

SELF ADVOCACY

Adapted from "The Secrets of Self-Advocacy: How to Make Sure You Take Care of You" by Stephen M. Shore, Autism Advocate, 2006, Vol. 44, No. 4

Self-advocacy involves knowing when and how to approach others to negotiate desired goals, build better mutual understanding and trust, and achieve fulfillment and productivity. Successful self-advocacy often involves an amount of disclosure about oneself to reach the goal of better mutual understanding. In other words, it can be necessary to explain that you have autism and what that means to explain why an accommodation is needed or helpful.

Ideally, parents lay the groundwork for self-advocacy when the child is young. An important precondition for successful self-advocacy and disclosure is self-awareness. **People with ASD need to understand how autism affects their interactions with others and the environment.** Also, they need to be familiar with their strengths and challenges. A parent or caretaker can do this with a child from a very early age. **In fact, the earlier a child has an explanation about his differences, the better off he will be.**

Parents should let their child know of their strengths in any way they can. In addition to developing greater self-understanding, it means talents can be fostered for future academic and professional pursuits.

SELF-ADVOCACY ORGANIZATIONS

These groups promote equality for people with disabilities, share community news, and provide forums for learning and sharing opinions. Following their activities is a great way to learn about self-advocacy and show your support for the community.

[Autistic Self Advocacy Network](#)

[Global and Regional Asperger Syndrome Partnership](#)

[Self-Advocates Becoming Empowered](#)

TEACHING SELF-ADVOCACY SKILLS

Just as social skills and an understanding of nonverbal communication are necessary for those on the autism spectrum, self-advocacy and disclosure requires direct instruction to develop skills.

Areas of instruction can include a variety of topics and skill areas, including:

- Using a child with autism's IEP as a tool to teach her about [self-advocacy and disclosure](#)
- Teaching children or adults about sensory systems and how to ask for environmental accommodations
- Supporting a person on the spectrum in learning how and when to self-disclose
- Introducing a person with ASD to the basics of the [Americans with Disabilities Act](#) and [other important laws](#).
- Assisting a child or adult in creating self-advocacy scripts to use a variety of settings and situations.

SSI AND OTHER BENEFITS

SUPPLEMENTAL SECURITY INCOME (SSI): THE BASICS

People who are disabled, blind, or elderly may not be able to work or afford to live on their own. If you can't work, have no other sources of [income](#), and have limited [resources](#), you may be eligible for [Supplemental Security Income](#) (SSI).

The federal government created the SSI program to help people in this situation. Those who qualify for SSI benefits get monthly cash payments to pay for those basic needs. The SSI program is run by the [Social Security Administration](#). In California, people who get SSI also get a smaller benefit from the [State Supplemental Program](#) (SSP) included with their monthly SSI benefit. For most people, the maximum possible SSI benefit (including the SSP) is \$910.72 for an individual and \$1,532.14 for a couple. If you're blind, the maximum is \$967.23 for an individual and \$1,683.19 for a couple.

In California, people who qualify for SSI also get [Medi-Cal](#) benefits automatically. **Don't get SSI mixed up with other programs. Three disability benefits have very similar names: SSI, SSDI, and SDI:**

- [Supplemental Security Income](#) (SSI) is a federal program that gives a cash benefit to people who have disabilities and have low income and resources. You do not need to have worked in the past to get SSI. **SSI is explained in this article.**
- [Social Security Disability Insurance](#) (SSDI) is a federal program that gives a cash benefit to people with long-term disabilities who qualify because they used to work or have family members who worked.
- [State Disability Insurance](#) (SDI) is a state program that gives a cash benefit for one year or less to Californians with disabilities who worked before becoming disabled.

You may be able to qualify for more than one of these programs at the same time. For example, if you become disabled, you might get SDI at first and later start getting SSDI. If you get SSDI and also have low resources, you may qualify for SSI as well. Make sure you know which benefits you get and which you might qualify for if you applied.

Social Security

- The Red Book- The Red Book is a general reference tool designed to provide a working knowledge of these provisions. <https://www.ssa.gov/redbook/documents/TheRedBook2018.pdf>
- Benefits Planning Query- This provides information about a beneficiary's disability cash benefits, health insurance, scheduled disability reviews, representative payee, and work history, as stored in SSA's electronic records. This is an important planning tool for a beneficiary, benefits counselor, or other person who may be developing customized services for a disability beneficiary who wants to start working or stay on the job.
- Work Incentives through SSI <https://www.ssa.gov/ssi/text-work-ussi.htm>

2. Disability Benefits 101

- Gives you tools and information on health coverage, benefits, and employment. You can plan and learn how work and benefits go together. <https://ca.db101.org/>

3. Disability Rights CA

- Disability Rights California advocates, educates, investigates, and litigates to advance the rights, dignity, equal opportunities, and choices for all people with disabilities.
<http://www.disabilityrightsca.org/>

According to SCDD Central Coast, with very rare exceptions, you are better off working than relying on SSI or SSDI. You can keep Medicare or Medi-Cal long after you begin working.

Supplement Security Income (SSI)

To calculate the impact of your wages on your SSI monthly benefit, subtract the \$85 exemption from gross earnings, (\$65 if you also receive SSDI) and then divide the remainder in half. This number is the amount that will be subtracted from your monthly SSI benefit check. Below is an example of a person earning \$1085 per month and receiving \$910 per month in SSI Benefits.

$$\$1085 - 85 = 1000 \quad 1000 \text{ divided by } 2 = 500 \quad 910 - 500 = 410$$

$$\text{Monthly income equals } \$1085 + \$410 = \$1495$$

Wages must be reported to Social Security by the 6th of each month. Once your monthly SSI check is zero, and you continue to report earnings, you are automatically enrolled in the 1619(b) provision that continues Medi-Cal coverage, at no cost to you, as long as your annual income (in 2018) is below \$37,202. Certain conditions apply but SSI recipients almost always meet them.

If you continue reporting your earnings once your benefit checks have stopped and your income drops or you lose your job, your benefits check will start coming right away – usually within 30 days. If you stop reporting your income (not recommended!) and your income drops or you lose your job and it has been longer than 12 months, you will not automatically receive benefits again and you will need to reapply. There is an SSI resource limit (including checking & savings, stocks, 401k, and other retirement plans, etc.) of \$2,000 for individuals.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

The 9-month Trial Work Period (TWP) lets you work and get benefits at the same time no matter how much you make and most people qualify for an additional 3-month Grace Period for a total of 12 months of benefits with unlimited earnings! (This provides a great opportunity to save money with double income) There is not limit on savings and resources. A TWP month is any month in which gross earnings are above \$850 (in 2018). All changes in employment and/or wages should be reported immediately to Social Security. There is not a monthly reporting requirement.

When the Trial Work Period ends, the 3-year Extended Period of Eligibility (EPE) begins and lets you work and get benefits for every month that you earn less than the Substantial Gainful Activity (SGA) level (\$1180 in 2018). If you earn above SGA, you will not get cash benefits. After the EPE, the first time you earn above SGA, your benefits are terminated but if you quit work due to your disability, you have up to 5 years to request Expedited Reinstatement (EXR) of benefits. When you request EXR, you receive benefits while your case is being reviewed. If approved, you will begin a 24-month Initial Reinstatement Period after which you are again eligible for a new Trial Work Period and Extended Period of Eligibility. SSDI Medicare recipients continue to be eligible for Medicare for many years after working but will have to continue to pay for some or all of it, but most will have medical insurance through their employer.

MEDICAID WAIVERS

Most states have a program for individuals with developmental disabilities called a Medicaid Waiver (also known as 1915(c) Home and Community Based Services). A Medicaid Waiver is designed to provide support services and care to allow an individual to remain at home or in the community, rather than in an institution, nursing home, or hospital. The benefits provided by these waiver programs vary by state, but most generally provide coverage for medical treatments, respite care, transportation, in-home support, and more. In some states, children **do not** need to meet eligibility criteria for Medicaid to qualify for a waiver. However, just like insurance laws, waiver criteria and availability vary from state to state.

You should also note that waivers may have different names in your state. For example, the "Katie Beckett waiver" is one type that is available in a number of states. Others may have names such as "Autism waiver," "Person Directed Support waiver," "Developmental Disabilities waiver," or "Individual and Family Support waiver."

WAIVERS IN CALIFORNIA:

California currently has seven Home and Community Based Services 1915(c) waivers.

- CA HCBS Waiver for Californians w/DD
- CA Nursing Facility/Acute Hospital Waiver
- CA HIV/AIDS Waiver
- CA Pediatric Palliative Care
- CA Assisted Living
- [CA Multipurpose Senior Services Program](#)
- CA In Home Operations

Click Here for updated waivers search: <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>

ABLE ACCOUNTS

A new type of savings option was made available for families of individuals with disabilities through the Achieving a Better Life Experience (ABLE) Act of 2014. The ABLE Act authorized the establishment of private tax-advantaged savings accounts that can help you save for long-term expenses without sacrificing eligibility for public benefits such as Medicaid and Supplemental Security Income (SSI).

These accounts are modeled after the current 529 education savings plans that help families save for future college costs. Once an account is established for a beneficiary, account contributions will accumulate tax deferred and any earnings will be tax free at the federal level if the money is used for qualified expenses.

Each state is responsible for establishing and operating an ABLE program. For information of California's Able Act, Click Here: <https://www.treasurer.ca.gov/able/>

HOUSING ASSISTANCE

The [Department of Housing and Urban Development](#) (HUD) can provide you with advice on finding affordable housing. HUD sponsors housing counseling agencies throughout the country to provide free or low cost advice. For more information, you can call HUD's interactive voice system at: (800) 569-4287.

You can locate your local HUD office on https://www.hud.gov/program_offices/field_policy_mgt/localoffices#CA.

They can give you information on affordable housing programs, rental assistance, and more. There are also a number of programs through the federal government to help families purchase a new home. Some resources below:

- [U.S. Department of Agriculture \(USDA\)](#)
- [U.S. Department of Housing and Urban Development \(HUD\)](#)
- [Federal Housing Administration \(FHA\)](#)
- [AmeriDream, Inc.](#)

OTHER PLACES TO SEARCH FOR FINANCIAL ASSISTANCE

The United Way can help you connect with many resources and services in your area, and answer many questions about obtaining assistance. Call 2-1-1 or visit 211.org to learn about some of the options available to you.

NeedHelpPayingBills.com is a website which lists many sources of financial assistance. Follow [this link](#), then scroll down and click on your state to locate additional sources of assistance.

USA.gov maintains information on a variety of government and other assistance. In particular, see the page on [Government Benefits, Grants, and Loans](#).

The *Patient Advocate Foundation* is also a good place to search for grants and other financial assistance, particularly if someone in your family has a medical condition. You can search for resources based on medical diagnosis. [Click here](#) to search their page.

EMERGENCY ASSISTANCE

In a crisis, it is often helpful to go to your *Community Action Agency* ([click here](#) to find the agency for your area). Staff can connect you with any available resources, financial or otherwise, that are available in your area.

You can also contact your local *United Way* by calling **2-1-1** to be connected with many services and resources to help, or visit 211.org.

The *Salvation Army* can often assist in emergency situations as well, although funding may be limited. They can provide rental and housing assistance, utility help, food, shelter, and more. You can find your nearest center by [clicking here](#).

You can also use the following links to locate shelters in your area:

- homelesshelterdirectory.org
- shelterlistings.org
- womenshelters.org