no individual is specifically designated to help transition-aged youth and their families navigate the transition into adulthood, the following recommendations are offered to support individuals with disabilities and their families in achieving positive postschool outcomes.

Recommendation 1: Provide Information

The first recommendation is to provide readily available, user-friendly, accurate information about the SSI program to service providers and to transition-aged youth and their families. Specific strategies include the following:

- Information about the SSI program should be available both on paper and through the World Wide Web. The information should be universally designed so that nonreaders or non-English speakers can access the information.
- Service providers and transition-aged youth and their families should receive information that increases their awareness about the processes and criteria that SSI uses to establish initial eligibility and redetermination eligibility for receiving SSI benefits. For those young adults redetermined as ineligible, more information is needed about the appeals process.
- Personnel who are primarily responsible for supporting a young person's transition from school to adult life need clearer information to support the identification of appropriate work incentives and to discuss the implications of employment in relation to SSI benefits. Students and their families critically need this information on which to base decisions concerning current and future employment options.
- Preservice programs should place more emphasis on providing detailed information about SSA and other agencies to preservice teachers. Transition professionals need continuous training on SSA and other benefit programs. This training should incorporate multicultural, socioeconomic, and linguistic perspectives so that transition professionals are able to integrate these perspectives into their work with clients around social benefit programs.

Recommendation 2: Facilitate Discussions

The second recommendation is to facilitate discussions among service providers, youth, and families through the following strategies:

- Designate an individual to facilitate discussions between service providers and transition-aged youth and their families about the connection between SSI and other benefit programs and postschool outcomes, such as employment, independent living, and community participation.
- States should increase their use of the Benefits Planning, Assistance, and Outreach (BPAO) Program.
- Schools and families should begin discussing future work roles early in a student's educational program, including information on SSI, Vocational Rehabilitation, and Workforce Investment Act (WIA) programs.

- Identify a service provider to work with transition-aged youth and their families to incorporate SSI work incentives into the IEP/transition planning process.
- Identify a service provider who can assist transition-aged youth and their parents in preparing for the age 18 redetermination process by collecting the appropriate documentation on students' disabilities, limitations, performance, and behaviors to assist SSA in the disability review for age 18 redetermination eligibility.

Recommendation 3: Improve Collaboration and Coordination

The third recommendation is to improve interagency collaboration and service coordination among agencies working with transition-aged youth and their families through the following:

- Engage SSA staff to facilitate communication among students, parents, and school personnel regarding the meaning of going to work in relation to their SSI benefits.
- Involve SSA in the transition planning process. Despite obvious cost constraints, this would substantially aid school-aged youth and their parents to better understand the interrelationships and implications of working.
- Crosswalk the eligibility requirements for different programs, such as SSA, Medicaid, and Vocational Rehabilitation, so that information can be more easily shared among those agencies. This information would be helpful to service providers as they work with transition-aged youth and their families to help them achieve their postschool goals.

Significant Obstacles

The young adults with disabilities, parents, and service providers interviewed for this study reported significant obstacles for transition-aged youth with disabilities trying to achieve their employment, independent living, and community participation goals. The obstacles included (a) workplace environments that are not prepared for employing persons with disabilities; (b) various constraints particular to the young adults and their disabilities; and (c) family dependence on SSI benefits and related benefits, such as Medicaid.

As reported by study respondents, many work environments do not support the training needs of individuals with disabilities. Additionally, employers are not generally knowledgeable about the types of accommodations that might enable young adults with disabilities to succeed in a job, and the young adults are not always able to articulate the accommodations they need to be successful in a job. For example, respondents talked about inadequate training using cash registers and other skill-based equipment, subtle forms of harassment by other employees, and inflexibility around scheduling.

The issues of transportation and personal safety compound these challenges to achieving and maintaining employment. As mentioned above, many of these young adults and their parents were concerned about the safety of the young adults traveling independently to and from a job, and many of these young people also had limited access to reliable transportation. In this study, some parents and young adults felt that, given the nature of the young adult's disability, it would not be feasible for the young person to work in a full-time job.

Another barrier to employment for young adults on SSI is that parents (and the young adults) fear that working will mean losing SSI and related benefits. One common concern was the loss of Medicaid benefits if the transition-aged youth moved into paid work without benefits. As mentioned above, SSA's programs to improve employment outcomes – such as Ticket to Work, PASS, and other SSA work incentives – are underutilized. It is important to note that the disincentive to work is caused not only by complicated SSA policies and the related fear of losing SSI benefits, but also by the limited capacity of service organizations to facilitate work opportunities and by poor employment prospects (low wages, no health benefits) for these transition-aged youth with disabilities.

Based on the employment histories that participants reported, none of these young adults could have afforded to live independently on earned income alone. They worked in very low-paying jobs, if at all, which rarely offered health insurance or any other benefits. Employment is a precursor to independent living, so the obstacles to employment for these individuals also blocked, or could block, the path to independent living. The reliance of families on SSI also acted as a disincentive to actively pursuing independent living arrangements. Because many of the young adults in this study had limited independent living skills, parents were often concerned about the safety and/or ability of their child to live independently.

Without knowledge of the services available to help an individual access and navigate the workplace and independent living arrangements, transition-aged youth cannot take full advantage of existing opportunities to participate in the community. The transition-aged youth and their family members expressed both an inability and hesitancy to participate in the community. Additionally, low-income families were hesitant to jeopardize a reliable and critical income source, SSI, for an unknown such as employment and/or placement in an independent living arrangement. By not taking these two risks, the young adults in transition had little opportunity to experience the measure of independence that might lead to community participation. In short, without some sense of ongoing support, families were hesitant to lose SSI and possibly Medicaid for a world they perceived as risky at best.

Recommendations for Removing Obstacles

Given the obstacles to the achievement of employment goals and subsequent independent living and community participation for transition-aged youth with disabilities, the following recommendations are offered to support individuals with disabilities and their families in achieving positive postschool outcomes.

Recommendation 1: Increase Awareness

The first recommendation is to increase the awareness of professionals and parents about the capacity of individuals with disabilities to work through the following strategies:

- Personnel who are knowledgeable about SSI and the array of services and supports available to help young adults both work and maintain SSI and related benefits must be available to counsel transition-aged youth and their families, ideally during IEP transition planning meetings. These service providers must also be knowledgeable about the socio-cultural context of the families and individuals they are counseling. It is particularly important to dispel myths about the implications of working while on SSI benefits.
- The safeguards on potential benefit loss due to employment need to be thoroughly explained to parents. Professionals and parents must discuss the implications of going to work on their child's SSI benefits as early as possible.
- The Benefits Planning, Assistance, and Outreach (BPAO) Program should be used to provide information to service providers, transition-aged youth, and their families.

Recommendation 2: Develop IEP/Transition Plans

The second recommendation is to work with transition-aged youth and their families to develop a culturally and socially appropriate IEP/transition plan that addresses employment, independent living, and community participation outcomes, with attention to the following:

- The IEP/transition plan should be designed to help the individual attain his or her desired postschool outcomes, while taking into consideration the individual and his or her families' socioeconomic status, reliance on SSI and related benefits, and cultural/societal context within which they are navigating these benefit systems.
- Specific SSI work incentives that would support the individuals' intended postschool outcomes should be discussed with the transition-aged youth and their parents, and these should be incorporated into the student's IEP/transition plan.

Conclusion

This brief provides a picture of how young adults with disabilities and their families attempt to navigate a variety of systems during transition, and the complex impact of the SSI age 18 redetermination on their lives. The stories researchers heard in these interviews provided a picture of how some young adults with disabilities and their families maneuver through a system that often confuses both them and their service providers. Meanwhile, researchers also heard from service providers who are trying to help the young adults with disabilities achieve employment, independent living, and community participation outcomes. However, given the obstacles encountered in trying to obtain a representative sample, further systematic study is warranted. A future study would best be conducted with access to a wider spectrum of young adults and their families. It is critical that these young adults move from a dependence on SSI to employment and independent living. Thus, young adults, parents, and service providers need to better understand various work incentive programs and health care options; and transition service providers would benefit from additional information about SSI and other benefit systems in order to help youth and families better understand how to achieve their goals for the future.

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■ Related Institute Publications

The following Institute on Community Integration publications may be of interest to readers of this brief. They can be found online at <http://ici.umn.edu/products>; for information on print copies call 612/624-4512, or e-mail publications@icimail.umn.edu.

- *Impact: Feature Issue on Parenting Teens and Young Adults with Disabilities* (2006). A newsletter issue exploring strategies for families of teens and young adults with

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- *Impact: Feature Issue on Supporting Success in School and Beyond for Students with Autism Spectrum Disorders* (2007). A newsletter issue providing information on strategies and resources that can assist educators, families, and others to support the academic, social, and vocational success of PreK-12 students with Autism Spectrum Disorders.
- *Impact: Feature Issue on Fostering Success in School and Beyond for Students with Emotional/Behavioral Disorders* (2005). A newsletter issue providing information on strategies and resources that can assist educators, families, and others to support the academic, social, and vocational success of students with emotional/behavioral disorders.
- *Impact: Feature Issue on Achieving Secondary Education and Transition Results for Students with Disabilities* (2003/04). A newsletter issue focusing on policies, strategies, and success stories supporting positive outcomes for transition-age students with disabilities.
- *NCSET Information Brief: Transition Services for Students Aged 18-21 with Intellectual Disabilities in College and Community Settings: Models and Implications of Success* (2006). A brief providing an overview of some successful models of transition services being implemented in postsecondary settings, describes one such model implemented by the Baltimore City Public School System in three local colleges, and presents some of the implications and strategies for success of this model.
- *NCSET Information Brief: Choices in Transition: A Model for Career Development* (2006). A brief describing the Choices in Transition program for low-income ethnic minority youth with disabilities in Chicago. Recommendations for improving the transition outcomes of youth with disabilities are included.
- *NCSET Information Brief: Social Security and Undergraduates with Disabilities: An Analysis of the National Postsecondary Student Aid Survey* (2004). A brief providing a rich demographic profile of the utilization of postsecondary education by recipients of Social Security Income (SSI) and Social Security Disability Insurance (SSDI). The brief summarizes the results of the National Postsecondary Student Aid Survey and also provides information about resources for further information.
- *Essential Tools: Handbook for Implementing a Comprehensive Work-Based Learning Program According to the Fair Labor Standards Act (3rd ed.)* (2005). A handbook designed to encourage adoption of work-based learning

programs and to guide school personnel who operate such programs to make them consistent with the Fair Labor Standards Act (FLSA).

- *Essential Tools: Increasing Rates of School Completion – Moving From Policy and Research to Practice* (2004). A cutting-edge manual for educators, administrators, and policymakers describing 11 proven interventions for increasing school completion among youth with disabilities.
- *National Standards & Quality Indicators: Transition Toolkit for Systems Improvement* (2005). A toolkit providing a common and shared framework to help school systems and communities identify what youth need in order to achieve successful participation in postsecondary education and training, civic engagement, meaningful employment, and adult life. It contains a set of national standards and quality indicators, and strategic planning tools for use by states and school districts.

■ Other Institute Publications

The following are other research-based Institute publications that may be of interest to readers.

DD Data Brief

DD Data Brief is a series summarizing analyses of the 1994/1995 National Health Interview Survey – Disability Supplement, conducted by the Institute’s Research and Training Center on Community Living. The following issues are available online at <http://rtc.umn.edu/nhis/pubs.asp>.

- *Characteristics of Aging Caregivers in the NHIS-D*. (2006)
- *Mothers With Disabilities – Characteristics and Outcomes: An Analysis From the 1994/1995 NHIS-D*. (2005)
- *Social Activities of Non-Institutionalized Adults in the NHIS-D: Gender, Age, and Disability Differences*. (2005)
- *Problems in Defining Mental Retardation and Developmental Disability: Using the National Health Interview Survey*. (2005)
- *Response Patterns Among Adult Respondents With Mental Retardation in the National Health Interview Survey, 1997-2002*. (2004)
- *Gender, Age, and Disability Differences in Functional Limitations for Non-Institutionalized Adults in the NHIS-D*. (2004)
- *Service Use by and Needs of Adults With Functional Limitations or ID/DD in the NHIS-D: Difference by Age, Gender, and Disability*. (2003)

- *Health Insurance Coverage and Health Care Experiences of Persons With Disabilities in the NHIS-D*. (2003)
- *Children With Disabilities: Social Roles and Family Impacts*. (2002)
- *Functional Limitations of Adults in the U.S. Non-Institutionalized Population*. (2001)
- *Demographic Characteristics of Persons With MR/DD Living in Their Own Homes or With Family Members*. (2001)
- *Characteristics of and Service Use by Persons With MR/DD Living in Their Own Homes or With Family Members*. (2001)
- *Prevalence of Mental Retardation and/or Developmental Disabilities*. (2000)

Reports

- *Alternative Schools: Policy and Legislation Across the United States (Research Report 1)* (2003). Available on the Web at http://ici.umn.edu/alternativeschools/publications/Legislative_Report.pdf
- *Alternative Schools: Findings From a National Survey of the States (Research Report 2)* (2004). Available on the Web at http://ici.umn.edu/alternativeschools/publications/alt_schools_report2.pdf
- *NCEO Special Report: A State Guide to the Development of Universally Designed Assessments* (2006). Available on the Web at <http://education.umn.edu/nceo/OnlinePubs/specialreports.html>
- *NCEO Special Report: Universal Design Online Manual* (2006). Available on the Web at <http://education.umn.edu/nceo/OnlinePubs/specialreports.html>
- *NCEO State Report: 2003 State Special Education Outcomes: Marching On* (2003). Available on the Web at <http://education.umn.edu/nceo/OnlinePubs/statereports.html>
- *NCEO Technical Report 43: Uneven Transparency: NCLB Tests Take Precedence in Public Assessment Reporting for Students With Disabilities* (2006). Available on the Web at <http://education.umn.edu/nceo/OnlinePubs/technicalreports.html>

The New NCEO Data Viewer

(<http://data.nceo.info/>)

■ What is the NCEO Data Viewer?

The Data Viewer is an interactive data Web site available online from the National Center on Educational Outcomes (NCEO), Institute on Community Integration, at <http://data.nceo.info/>. It contains information on:

- State policies on assessment participation and accommodations
- State Annual Performance Report data

Users can create customizable reports (color-coded maps and tabular charts) based on criteria they can choose.

■ Reporting Capabilities: State Policies on Assessment Participation and Accommodations

The Data Viewer has the following capabilities when looking at state policies on assessment participation and accommodations for students with disabilities:

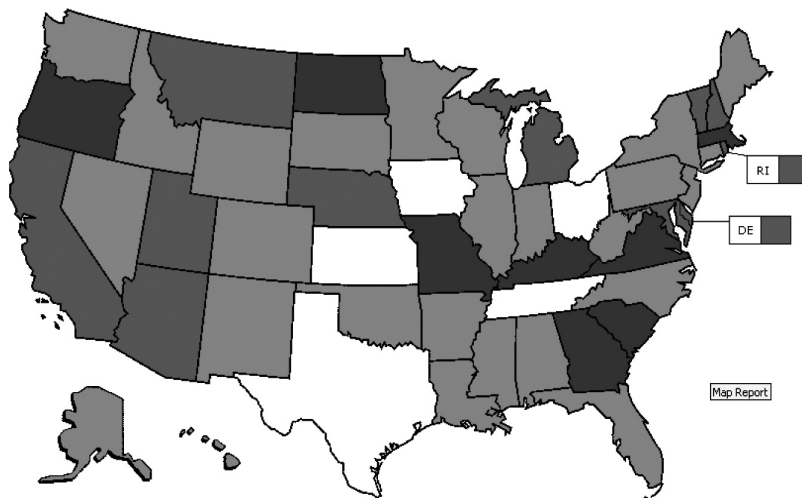
- **Report Designer** – Produces customizable data reports that allow for deeper analysis of participation and accommodations issues. Participation reports include information such as how students participate in state assessments, additional testing options, criteria that can/cannot be used to guide accommodations decision-making, and how states make decisions about accommodations that are not on an approved list. Accommodations reports can be generated based on selected states and accommodations categories (e.g., presentation, equipment, response, setting, and timing), and reports can be created to illustrate policies in one state, to compare two states, or to see policies in all states.
- **Summary Reports** – Produces customizable summary data reports on state policies for assessment participation and accommodations for students with disabilities.
- **State Profiles** – Provides verified information from states that was used to develop the tables in the Data Viewer.

■ Reporting Capabilities: State Annual Performance Reports

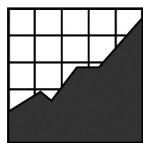
The Data Viewer has the following capabilities for data from State Annual Performance Reports:

- **Report Designer** – Produces customizable summary data reports that allow for deeper visual and tabular analysis of participation and accommodations use and performance data.
- **Summary Reports** – Produces customizable summary data reports for one state or all states (regular or unique) including Enrollment data, Participation data (Regular Assessment, Out of Level Assessment, Alternate Assessment, No Assessment), and Performance data (Regular Assessment, Alternate Assessment Based on Grade Level Standards, Alternate Assessment Based on Alternate Achievement Standards), as well as Overall Statistics.

Sample Map Using the Accommodations Report Designer Showing Read Aloud Questions



- Legend**
- Allowed (A)
 - Allowed with Implications (AI)
 - Allowed in Certain Circumstances (AC)
 - Allowed with Implications in Certain Circumstances (AI/AC)
 - Prohibited (P)
 - No Policy
 - Not included in report



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Policy Research Brief July 2007 • Vol. 18, No. 1

Policy Research Brief is published by the Research and Training Center on Community Living, Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota. This publication is supported, in part, by Cooperative Agreement #H133B031116 from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Managing Editor is Sheryl A. Larson. The opinions expressed are those of the authors and do not necessarily reflect the position of the Center or its funding sources.

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