

ADULTHOOD CHECKLIST



Shane Tarkington

Parents of children with autism/DDs are often overwhelmed by the complexities of transitioning out of the school system into the fragmented system of adult care. This checklist is intended to provide an overview of many of the elements to consider during this transition period and beyond.

AROUND AGE 16

IEP TRANSITION PLAN

Special Education services end after high school graduation or age 22, whichever comes first. By age 16, or earlier if deemed necessary, the IEP must include post-secondary education goals towards the functional life skills, higher ed, employment and other goals for adulthood, based on assessment. Seek referrals to maximize appropriate support and service options as individuals age out of school. The IEP team may include regional center and/or Dept. of Rehabilitation staff for input on services and supports such as job training or other services, including counseling on post-secondary options, community living services, independent living skills and assistive technology.

BEFORE AGE 18

POST-SECONDARY ACCOMMODATIONS

For the young adults who can take advantage of post-secondary programs such as community colleges or 4-year colleges, Section 504 accommodations can be sought through the disability centers of those schools. Specialized programs specifically for young adults with ASD are also available, for example College Living Experience and College Internship Program. Accommodations may also be requested for employment. *Askjan.org*.

HIGH SCHOOL

REGIONAL CENTER IPP

Most adults with significantly disabling autism are clients of the regional centers where each client's services are governed by an IPP, or Individualized Program Plan. Regional center is the "payer of last resort" — it funds services after generic resources are exhausted (e.g., Social Security, IHSS). The RC taps into the federal Medicaid Waiver/Home and Community-Based Waiver Services (HCBS) to help pay for community-based services. This allows individuals otherwise requiring an institutional level of care to be served at home or in the community. An IPP can include, for example:

- In-home respite / Out-of-home respite, camp / Personal assistance / Behavioral respite
- Adult day programs / Supported employment
- Behavioral services (must exhaust private health insurance first) / START services
- Residential/living options: Board and care (group homes) / Intermediate care facilities / Supported living services / Independent living services / Family home agency / Assistance with finding affordable housing
- Self-Determination Program: provides participants with an individual budget, which they can use to purchase services and supports to implement their person-centered plan (PCP) and IPP.
- Transportation services

AROUND 17 1/2

CONSERVATORSHIP

Once an individual turns 18, he or she is considered a legal adult, no matter how dependent or disabled. Conservatorship is a legal means to protect vulnerable adults by transferring some authority to parents or others who the court finds will act in the best interests of the disabled

individual. It is prudent to have a conservatorship hearing before the 18th birthday. After the birthday, your child is legally an adult, and you would have no legal standing, even in the emergency room. (Note: obtain copies of important health records, especially diagnosis records, before the 18th birthday, to assist with SSI and conservatorship processes.)

Parents typically start the petition process about six months before their child's 18th birthday, assuming the child is already a regional center client. If not, more time may be needed to first establish RC eligibility, as the RC plays an important role in the conservatorship process. Note: the courts are suffering a significant backlog, you may consider allowing more than 6 months.

Conservatorships are filed in the Probate Court of the Superior Court where the proposed individual resides. There are two main types of conservatorships in California:

- **Conservator of the Person** – Charged with overseeing personal affairs (including health care)
- **Conservator of the Estate** – Charged with overseeing financial affairs. Typically, parents file to be conservators of the person, and not of the estate, since the latter involves bonding and regular reporting to the court, and in most families, few assets are involved.

Most conservatorships of adults with autism/DD are classified as "Limited Conservatorships." The disabled person retains all rights except for those explicitly delegated to the conservators. The conservators are required to get treatment, services, and opportunities to help the disabled person become as independent as possible and are required to always act in the best interests of the conservatee.

An alternative to a conservatorship is a **durable power of attorney**, which may be appropriate when the individual has mental capacity to make such an informed delegation. It is important to consult an attorney to determine which option fits your particular situation.

AT AGE
18

SOCIAL SECURITY: SSI AND SSDI

Social Security offers two types of benefits for people with disabilities over 18:

SSI: To qualify, a person must have a disability that prevents him/her from engaging in gainful employment, and also must have low income/resources (means-tested). Most adults with autism apply for SSI at age 18 (you can do this earlier if your child is in a residential placement, or if your family income is low enough). Make sure your child does not have more than \$2,000 in assets (excluding primary residence). At age 18, the income and resources of family members are not counted, even if the individual lives at home. Retroactive benefits are paid as of the application date. Call 1-800-772-1213 to start the process.

SSDI: For people with long-term disabilities who used to work or have family members who have worked but are retired or disabled. There are fewer income restrictions and the benefits are higher than SSI. It can be possible to get both (up to a certain cap).

Also: Open a checking account for the representative payee for SSI and other public benefits.

Learn more: Disability Benefits 101 (db101.org). Also PHP (php.com) provides free workshops on accessing public benefits such as In Home Supportive Services, Supplemental Security Income, and Medi-Cal. PHP also provides 1:1 consultations for a fee. If your child is a client of regional center, you can request a POS to cover the cost of this service.

ANY
TIME

HEALTH BENEFITS

Medi-Cal: Individuals who qualify for SSI are eligible to receive Medi-Cal health insurance. Medi-Cal asset limit was increased to \$130,000 effective 7/1/2022. It is completely eliminated in 2024.

Private: Private health insurance must be tapped for behavioral health services before the regional centers will fund those types of supports. Most parents' policies will now allow continued coverage for dependents up to age 26, and some even beyond for disabled dependents.

Crisis care: Consult your regional center for resources, and National Council on Severe Autism NCSAutism.org national resource listings.

BEFORE
AGE 18

IHSS (IN-HOME SUPPORT SERVICES)

Eligibility for IHSS is only available to those with Medi-Cal, including through “institutional deeming” available from regional centers. Your child may be living at home with you or in their own home to be eligible (not in a group home). A parent could be paid as the provider of these services. A provider paid 80 hours or more per month is eligible for medical benefits, see, eg: <https://ac-pa4ihss.org/homecare-workers/homecare-worker-health-benefits/>

IHSS services include: domestic services, related services (meal preparation, shopping, running errands, etc.), non-medical personal care services, transportation, yard hazard abatement, and protective supervision. The maximum number of IHSS hours for a person that is considered non-severely impaired is 195 hours per month. The maximum number of IHSS hours for a person who is considered severely impaired (with autism, this could be aggression, self-injury or prone to elopement) is 283 hours per month. This is called protective supervision.

IHSS providers who live with a disabled person may not have to pay taxes on their earnings. See <https://www.ftb.ca.gov/file/personal/income-types/in-home-support-services.html/>

ANY
TIME

ABLE ACCOUNTS

The ABLE (Achieving a Better Life Experience) Act allows tax-exempt savings accounts to be used for maintaining health, independence, and quality of life for individuals with disabilities diagnosed prior to age 26. It allows money to accumulate that won't affect means-tested benefits received based on the individual having a disability. It allows for savings up to \$16,000 per year and up to \$100,000 total without losing public benefits. In addition, up to \$12,880 of contributions from earned income are allowed per year. An individual can only have one ABLE account.

Earnings in these accounts are not subject to federal or state income tax, so long as the earnings are spent on Qualified Disability Expenses, which can include education, housing expenses and rent, transportation, employment support, health, prevention and wellness, assistive technology, financial services, home improvement, and funeral services. You need not choose California's ABLE program but if you do: CalABLE.ca.gov

ANY
TIME

SPECIAL NEEDS TRUSTS

SNTs are created to hold assets for a special needs beneficiary. SNTs can be useful for those who receive means-tested public benefits, to avoid impacting their eligibility. SNTs can be funded during the life of the beneficiary or can hold a life insurance policy funded at the death of a parent or parents. If designed incorrectly, the SNT can render the beneficiary ineligible for public benefits, or cost the beneficiary unnecessary expenses or penalties. Parents are advised to consult an attorney about creating an SNT. A source to find a lawyer: SpecialNeedsAnswers.com

ANY
TIME

LETTERS OF INTENT

As part of the crafting of an SNT or even without an SNT, parents should write a letter of intent, which explains your loved one's abilities, support needs, preferred and necessary services, current and future benefits, etc. as well as your wishes for his or her future. This is an informal document that is often considered by successor caregivers, trustees, conservators, as well as attorneys and courts in making decisions about your child's life. You might consider employing person-centered planning techniques in developing your document.

AT AGE
18

HOUSING WAITLISTS

Housing Authorities administer Housing Choice Vouchers (Section 8) but most Section 8 wait lists are closed. Individual affordable housing properties each have separate wait lists. Regional Centers will fund housing navigation services provided by organizations like Housing Choices to identify and pursue appropriate affordable housing wait lists. Section 8 vouchers can subsidize

monthly rent excepting approximately 30% of monthly income (tenant portion of rent would be about \$300 for those receiving SSI).

Check out housing information resources:

- Housing Choices (serving the four SARC counties, and San Mateo County): [HousingChoices.org](https://www.housingchoices.org)
- Lanterman Housing Alliance (California advocacy): [lantermanhousingalliance.org](https://www.lantermanhousingalliance.org)
- Brilliant Corners (SF): [brilliantcorners.org](https://www.brilliantcorners.org)
- Housing Consortium of the East Bay: [hceb.org](https://www.hceb.org)
- Together for Choice (National advocacy): [togetherforchoice.org](https://www.togetherforchoice.org)
- Autism Housing Network (national advocacy): [autismhousingnetwork.org](https://www.autismhousingnetwork.org)

AT AGE 18

CALFRESH

Adults receiving SSI are eligible for CalFresh food benefits, which can include up to \$281 every month in food assistance. A county worker will determine your exact benefit amount by looking at your income and comparing it to your expenses. The more you can prove in expenses, like rent or medical expenses, the higher your benefit amount will be. Learn more at <https://www.getcalfresh.org/en/ssi> or call 1-877-847-3663 (FOOD) to find out how to apply.

VARIOUS TIMES

OTHER TO-DO'S

- **Obtain California I.D. or driver's license** from the DMV.
- **Register to vote**, also from DMV.
- **Register for Selective Service:** All males, regardless of disability, must register for Selective Service at age 18. Access to certain government benefits in the future may be at risk for failure to register. Register at the post office or online at www.sss.gov.
- **Visit transition fairs:** Check with your school district and regional center.
- **DMV Handicap Placard:** <https://www.dmv.ca.gov/portal/dmv/detail/vr/disabled>
- **Discount passes:** Transportation, parks and other agencies often offer disability discounts. For example:
 - National Parks: store.usgs.gov/pass/access
 - California State Parks: https://www.parks.ca.gov/?page_id=30236
- **Skills assessment:** e.g., Identifor, [identifor.com](https://www.identifor.com), or Autism Speaks Community Based Skills Assessment: <https://www.autismspeaks.org/tool-kit/community-based-skills-assessment>
- **Social groups:** See groups listed at [sfautismsociety.org](https://www.sfautismsociety.org), [AASCEND.org](https://www.aascend.org), [php.com](https://www.php.com)
- **Sexuality education:** <https://odpc.ucsf.edu/advocacy/sexuality-sexual-health/our-sexuality-our-health-a-disabled-advocates-guide-to>
- **Seek legal help:** [PHP.com](https://www.php.com) directory lists many attorneys who work in conservatorships, social security appeals, special needs trusts and regional center advocacy.
- **Update your child's medications.** It may be time to review psychiatric and other medications. Please check with your private provider, or if applicable, MediCal provider.

DISCLAIMER

This document was created by parent volunteers of Autism Society San Francisco Bay Area (SFASA) as part of the October 15, 2022 conference sponsored by SFASA and Stanford Autism Center, in an effort to provide general information to the community. SFASA makes no representations or warranties in relation to this document or the information and materials referenced in this document. SFASA does not warrant that the information in this document is complete, true, accurate or non-misleading. Nothing in this document constitutes, or is meant to constitute, advice of any kind. If you require advice in relation to any legal, financial, medical or any other matter you should consult an appropriate professional. Inclusion of any organization does not imply endorsement, and omission does not imply disapproval.

Autism Society San Francisco Bay Area wishes to thank Ken Prodger, financial planner, for providing helpful suggestions.