

AUTISM/DD ADULTHOOD CHECKLIST

Families of teens with autism and developmental disabilities are often overwhelmed by the complexities of transitioning out of the school system into the fragmented and confusing 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.



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 Department of Rehabilitation staff for input on services and supports such as job training or other services, including counseling on post-secondary options, and training on technology.



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.

Accommodations may also be requested for employment. https://askjan.org/ Specialized programs specifically for young adults with ASD are also available, for example College Living Experience and College Internship Program.



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 "payor 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 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
- Transportation services
- Adult day programs / Supported employment
- Behavioral services (must exhaust private health insurance first)
- 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



CONSERVATORSHIP

Once an individual turns 18, he or she is considered a legal adult, no matter how dependent or disabled. Parents no longer have access to medical, financial, school, or legal records. 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.

Parents should start the petition process about 6 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.

Conservatorships are filed in the Probate Court of the Superior Court where the proposed individual resides. There are two main types of Conservatorship 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 he court.

Most conservatorships of adults with autism 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 of power. It is important to consult an attorney to determine which option fits your particular situation. Learn more: http://www.scscourt.org/self_help/probate/conservatorship/conservatorship_limited.shtml

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 to do: Open a checking account for the representative payee for SSI and other government benefits.

Learn more: PHP 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.



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 for this service (not in a group home). You might even be paid as the provider of these services. If you are considering Supported Living, this service must be tapped first. 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, could be aggressive, self-injurious or prone to elopement) is 283 hours per month.

IHSS providers who live with a disabled person may not have to pay taxes on their earnings. To learn more, see http://ihssadvocate.com/news/ihssincome-not-federally-taxable



HEALTH BENEFITS

Individuals who qualify for SSI are eligible to receive Medi-Cal health insurance. 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.



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. 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 \$15,000 per year (beginning 2018) and up to \$100,000 total without losing public benefits. 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, transportation, employment support, health, prevention and wellness, assistive technology, financial services, home improvement, and funeral services.



SPECIAL NEEDS TRUSTS

SNTs are created to hold assets for a special needs beneficiary. SNTs can be useful for beneficiaries 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 the creation of an SNT.



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.



HOUSING WAITLISTS

Sign up for Section 8 (portable voucher) waitlists and other low-income housing (set-aside) waitlists. Most voucher waitlists are closed, however contact your county Housing Authority to inquire as to when your waitlist will open up. For more waitlist information: affordablehousingonline.com.

Section 8 vouchers can subsidize all monthly rent excepting 30% of monthly income (about \$300 for those receiving SSI).

BEFORE OR AT

AGE 18

ANY

TIME

OTHER TO-DO'S

- Obtain California I.D. or driver's license from the Department of Motor Vehicles.
- **Register to vote.** See https://www.dmv.org/ca-california/voter-registration.php. (Note that a person may be disqualified from voting by reason of mental incompetence by the Probate Court as part of a conservatorship.)
- 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.
- Safety and understanding law enforcement training, e.g., Students Guide to Police Practices https://www.sanjoseca.gov/DocumentCenter/View/65633, Be Safe, the Movie besafethemovie.com
- 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/pages/737/files/dpr818a.pdf
- **Do a skills assessment:** e.g., *identifor.com* (free), Assessment of Functional Living Skills (fee)

Autism Speaks Community Based Skills Assessment: https://www.autismspeaks.org/family-services/community-based-skills-assessment or https://www.identifor.com

- **Join a social group:** See, for example, our Panel on Social Opportunities for Bay Area Adults on the Spectrum at *sfautismsociety.* org/webinars
- **Seek legal help:** *PHP.com* directory lists many attorneys who work in conservatorships, social security appeals, special needs trusts and regional center advocacy.

REFERENCES

Autism Housing Network http://www.autismhousingnetwork.org/education/turning-18-checklist/ Autism Housing Pathways www.autismhousingpathways.net

Autism Speaks Tool Kits https://www.autismspeaks.org/family-services/tool-kits

CalABLE Program http://treasurer.ca.gov/able/

Conservatorship http://www.courts.ca.gov/documents/handbook.pdf

Disability Benefits 101 https://ca.db101.org/

Disability Rights California http://www.disabilityrightsca.org

IHSS http://www.cicaihss.org

IHSS Protective Supervision http://www.disabilityrightsca.org/pubs/549301.pdf

Parents Helping Parents php.com

Social Security www.socialsecurity.gov

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OPTIONS POLICY

SFASA subscribes to the Autism Society of America's Options Policy which promotes the active and informed involvement of family members and the individual with autism in the planning of individualized, appropriate services and supports. Each family and individual with autism should have the right to learn about and then select, the options that they feel are most appropriate for the individual with autism. Learn more at: http://www.autism-society.org/about-the-autism-society/guiding-principles/options-policy/.

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