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ABSTRACT

This final report describes the activities and outcomes of Opening Doors: Decisions about Life and Work Project, a project designed to assess the effectiveness of integrating information and support on Supplemental Security Income work incentives into the transition planning process for students with disabilities. The primary goal of the project was to increase student, family, and school expectations for employment and improving employment outcomes. At a local level, project activities included a longitudinal study of youth and parents, as well as training and capacity building in four local communities. Three years of longitudinal data were collected and research findings were summarized in brief products intended to be easily read and used by families and personnel. To affect change at a local level, project staff assisted in the development of Student Support Teams in four school districts. The purpose of these teams was to improve the transition planning and outcomes for students leaving high school. Support concerning the work incentives and person-centered planning were incorporated into services for 40 students. Formal training on the SSI work incentives was also provided to both teachers and parents. Project products addressing expectations, SSI, and the Plan for Achieving Self-Support program are included. Appended are: (1) "Research to Practice" Volume 6, Number 1 (April 2000); (2) "Tools for Inclusion" Family and Consumer Series Volume 9, number 3 (December 2001); and (3) "Tools for Inclusion" volume 7, number 2 (July 1999). (CR)

Final Report

for

Increasing Utilization of SSI Work Incentive by
Students Approaching Graduation Project

Project Period

10/1/97 through 12/31/01
(3 month no cost extension)

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Research and Innovation to Improve Services and Results for Children
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II. Project Summary

The Opening Doors: Decisions About Life and Work project was assessing the effectiveness of integrating information and support on SSI work incentives into the transition planning process for students with disabilities with a primary goal of increasing student, family, and school expectations for employment and improving employment outcomes. At a local level, project activities included a longitudinal study of youth and parents as well as training and capacity building in four local communities. Three years of longitudinal data were collected. Research findings were being summarized in brief products called Research to Practice and were intended to be easily read and used by families and school personnel. Journal articles have also been developed to share this information with a professional audience. Copies of this material are included in this packet.

To impact change at a local level, Project staff assisted in the development of Student Support Teams in four school districts. The purpose of these teams was to improve the transition planning and outcomes for students leaving high school. Support concerning the Work Incentives and person-centered planning were incorporated into services for some students and the goal of the Student Support Team was to generalize these accomplishments to the entire system. A significant obstacle in the transition process has been a lack of employment experiences for students. There was limited concern about the impact of work on Social Security benefits since there was not an expectation that students were work at the completion of school. Project staff provided more technical assistance and support to school personnel on helping students to access employment. Over the course of the project, the school liaison had an increased presence in the school to support their efforts toward employment.

Formal training on the SSI work incentives was provided to both teachers and parents. It became apparent that for both groups more informal consultation and assistance has been more helpful. Resource materials, such as packets for families when a student first begins a job, were developed and provided to the schools. A resource manual that provides detailed information on a variety of SSI Work Incentive topics was developed. The intention of the manual is that a teacher can turn to a section and find a one-page summary of an issue. If they need more detailed information they can continue in the section and will find sample documents they can use for reference. Copies of the manual have been provided to members of the Student Support Team and the possibility of posting all o the resource information on the ICI web site is being considered.

In addition to the project specific activities, staff from the Opening Doors project have participated in the Work Incentive Transition Network. In addition to joint publications, ICI staff organized joint presentations at the national TASH conference and participated in a poster session presentation at the Project Director's meeting.

III. Project Status

Goal 1: Establish statewide policy and a statewide technical information network that support identifying and implementing SSI and work incentive related support needs during transition planning

Project staff became members of the Massachusetts Partnership for Transition. The Partnership has representatives from the Departments of Education, Public Health, and Mental Retardation for the state as well as staff from School to Work initiatives and advocacy groups. In this forum the project was able to orient statewide representatives to some of the new issues regarding Social Security and transition age youth. Project staff provided an orientation to the MPT group on the Ticket to Work and Work Incentive Improvement Act.

Project staff met quarterly with the state-wide coordinator of employment service for the Department of Mental Retardation. Local service coordinators also attend these meetings and the focus was on improving employment outcomes for students transitioning from schools into adult services. The role of SSI work incentives in supporting these efforts was consistently addressed.

To extend the impact of the project activities, staff became involved with state-wide efforts related to work for individuals who are SSI recipients. Project staff attended a quarterly SSI networking group which is hosted by the Department of Public Health as well as the SSI Coalition sponsored by the Disability Law Center.

The Project Director was also a member of the Transition to Adult Orientated Care Advisory Committee, which is the Massachusetts Healthy/Ready to Work project. Since the majority of members of this committee represent pediatric care, they had limited information about the relationship of SSI and work. SSI and the SSI work incentives were a consistent component of discussion at the Advisory Committee meetings. In addition, project staff completed a separate training for medical personnel associated with the Healthy/Ready to Work projects on the SSI Work Incentives and the effect of working on benefits.

In conjunction with Federation for Children with Special Needs and the Massachusetts Organization of Educational Collaboratives, project staff continued to be involved in statewide training on transition issues. Project staff conducted a regional SSI Work Incentive training for trainers who conduct transition training for local school districts and parents.

Project staff presented findings from the research at the New England Rehabilitation Associate conference in April 1999. They also had a poster session at the Massachusetts Council for Exceptional Children conference in October, 1999. In December of 1999, project staff in conjunction with other WITN sites presented at the national TASH conference. Information from this project was presented at the APSE (Association of Persons in Supported Employment) conference in 2000 and 2001. See Appendix A for full listing of training and conference events.

Project staff participated in a cable access call-in show dealing with transition issues. Through the sponsorship of the VCU Work Incentive project, ICI staff also participated in a national satellite telecast to report findings from this project.

Benchmark Objectives (Due date)	Status	Comments
Implement Massachusetts Partnership for Transition (formerly MTI) as project advisory committee (1/98)	Completed	
Integrate info. on SSI and work incentives into statement of needed transitional services (10/98)	Not accepted	Was presented to MPT and Department of Education but decision was made not to include in statement of need
State-specific fact sheet (10/98)	Utilized WITN document on work incentives 4 WITN briefs were developed	In addition to project materials, staff have incorporated materials developed by other WITN sites in training and info sharing.
Create state-wide network of experts (3/98)	Identified local resources and material is provided in resource manual available at the schools	
Provide work incentive training to family advocates (7/98-7/01)	A training of parents and advocates occurred each year (See Appendix A)	Training has occurred in conjunction with Federation and Mass. Organization for Educational Collaboratives
Establish and moderate chat room (7/98-7/01)	Was not implemented	Through collaboration with other projects, it was determined that VCU project will develop web site with links to other projects.
Information referral phone line	Staff from Federation and Disability Law Center were available for phone inquires as well as the school liaison staff person	

Goal 2 Develop and implement a longitudinal study of the barriers to employment and the factors that influence career development for 80 young adults with disabilities who receive SSI and 80 young adults with disabilities who do not receive SSI

Three years of data collection were completed with the same families and students. In year 1, 160 parents and 154 students completed surveys. IN year 2 it was 143 parents and 151 students and year 3 was 128 parents and 137 students. Students and families that participated in the study represented a variety of Social Security benefit statues including Survivor’s benefit and SSDI. Families reported very limited knowledge about the Work Incentives and have not been using these incentives. Another concerning finding was that 2/3 of the students were not working or looking for work. The barrier for these students seem to be less about concerns regarding SSI but a lack of exposure to work in general.

A component of the longitudinal study were the expectations that parents and students had for their short and long term achievement. Key findings include that students typically have higher expectations for themselves than their parents and that SSI status is a factor in parental expectations. Parents of students who receive some type of SSA assistance have lowered expectations than parents of other special education students. Student’s who receive and do not receive Social Security Assistance report the same level of expectation and self-determination.

Benchmark Objectives (Due date)	Status	Comments
Train data collectors (2/98)	All project staff were trained on instrument and adaptive formats	
Pilot data collection (2/98)	Completed	
Develop sample and secure informed consent (4/98)	Completed	
Conduct qualitative data collection (4/98)	Three round of qualitative interviews were completed with the same families	Year 1: 12 students who are SSI recipients and 9 parents. Year 2: 9 students and 7 parents Year 3: 4 students, 3 parents
Collect data (4/98)	Completed	

Benchmark Objectives (Due date)	Status	Comments
Conduct qualitative analysis of data (4/98-6/01)	Completed	
Conduct Quantitative analysis (1/99-6/01)	Analysis completed	
Develop interim report (7/99-6/01)		
Develop Brief reports and journal articles (10/99-0/01)	Most completed—3 articles still in process	In addition to brief products, 2 journal article are being developed on the quantitative findings and 2 articles on the qualitative interviews.—See dissemination products in Appendix B

Goal 3: Develop a model approach to promoting and supporting work incentives used in 4 schools that emphasizes local capacity building and self-determination

Project staff participated in Student Support Teams at each of the project school. The focus of these teams was to do individual planning for students as well as discussing strategies to increase employment and transition resources for all students served in the school. Members of the team differed somewhat from school to school but typically include school personnel, school to work staff, representatives from the Departments of Mental Retardation and Vocational Rehabilitation as well as community rehabilitation providers.

Through these teams it has become clear that a lack of community employment experiences have been a major obstacle for students transitioning into adult services. Historically students have transitioned from these schools into segregated programs such as sheltered workshops and day habilitation. Through a larger system change effort, considerable progress has been made with the schools to develop jobs for students while they are still in school and establish the long term supports that may be necessary outside of school. Project staff have been working closely with school personnel on how to incorporate employment activities in students' educational program. The goal of this intervention was to model for school personnel the strategies to help students get jobs. These meetings have continued in the schools after project staff ended their participation. Sample transition resource material from Brockton Student Support Team is included.

Employment Portfolios were developed to ease the process of sharing referral and assessment material between the school and the adult agencies. An outline of what was included in the portfolios is in Appendix C.

Formal training on SSI and the work incentives occurred in the schools. Teachers were more receptive to information related to the SSI when it was been closely tied to issues they are immediately facing. For example, as teachers were preparing for summer employment opportunities, a brief training session was held on how to report jobs to Social Security and requesting student earned income. Sample materials were developed for the teachers to use with parents as any changes occur in a student's SSI status.

A training manual was developed that provided all the overheads used in teacher and parent trainings so that teachers could conduct the training independently.

To build the capacity of the broader community to support the school efforts and to encourage employment for students leaving the high school, training and support was provided to community organizations. The school liaison became a member of the Brockton Area Committee on Employment and presented at a transition conference they were hosting for parents. Other training was conducted with the Brockton Latino Health Institute, a Latina parent group in Worcester and at three community rehabilitation providers. Outreach was undertaken with case managers at the Department of Public Health who can serve as support to parents working within the Social Security system.

Parent trainings and individual consultation with parents was conducted. There was been limited attendance at formal parent training and the project staff found it more effective to work individually with families as concerns arose.

Benchmark Objectives (Due date)	Status	Comments
Establish work support teams at schools (4/98)	Teams were created in all four school sites	
Train and support members to provide training (1/98-1/01)	Training with teachers occurred in all four schools	Smaller focused trainings have been found to be more effective with teachers
Develop curriculum (7/98)	Developed See Appendix D for training material	Representatives from Federation and DLC have participated in curriculum development and training.

Benchmark Objectives (Due date)	Status	Comments
Provide training to students and parents	Completed	Trainings have occurred in each school district and have typically been done in conjunction with a DMR office or PAC meeting.
Provide training to school personnel	Completed	Formal training has occurred and informal training options are being expanded.

Goal 4: Support 60 students to complete a person-centered career planning process and implement a personal work incentives plan

Person centered planning activities were conducted with ten students per site. These person-centered plans were the basis of the vocational development activities in the school. Teachers received support on finding jobs that were consistent with the student's vision. These students have also been the focal students for the Student Support Team discussions. As success was achieved with these students, the team was able to generalize these strategies to more students.

Benchmark Objectives (Due date)	Status	Comments
Train 20 individuals on person-centered planning (12/98-3/99 and 12/99-3/99)	Plans were conducted in conjunction with school personnel	
Implement person centered career plans for 60 individuals (3/99-12/00)	Person-centered planning was completed with 40 students	
Co-facilitation person-centered plans with facilitator (3/99-12/00)	Occurred with existing person-centered plans	
Develop personal work incentive plans for peer to peer support (3/99-12/00)	Ongoing	Needs concerning work incentives are addressed in planning process and through discussion at Student Support Team meetings

Goal 5: Assess the relative efficacy of state, local, and individual interventions on the utilization of work incentives and personal work-related outcomes

Significant errors on the data tape provided through Social Security made it difficult to use for analysis. Quarterly data provided on the SSA web site was be used to compare differences in use of work incentives for Massachusetts.

Benchmark Objectives (Due date)	Status	Comments
Acquire data quarterly from SSA (1/98-9/00)	Data tape was not able to be used because of errors	
Implement changes in Statement of Needed Transitional Services (9/98)	Not approved	
Develop fact sheet (4/98-10/98)	Completed	
Disseminate fact sheet (10/98-12/98)	WITN fact sheet was distributed to Sped Administrators state wide and to parents	
Assess use of phone/Internet information (1/99-7/01)	Ongoing	Column in Federation newsletter has led to numerous phone inquires
Develop research report/journal articles(5/00-7/01)	See attached materials	

Goal 6: Implement a broad dissemination plan that addresses the needs of individuals, families, LEAs and policy makers using a range of media and formats

In addition to products developed with WITN, the project developed Tools for Inclusion that focused on the development of a PASS, working with the Social Security system, a draft product on use of networking to develop self-determination.

Project staff contributed to a monthly column in the Federation for Children with Special Needs newsletter. The mailing list for this newsletter is 10,000 individuals, primarily families. The column focused on questions families have about SSI Work Incentives and transition age youth.

The Project web site was expanded and included resource material for parents and teachers as well as links to the WITN site and other project sites.

The Disability Law Center, a subcontractor of the Project, had developed a booklet for individuals. For this project, they had the materials translated in Spanish. Copies of the booklet in English and in Spanish were provided to all of the other WITN sites. (see attached booklets)

Benchmark Objectives (Due date)	Status	Comments
Develop fact sheet (4/98-10/98)	Completed	
Publish info on work incentives in Federation Newsletter 4/98-10/01)	Completed	Column appears in the quarterly newsletter
Develop and moderate chat room 7/98-10/01)	Was not implemented	Developed a collaborative web site with other members of the Network
Post facts sheets and links between Network and local collaborators (7/98-12/98)	Completed	Information has been posted on ICI web site in addition to WITN
Develop trainers guide (4/98-3/99)	Trainers guide was developed	
Develop manual for local work incentive teams (3/99-7/01)	Completed	
Develop curriculum for work incentives teams to train teachers (7/98-1/00)	Completed	
Develop curriculum for work incentives teams to train parents (7/98-1/00)	Completed	
Develop brief products on research findings (5/01-9/01)	Completed	
Develop individual reports for each study (5/01-9/01)	Underdevelopment	

Part IV Budget Information

Final Budget information will be provided by the research accounting department at Children's Hospital as required for termination of the grant.

Part V Supplemental Information/ Changes

In addition to the state specific activities for this project, project staff were actively involved in the Work Incentive Transition Network (WITN). Staff took part in regular teleconferences with project directors to discuss implementation issues related to the project and to share strategies each site had developed. Project staff also participated in teleconferences with all representatives from WITN to discuss policy issues such as the use of teachers to inform about fraudulent applications for SSI. Teleconferences with representatives from the Regional Resource Centers and WITN project directors also occurred.

As part of the Work Incentive Network, this project took a lead on coordinating the product development and dissemination subcommittee. Four WITN products have been developed and disseminated.

In conjunction with the other members of WITN, project staff participated in a day long, pre-conference session at the TASH conference in December 1999. An additional session was also presented at that conference on the research findings from each of the WITN sites.

The staff person previously in the school liaison role also presented at a national conference focused on issues for individuals of Hispanic backgrounds. Her presentation was conducted in Spanish and one session occurred in Southern California and a second session in Mexico. The presentation was done in conjunction with a representative from the Social Security administration and focused on SSI Work Incentives.

Project staff hosted a site for the VCU SSI project satellite training on April 21, 1999. Recruitment for the training was conducted in conjunction with the Department of Education. The satellite conference occurred during school vacation week and so attendance was very limited. Individuals who did attend reported finding the information very helpful.

ICI staff replicating the Virginia Commonwealth University teacher survey on SSI and fraud and provided the data to VCU for analysis. The project sampled Massachusetts' teachers who participated in a transition conference as well as special education administrators. The project also used this opportunity to mail resource materials to this group.

Training or TA	# of Attendees	Topic	Location
TA	3 School staff	Person-Centered Planning & Work	Worcester South High School
TA	2 Professionals	CBES Service Provision	BAMSI, Lakeville
TA	4 School/agency staff	Interviewing Tool	Malden HS
TA	3 Family members	Writing a PASS plan	Sudbury
TA	15 Professionals	Supporting Students in Employment	Brockton HS
TA	10 School/agency staff	Collaborative funding pool to support students in transition	Brockton HS
TA	10 School/agency staff	Employment Portfolio Use	Brockton HS
TA	15 School staff	Employment options: Long-term planning seminar	Westminster: for Worcester staff
TA	5 School/agency staff	Interview Book Development	Worcester
TA	3 Students	Writing a PASS	Sudbury, Worcester, Brockton
TA	5 Students	Assistance at SSA appointments	Worcester, Brockton
TA	15 Students	Interviewing preparation	4 grant sites
TA	5 Students	Person-centered planning	Worcester, Malden, Chicopee
TA	3 Students	Assistance at job interviews	Worcester, Malden
TA	6 students	Vocational interest assessment	Worcester
TA	10 Parents	Guardianship issues	Worcester, Maynard, Brockton
TA	20 Parents/students	Accessing SSI	4 grant sites
TA	30 Parents/students	SSI benefits and work	4 grant sites
TA: monthly	6 School/agency staff	Supporting students in employment	Malden High School
TA: monthly	9 School/agency staff	Supporting students in employment	Worcester South High School
TA: monthly	9 School/agency staff	Supporting students in employment	Brockton High School
TA: monthly	7 School/agency staff	Supporting students in employment	Chicopee Comprehensive High
Training	27 Professionals	Best Practices in Transition	RATTAT, Wareham
Training	10 Parents/students	SSI Work Incentives	Chicopee Comp HS
Training	8 Parents of students	SSI Work Incentives	Brockton HS
Training	17	CBES activities	Worcester HS
Training	9 Parents/students	SSI Work Incentives	Framingham
Training	12 Parents/students	SSI Work Incentives	Brockton HS

Training or TA	# of Attendees	Topic	Location
Training	8 Federation Staff	Train the Trainer: SSI & Transition	Boston
Training	15 Parents/students	SSI & employment	Worcester
Training	11 Parents/students	PASS Workshop	Quinsigomund CC
Training	25 Professionals	TWWIA	APSE Conference, D.C. 2001
Training	18 Parents/ Professionals	SSI Work Incentives	Seven Hills, Worcester
Training	16 Professionals	Policy to Practice: SSI/DI Work Incentives	UMass, Boston
Training	25 Professionals	SSI/DI Work Incentives	College of the Holy Cross, Worcester
Training	8 Professionals/ Parents	SSI Work Incentives	Greater Newburyport Ed Collaborative, Salisbury
Training	8 Parents	SSI Work Incentives	Casa Primavera
Training	3 Teachers	SSI Work Incentives	Malden HS
Training	8 Parents/Teachers	SSI Work Incentives	Chicopee HS
Training	7 Professionals	SSI/DI Work Incentives	Salisbury
Training	75 parents and consumers	Employment and Social Security	Minute Man ARC
Training	25 parents	SSI Work Incentives	Massachusetts Down Syndrome Congress
Training	40 professionals/ consumers	Research from longitudinal project	APSE 2000
Training	70 parents/ consumers	SSI and work incentives	National Down Syndrome Congress
Training	25 professionals	Research from longitudinal study	OSEP Project directors meeting

Other	Topics	Source
Quarterly Newsletter Article	SSI Work Incentives	Federation Newsline
Employment Portfolio Development	Transition & Employment	High School to Primary Agency
Radio Interview	SSI/DI Work Incentives	Allston-Brighton Free Radio
Local Cable Show	SSI/DI Work Incentives	Boston Neighborhood Network
School & Community Newsletter	Summer Jobs	Worcester, Malden, Brockton, Chicopee
Tools for Inclusion publication	Helpful Hints: How to fill out a wining PASS	ICI
The SSI Answer Book	Resource manual of SSI/DI work incentives	ICI
Tools for Inclusion publication	Stories of Success: Using Networking and Mentoring Relationships in Career Planning for Students with Disabilities and their Families	ICI
Tools for Inclusion publication	From Stress to Success: Making Social Security Work for your Young Adult	ICI
Research to Practice	Building a Future: Working with post high school expectations of students and parents	ICI
Tools for Inclusion publication—in development	Strategies in Development of Self-determination for your adults with disabilities	ICI
Journal Article—in development	Differing expectations of parents when students receive SSI	
Journal Article—in development	Student and Parent Short and Long term expectations	

Building a Future: Working with the Post-High School Expectations of Students & Parents

by Jennifer Schuster, Steven Graham, & Máiread Moloney

Introduction

The transition from school to adult life can be a difficult process for high school students and their families. During this period of change, students must begin to set goals for their futures and plan with their families on how to reach these goals. This period of change may be even more difficult for students with disabilities who may have additional barriers to face when making plans for the future. To better understand this transition process, the Institute for Community Inclusion is conducting a study of high school students in Massachusetts who are receiving special education services and their families. The goals of this project include examining student and parent expectations, understanding what factors play an important role in the planning process, and discovering what circumstances may predict high expectations for students and parents. The study will also examine the impact of Social Security on the transition process for students who receive Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). This brief reports the findings from the first year of the project and offers suggestions for parents and educators who are involved in transition planning with high school students.

Methodology

Students and parents will complete a survey once a year for three years. On the survey, participants rate a series of statements on a scale of 0 ('not true') to 3 ('completely true'). The survey questions address short-term and long-term expectations for life after high school, expectations for employment, the importance of work, student level of self-determination, and level of parent involvement in the planning process. Student responses are compared with the responses of the parents in order to note similarities and differences in the student and parent views.

Participants

The study participants are students receiving special education services and their family members from the Brockton, Chicopee, Malden, and Worcester school systems. To date, 181 students and 159 parents have completed surveys. See Table 1 for a description of the student participants.

Table 1: Student Demographics

		% of students
Gender	Male	46
	Female	54
Ethnic/racial Background	Caucasian	57
	Latino/Hispanic	16
	African-American	10
	Native American	8
	Haitian	1
	Other	7
Age	18 or under	80
	19 or older	20
	16-modal age	30
Grade level	Freshman	35
	Sophomore	31
	Junior	15
	Senior	19
Community	Urban	46
	Suburban	39
	Rural	15

The type of disability identified for each student was quite varied, and in some cases more than one disability was reported for a particular student. See Table 2 for the distribution of disability types.

Table 2: Student Disability Type

Disability	% of students
Physical	11
Cognitive	20
Learning	58
Emotional / Psychiatric	6
Behavioral	13
Sensory	9
Other (Autism, etc.)	3

Of the sample, 102 of the students and their families reported receiving no public benefits, 34 reported receiving SSI, 7 received SSDI, and 6 of the students received Social Security Survivor Benefits. When asked if they were currently looking for work, 34% of the students responded that they were, and most were hoping to find a paid job in the community. Twenty-eight percent of the students surveyed already held part-time jobs. Thirty-nine percent of the students were receiving career services in the school, although the majority of the students (61%) were not.

Findings

Most students thought they were likely to find a job immediately after high school.

Students were asked to judge how successful they thought that their lives would be shortly after high school in terms of reaching their short-term goals and finding employment. Seventy-six percent of students thought that it was at least mostly true that they would have a job shortly after finishing high school. While this finding is encouraging, it is perhaps more important to note that almost one quarter of students expected to be unemployed after high school.

Although both parents and students thought that work was important, they valued employment for different reasons.

Students and parents were given a list of characteristics that might be important about

work, and asked to rate how significant those reasons were to them. Although parents and students rated all of these items as very important, they had different views about which reasons were most important. Parents thought that work was important because it makes their child feel productive, successful, independent, and responsible. Students thought that making money, meeting new people, and feeling responsible were the most important benefits of work.

Students had higher expectations for work and rated their own level of self-determination higher than their parents did.

Students and parents rated their expectations for the student's work life after finishing school. These ratings applied not only to finding a job, but also to being able to obtain the necessary supports in the workplace and being satisfied with their occupation. Students' expectations were higher than the parents' for both the short-term and long-term with a statistically significant difference.

Self-determination involves having defined goals and knowing the best means of achieving those goals. Parents and students rated the extent to which students made their own decisions about life after school, and their ability to make these decisions. Students rated themselves higher in this regard (2.46 out of 3) than their parents rated them (1.86 out of 3). This finding indicates that students have higher levels of self-determination and feel more competent about planning and decision-making than parents recognize.

Parents perceived themselves as more involved in students' life planning than students perceived them to be.

Both parents and students rated the involvement of the parents in planning for the long-term goals of the students. Parents rated their own level of involvement in planning for the students' future higher than the students rated their parents' involvement (average rating of 2.56 compared to 2.33).

Implications

The findings of this study highlight some of the issues regarding short-term and long-term expectations for students as they prepare for the transition to adult life. In general, most students have high expectations for their employment after high school. To build on these expectations, schools need strategies to bring student and parent expectations more in line and to ensure that students are encouraged and supported in their career goals. Parents of young adults with disabilities and school staff working with these students might consider the following recommendations to meet students' expectations and improve employment outcomes:

Strengthen parent and student expectations early.

Parents and students have high expectations for work after high school. Providing early and frequent opportunities for career exploration and planning will make it more likely that these expectations will be fulfilled.

- Introduce the concept of transition from school to work for all students as early as possible, because it is likely that students who are working while in school will have an easier time finding a job after high school.
- School staff should keep in mind the particular interests expressed by students with respect to the importance of work. Knowing that students rank earning a living and meeting new people as the most important aspects of work might help in designing various school-based efforts to promote career exploration and work experience.
- Develop and implement career-related curricula and materials which contain language and activities that reflect students' values related to work.
- Include competitive employment as part of students' Individual Educational Plans (IEP).
- Develop career portfolios for each student which contain information about the student's activities involving employment, such as work experience, internships, or job training.
- Work with local school-to-work partnerships as a way to link students with opportunities in local businesses. School-to-work activities provide a rich resource for career exploration and

employment experience. Special education personnel should help to create and maintain a strong presence in school-to-work partnerships through membership on steering committees and the participation of special education students in all partnership activities.

- Give students and parents examples of students working in the community. Teachers should communicate success stories through meetings or newsletters, and have successful student workers return to talk to students and parents. These role models encourage students to work towards their goals.
- Learn about the impact of work on the students' Social Security benefits and how Work Incentives may help students save money for employment goals.

Connect students and parents as planning partners

Students and parents have differing views regarding expectations for work and beliefs in the student's level of self-determination. These differences in perception suggest that communication is an important area to focus on, particularly at the onset of the transition process. Parents and students who understand each other's ideas will be better able to work together to reach employment goals.

- At home, begin discussing career-related issues with students at an early age.
- Teachers should assign both classroom and take-home exercises related to career choices in order to promote discussion among their peers and with family members.
- Support students in actively participating with teachers and parents in the discussions related to their IEP by reviewing meeting agendas in advance and assisting them in developing questions and responses.
- Share career portfolios and work experiences routinely at parent-teacher conferences and IEP meetings.
- Engage in family activities which promote ongoing conversations about career exploration and expectations for future work.
- Encourage family members to allow students to accompany them to their job sites and then discuss the experience.

Resources

The **Work Incentives Transition Network** is a collaborative effort of four projects funded by the Office of Special Education Programs to examine strategies for increasing the use of SSI work incentives by transition age young adults. Further information about this network and related projects may be found at:

www.vcu.edu/rrtcweb/witn/ssi.htm

The **Massachusetts Partnership for Transition (MPT)** is a statewide coordinating council which brings together projects, resources, and activities aimed at supporting the transition of all youth. This organization moderates a Web-based message board to assist schools and families in learning about and working with issues related to transition. This message board may be accessed at:

www.childrenshospital.org/ici/icinet/forum

A more detailed introduction of transition issues and resources may be found in *Moving On: Planning for the Future*, the ICI's transition guide for parents, students, and educators. This publication can be accessed online at:

www.childrenshospital.org/ici/publications/fulltext/mti_guide/index.html

For more information about this study, contact:

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From Stress to Success: Making Social Security Work for Your Young Adult

by Danielle Dreilinger and Jaimie Ciulla Timmons

INTRODUCTION

How does Social Security affect families as their children move into adulthood? The Institute for Community Inclusion (ICI) conducted a study with parents of high school students with disabilities who receive Supplemental Security Income (SSI), a Social Security benefit for people who have disabilities and meet income guidelines. This brief shares their experiences and suggests ways that your family can manage SSI and use it to help your young adult plan for a career.

THE FAMILIES

The ten parents who participated in this study came from four ethnically diverse communities across Massachusetts. Their children, ages 16-21, had a wide range of disabilities: learning, cognitive, physical, behavioral, sensory, and psychiatric. Each parent participated in an interview that lasted approximately 45 minutes.

STRESSES OF DEALING WITH THE SYSTEM

While the Social Security Administration (SSA) offers many benefits and opportunities for recipients, dealing with SSA - or any - government agency can be confusing. Parents named **three main challenges** that blocked their ability to plan ahead.

1

SSI CHECKS ARE SMALL.

Parents found SSI helpful in meeting their children's basic needs. However, saving for the future was often impossible because there was no money left over to save.

"I have to tell them there's no bank account 'cause there's not enough there to put away."

2

SAVINGS RESTRICTIONS AND THE REQUIREMENT TO "SPEND DOWN" EXCESS CASH.

Families who tried to save money were frustrated by SSA's restrictions on how much money they were allowed to keep. Since SSI is designed for people who have little or no assets, a high level of savings conflicts with SSA requirements. Parents explained that they were required to "spend down" excess savings. When the money was gone, so were any plans they had for that money, such as using it for job training.

"I was reporting... what he had in [his savings account] and all of a sudden they called and took it away from him. I had to reapply, get rid of all the money and they cut him over \$200 after that."

"[I wish] we could have... saved more towards the future rather than to spend it all like that."

3

COMMUNICATION WITH THE SSI SYSTEM CAN BE CHALLENGING.

While the complexity of the system requires solid communication between families and SSA, paperwork, inconsistent staff knowledge, and bureaucratic "red tape" made it difficult for parents to get their questions answered.

"You talk to another person and you get a different answer... they are not coming out with the same answers."

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WHAT DO THESE FRUSTRATIONS MEAN FOR FAMILIES?

On a practical level, the financial realities of SSI make it tough for families to budget for the future. On an emotional level, the energy that these parents used in managing SSI took away from the energy they had to support their children's plans for the future. Just being a recipient and dealing with immediate challenges took up a lot of time and kept families from planning for the future in a confident, proactive way.

STRESS-FREE SSI

Try using the following strategies to manage SSI. Then, use SSI as a creative tool for planning and go from stressed and reactive to positive and playful!

SAVVY STRATEGIES TO SIMPLIFY SSI

- 1. Keep it on file.** Keep records of everything in a special notebook. Photocopy everything you send to SSA, including pay stubs.
- 2. Report changes in income immediately.** This is especially important if the monthly income from a job is inconsistent, as it often is for teenagers (if, for instance, they work a different number of hours every week or get paid biweekly).
- 3. Anticipate potential overpayments.** If you know an SSI check has not been adjusted to reflect a change in income, set aside some money to cover the upcoming overpayment so you don't feel squeezed when it happens.
- 4. Set up a meeting.** Sometimes it's easier to work out problems face-to-face. Meeting with a staff member at your local SSA office also allows you to develop a relationship with a person you can call on in the future.
- 5. Stick with the slow times.** Try not to contact SSA during busy periods, especially the beginning of the month (until the 5th or 6th). Early afternoons in the middle of the week and Friday mornings are often quieter. Check with someone at your local office for the best times.
- 6. Put it in writing.** After you talk to someone, write down their name, the date, what you discussed, and what you decided to do. That way, if there are complications down the road you can point to "hard evidence." For particularly important issues, you may wish to follow up your conversation with a letter that confirms what you discussed.
- 7. Prepare for possible complications.** The Social Security Administration is a big and complex system. It can make the whole process a lot less stressful simply to realize that while problems do happen, they can also be solved. Make sure that you ask to speak to someone about SSI, as not all local office staff has the same knowledge. In the event that efforts at problem solving are unsuccessful, you can always appeal a decision. Appeals are often effective.
- 8. Find an expert.** Many schools, human services organizations, and state agencies have experts who specialize in Social Security planning. For more information, see the "Resources" section.

FIGURING OUT THE FUTURE

Unsure about how to **"get there from here"**? Consider using a **formal planning process** to help your young adult develop dreams and action steps for adulthood.

In "person centered planning," a young adult with a disability gathers together family, friends, teachers, and service providers to discuss work and life goals. This group brainstorms ideas, resources, and steps the young adult can take to figure out what they want to do and how to do it. Having a plan can reduce stress and help you decide how to use SSI funds.

MONEY MANAGEMENT

Feeling frustrated by **savings restrictions and spend downs**? Try using SSI to teach your young adult **independent living skills** and money management.

△ Teach the value of work and responsibility by having your young adult help out around the house. Use a small percentage of the monthly check to reward them for their hard work.

△ Use a portion of the young adult's check to start a checking account in their name. Practice withdrawing and depositing money, and balance the checkbook together.

"He knows he has the money in the checking account and if he needs anything... we just go and get it. I charge it and pay it off with his money."

Under your supervision, they can write checks for necessary items such as clothes. One family in the study used SSI money as a "bank account." When her son wanted something, the mother reported, they would discuss it together and then use his money for the purchase.

△ Have your young adult participate in family bill-paying. For instance, use a percentage of the young adult's check to purchase groceries together. Show them the prices. Have them pay and collect the change. This way, they will learn the cost of housing necessities in preparation for living independently some day. At the same time, they will be contributing to the family.

△ Begin to have your young adult keep information for SSA. Show them your SSA notebook and what records you save. Photocopy pay stubs or other records together and mail them in. Have them accompany you to appointments and make or listen in on phone calls.

SAVING THE SSI WAY

Feeling the pinch as you try to save for your young adult's plans? **Make the most of the money** by using *Work Incentives* to save for career goals.

Parents in ICI's study thought that a person could either work or get SSI, not both at the same time. Their information came from other parents, not Social Security.

"If [my child] makes too much they will cut it out. I know that for a fact.... You make anything extra they take it away."

The above "fact" is actually a myth. Your young adult can work and continue to receive SSI. Receiving SSI does not mean that a person is incapable of contributing to their community. The reality is that income from a job results in a very gradual decrease in SSI checks. SSI checks are reduced only \$1 for every \$2 earned.

Furthermore, you can use Work Incentives to lessen the effect of earned income on benefits. SSA calls Work Incentives "special rules [that] make it possible for people with disabilities receiving SSDI or SSI to work and still receive monthly payments and Medicare or Medicaid."

In almost every case, students will have more income by working. And your young adult can always use volunteering and unpaid internships to build their resume with no effect on SSI checks at all.

Two Work Incentives: IRWE & PASS

IRWE: Work-related expenses that are specific to disability can be **deducted** from the income that SSA "counts."

PASS: Allows recipients to **save** for big career expenses.

CONCLUSION

These families' experiences show how the stresses of dealing with the system and limited awareness of resources can make it difficult to plan ahead. We hope that by considering these tips and tactics, your family can take advantage of the opportunities that SSA provides. People with all levels and kinds of disabilities do satisfying work in their communities and have fulfilling adult lives. **Your teenager can too!**

RESOURCES

Social Security and Youth with Disabilities

- Contact SSA for basic rules and eligibility.
- **The Work Site** promotes employment for beneficiaries with disabilities. www.ssa.gov/work
- Focus on youth with disabilities: www.ssa.gov/work/Youth/youth2.html
- **Graduating to Independence (GTI)** is an SSA multimedia package that guides young people with disabilities through the transition from school to work. www.ssa.gov/work/Youth/gradind.html

Contact SSA

1-800-772-1213 (voice)
1-800-325-0778 (TTY)
www.ssa.gov

Work Incentives

- SSA information on Work Incentives: www.ssa.gov/work/ResourcesToolkit/workincentives.html
- A free online training course on SSI Work Incentives is available at www.vcu.edu/rrtcweb/witn/product.htm. Contact Teri Blankenship at the Work Incentives Transition Network:
(804) 828-1851 (voice)
(804) 828-2494 (TTY)
tcblanke@saturn.vcu.edu (e-mail)

- Each region of the country has one or more SSA experts on Plans for Achieving Self Support, called **PASS cadres**. They can help you develop a PASS and give constructive feedback. Contact SSA or check online at:

www.ssa.gov/work/ResourcesToolkit/cadre.html

- For **sample PASS plans** and a manual on Understanding Social Security Work Incentives, contact Gail McGregor at the Rural Institute on Disabilities: (406)-243-2348, gmcgrego@selway.umn.edu, www.ruralinstitute.umn.edu/rises
- Cornell University's Program on Employment and Disability has an **online tutorial** on how to complete a PASS application: www.passonline.org
- **Benefit Counselors** are SSA specialists who can help families understand benefits and employment. These experts will become available in every state over the course of 2001. You can reach them through your local SSA office.
- **ICI Publications**
 - Helpful Hints: How to Fill Out a Winning PASS Application (July 1999, #TO9)
 - Understanding the SSI Work Incentives (updated Nov. 2001, #TO8)

Person Centered Planning

- Training Resource Network publishes materials on person centered planning, including *More Like a Dance: Whole Life Planning for People with Disabilities* (manual and video). 1-866-823-9800, trninc@aug.com, www.trninc.com/index.html

For more information or to order ICI resources:

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Helpful Hints: How to Fill Out a Winning PASS

by Jaimie Ciulla Timmons and Steven Graham

Introduction

This *Tools for Inclusion* provides information about PASS (Plan for Achieving Self-Support). PASS is a program offered by the Social Security Administration to help people receiving Supplemental Security Income (SSI).

Using the story of Danielle, this brief will explain PASS in more detail. As you read her story, you will see how she fills out a PASS application. Because the application can be confusing, helpful hints are provided. Danielle's story shows how a person can successfully apply for PASS and use it to reach work goals.

What do I need to know before I apply for a PASS?

Anybody who receives an SSI check, earns money at work, and is over the age of 15 can apply for a PASS. The Social Security Administration must approve the plan before you can use it. There are common mistakes that many people make when filling out a PASS application. This *Tools for Inclusion* will tell you about these mistakes and how to avoid them. The following example will show you how a typical person, Danielle, successfully uses a PASS, and how she avoids these common mistakes.

What is PASS?

PASS is a program that helps you reach work goals such as finding a job, finding a better job, or becoming more independent at work. This program allows you to set aside money from your check that will not reduce your SSI benefits or affect your eligibility to receive SSI. The money that you set aside must be used for things that help you reach your work goal. Examples of such things include classes that you need to take for a new job, use of a job coach (a trained professional who provides assistance with, and instruction in, job skills for people with disabilities), or transportation to and from a job. You need to mail your PASS application to the Social Security Administration and have it approved before you can start setting money aside.

Danielle's Story

Danielle is a 19 year old woman receiving SSI. She has been working 10 hours a week for the last six months at a local radio station through a school work program earning \$5.00 per hour. At the radio station she does filing and organizes promotional items. She will be graduating from high school in four months, and the radio station has offered her a job starting shortly after graduation that will pay \$7.50 an hour for 30 hours per week. This job is an assistant receptionist position, for which Danielle will need to learn new skills. Danielle and her teacher decide that she will need some job coaching to be successful in this position. They decide to write a PASS while Danielle is still working, so that Danielle can set aside some of her paycheck to pay for a job coach in her new position. They realize that they need to contact a Certified Rehabilitation Counselor (CRC) for a vocational assessment before completing the PASS application.

Helpful Hint:

Once you decide that you will apply for a PASS, the first thing that you need to do is have a vocational assessment. A vocational assessment is a meeting with a rehabilitation professional who will ask you about your job skills and interests. This meeting is necessary so that you and the Social Security Administration can be sure that your work goal is likely to be reached. The professional that does your vocational assessment needs to be a CRC. You can contact a CRC through the vocational education department at your school, your state's vocational rehabilitation agency, or a private agency that provides employment services to individuals with disabilities.

Danielle's counselor from her state vocational rehabilitation agency is a CRC and has been working with her throughout her high school years, so Danielle and her teacher decide that she is the right person to complete the vocational assessment. Danielle's counselor asks her questions about skills she has learned during her work at the radio station and about skills she will need to be successful in the new position. After speaking with Danielle, she decides that the position is a good match for Danielle's skills and goals, and encourages her to complete a PASS. Danielle's counselor also writes a letter to include with the PASS application, saying that Danielle is likely to succeed in this new position with the requested job coaching services.

Helpful Hint:

The CRC who conducts your vocational assessment should also write a letter that says that you are likely to reach your work goal. Including this letter with your PASS application will help your plan start more quickly.

Part I of the PASS application

The first question on Danielle's PASS application asks her to write down her work goal. Her teacher knows that it is important to write a specific work goal when answering this question. So, instead of writing down, "getting a better job at the radio station," (which is not very specific) they write "getting a job as an assistant receptionist" (which is very specific). This makes Danielle's application much more likely to be approved.

Helpful Hints for Part I:

- ⇒ *Make sure that the work goal you write down is as specific as possible (like Danielle's).*
- ⇒ *If a teacher or job coach helps you with your work, your goal may be to decrease the number of hours of help you receive. If this is your goal, be careful to write down the specific number of hours of help you receive now, and the specific number you expect to receive when the PASS is completed. For example, your goal could say, "decrease the number of job coach hours I receive at work from 15 per week to 5 per week."*
- ⇒ *You can only write down one work goal. For example, Danielle's goal could not be, "get a job as an assistant receptionist for a few years and then become a senior receptionist." When Danielle wants to become a senior receptionist, she can complete another PASS at that time.*
- ⇒ *Your work goal cannot be a college degree or finishing a training program. Your goal must be getting a new job or decreasing the help that you receive at your current job. The PASS could allow you to set aside money for school, but your goal needs to be the job you will get when you leave school.*

Part III of the PASS application

Danielle and her teacher think about all of the steps that Danielle will need to take in order to reach her work goal. They also estimate the dates that Danielle will start and finish each of these steps. These are important things to know in order to fill out Part III of the PASS application. Danielle's first step is to receive eight hours of job coaching per week for the first four months of her new job. Her second step is to decrease the hours of her job coach to five per week for three months and her third step is to decrease to two hours per week for two months. Danielle's last step is to receive assistance from her job coach on only a check-in basis.

Since Part III of the PASS application also requires Danielle to write down the cost of each of these steps, she and her teacher find out how much job coaches cost. Finding this out also tells Danielle how much money she will need to set aside to pay her job coach. They get a letter from the job coach saying exactly what her services will cost and include this with Danielle's application. This letter will speed up the approval of Danielle's PASS since the Social Security Administration will know that the amount of money Danielle wants to set aside is correct.

Helpful Hints for Part III:

- ⇒ *Each step of the PASS must have realistic dates.*
- ⇒ *You may list as many steps as needed to reach your goal.*
- ⇒ *There is no time limit for completing your PASS. If your plan is longer than 18 months, however, the Social Security Administration will review it every 18 months and re-approve it if everything is ok.*
- ⇒ *The last step of your PASS should always be to start a new job (unless your work goal was to reduce the hours of help you receive from a job coach). This step must be written down for your plan to be approved.*

Part IV of the PASS application

Danielle and her teacher must list the things or services that Danielle needs to buy in order to reach her work goal. All of the things listed on this part of the application must be necessary for reaching the work goal, and documenting the cost of these things is important for having a PASS application approved. Danielle and her teacher list the cost of the job coaching services that she will need and include the letter from the job coach as proof of how much the services will cost.

Danielle's teacher helped her complete her application, so Danielle must include her teacher's name and phone number with her application. Danielle's mother gets her daughter's checks in her name (this is called a representative payee), so she also has to sign Danielle's application. The PASS application is now complete, and Danielle sends it to her local Social Security office for approval.

Helpful Hint for Part IV:

- ⇒ *If you need to purchase something as part of your PASS (such as special tools or a computer), include a flier, newspaper ad, or a page from a catalog showing how much the item you need costs. In Danielle's case, she provided a letter from the job coach.*

More Helpful Hints:

- ⇒ *If someone helps you fill out your PASS application, you must include their name and telephone number with your application.*
- ⇒ *If somebody gets your SSI check in their name (a representative payee), they must also sign your application.*

Danielle's PASS application is approved by the Social Security Administration. She begins to set aside money for her job coach, and keeps careful records that she will need to show the Social Security Administration. She writes down the date and amount of every payment she makes to her job coach, and gets a receipt to keep as proof of payment.

After the first four months of Danielle's PASS, she and her job coach agree that she needs to have eight hours of job coaching per week for two more months. Since this is different than the dates listed on her application, Danielle needs to let the Social Security Administration know. She calls her local Social Security Field Office right away, and they authorize the change to her original application. Danielle receives the extra two months of job coaching at eight hours per week, and then finishes her PASS as she planned in the beginning. Danielle is now able to work independently as an assistant receptionist without regular help from her job coach!

Final Thoughts

- ⇒ *The Social Security Administration will want proof that you finish each of the steps in your PASS. Make sure to keep careful records of finishing each step, and keep all receipts for the money you spend for the plan.*
- ⇒ *If you are unable to complete any of the steps to your work goal or if you need to make any change to your PASS, you must call your local Social Security Field Office right away. If you do not call them, you may need to give money back to the Social Security Administration.*
- ⇒ *If you have a PASS and decide that you do not want to complete the plan, you must end the plan by calling your local Social Security Field Office. After ending the plan, you may apply for a new one. This will involve getting another vocational assessment.*
- ⇒ *You should call your local Social Security Field Office with any questions you have about applying for a PASS or about keeping a PASS.*
- ⇒ *For more information on PASS, call the Social Security Administration at 1-800-772-1213 to find the local field office nearest you. Also ask them to send you a booklet called *Working While Disabled, A Guide to Plans for Achieving Self-Support* (SSA publication No. 05-111017). This booklet is free of charge and will tell you more about PASS. The booklet can also be found on the SSA's web site at www.ssa.gov/pubs/11017.html*

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