



INSTITUTE FOR
COMMUNITY
INCLUSION

Tools for Inclusion

family and consumer series

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."

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 planful!

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. 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.

"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."

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.umt.edu, www.ruralinstitute.umt.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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