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FOR EXCELLENCE IN
DEVELOPMENTAL DISABILITIES

Planning for the Future

Things to Consider

Planning for the future for adults with developmental disabilities includes thinking of several different things. You should think about both your child with developmental disabilities and you. Parents may also need caregiving as they grow older.

This guide is divided into two sections: Aging Caregivers and Life After 22. Both sections suggest things to think about and some resources to help you learn more about each area. Remember you can ask your regional center for information on local resources and programs in each of these areas.

I. Aging Caregivers

As children become adults, their parents also get older. This may mean that parents aren't able to give the same level of caregiving and support as they did when they were younger. It may also mean that the parents need assistance and caregiving themselves. Since it is likely that children will outlive their parents, another thing to think about is the care and support their children will need after the parents have passed on. Planning for aging caregivers includes several different things. It includes:

- **Financial Planning**
- **Health care**
- **Identifying (quality) caregivers for themselves and their child**
- **Letters of Intent**

Financial Planning

Financial Planning for your child's future which can include

- How your child will be supported
 - Employment (see life after 22)
 - Supplemental Security Insurance (SSI) <https://www.ssa.gov/benefits/ssi/>
 - Social Security Disability Income (SSDI) <https://www.ssa.gov/benefits/disability/>



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- Special Needs Trusts <https://www.specialneedsalliance.org/the-voice/two-different-types-of-special-needs-trusts/> <https://www.dhcs.ca.gov/services/Pages/Special-Needs-Trust.aspx>
- ABLE Accounts <https://www.calable.ca.gov/>

End of Life Planning

It is also a good idea for parents to Pre-Plan for Funeral and/or Burial/Cremation, both for themselves and also for their child with a developmental disability.

- California Department Cemetery and Funeral Bureau https://www.cfb.ca.gov/consumer/pre_need.shtml
- DDS *Thinking Ahead* materials <https://www.dds.ca.gov/consumers/resources/consumer-friendly-publications/>

Health care

This includes the type and amount of intervention you want if you are nearing the end of life. You may also think about the type and amount of intervention you want for your child (as they age). It is a good idea for any adult to have an *Advanced Directive*.

- California Hospital Association <https://form-3-1-health-care-directive.pdfFiller.com/>
- Coalition for Compassionate Care in California <https://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>
- Healthy Aging.org <https://www.healthinaging.org/tools-and-tips/caregiver-guide-advance-directives>

Identifying (quality) caregivers- End of life planning for caregivers also includes identifying who and how your child will be supported when you are no longer able to do it. This can include 24/7 support caregiving but can also include the people your child can use for occasional support in different areas. This can include:

- Circle of Support https://laddc.org/userfiles/files/Natural_Supports.pdf
 - Family Members
 - Friends
 - Other Circle of Support Members
- In-home Supportive Services <https://www.cdss.ca.gov/in-home-supportive-services>
- Regional Center



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- Independent Living Supports <https://www.dds.ca.gov/general/eligibility/living-arrangements/independent-living-program/>
- Supported Living Supports <https://www.dds.ca.gov/general/eligibility/living-arrangements/independent-living-program/>
- Personal Assistance
 - https://www.dds.ca.gov/wp-content/uploads/2019/03/Publications_PASGuide_20190318.pdf
 - <https://www.healthinaging.org/tools-and-tips/caregiver-guide-advance-directives>

Letters of Intent

One of the most important things a parent can do, is to provide for a smooth transfer of care. A Letter of Intent can help with that. The Letter of Content details the care a person needs, a typical day, what they like and dislike and a list of current service and support providers. This helps people stepping into the caregiving role. It is also a good idea to ask future caregivers to become familiar with current supports and planning. That way, they start the caregiver role already knowing the routines.

- Special Needs Alliance
 - <https://www.specialneedsalliance.org/the-voice/letter-of-intent-4/>
 - <https://www.specialneedsalliance.org/the-voice/letter-of-intent-3/>
- It is also a good idea for parents to Pre-Plan for Funeral and/or Burial/Cremation, both for themselves and for their child with a developmental disability.
https://www.cfb.ca.gov/consumer/pre_need.shtml

II Life after 22

Things change when children with developmental disabilities become adults with developmental disabilities. They no longer have Special Education services and supports and are also more interested in adult issues. These can include:

- **Decision Making**
- **Employment**
- **Healthcare**
- **Higher Education**
- **Living Situations (including housing)**



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- **Person Centered Planning**
- **Recreation**
- **Regional Center Support**
- **Relationships**

General Resources

- Matrix Parent Network *Transition to Adulthood Resource Guide*
<https://www.matrixparents.org/adult-living-services-independent-living/>
- Warmline Family Resource Center *Moving On - Transition to Adult Living for Young Adults with Special Needs* http://www.warmlinefrc.org/uploads/5/9/5/8/5958794/moving_on_-_transtion_to_adult_living_for_young_adults_with_special_needs_2012.pdf

Decision Making

At age 18, a person becomes an adult and legally is the decision maker. Some people will need help with making decisions. There are several options

- Supported Decision Making
- Power of Attorney
- Conservatorship/Guardianship
 - ◆ **Resources for Decision Making Information**
 - ◆ Disability Rights California <https://www.disabilityrightsca.org/system/files/file-attachments/557801.pdf>
 - ◆ Disability Voices United https://disabilityvoicesunited.org/wp-content/uploads/2020/11/SDM-Handbook_Oct2020.6.pdf
 - ◆ Supported Decision Making.org <http://www.supporteddecisionmaking.org/>
 - ◆ <http://www.supporteddecisionmaking.org/state-review/california>
 - ◆ <http://www.supporteddecisionmaking.org/state-review/california> ,
 - ◆ The Arc <https://thearc.org/info-resources/conservatorship/>

Employment

A job is important to adults. California believes in Employment First (that we consider employment option for all adults) There are many choices and supports for employment.



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- Employment First <https://www.cde.ca.gov/sp/se/st/employmentfirstpolicy.asp> ,
<https://scdd.ca.gov/wp-content/uploads/sites/33/2016/10/Employment-First-Policy-Summary-SCDD-CECY.pdf>
- Department of Rehabilitation <https://www.dor.ca.gov/>
- Individualize Transition Plans (IEP) <https://www.cde.ca.gov/sp/se/st/>
<https://www.matrixparents.org/age-14-16-build-an-effective-individual-transition-program/> <https://www.autismspeaks.org/sites/default/files/2018-10/california-ttk.pdf>
- Regional Center <https://www.dds.ca.gov/rc/rc-services/>

Healthcare

It is important to think about who will provide healthcare for adults with developmental disabilities, how the health care will be funded and the role your child will play in their own healthcare.

IWDDs will have to transition to adult providers. Some systems such as California Children's Services (CCS) and children's hospitals only provide care until age 21, so your young adult child will have to have new providers. There are some clinics, such as the Achievable Clinic, that specialize in serving IWDDs or you may want to find a family practice physician or an internist who is willing to learn about your adult child's needs. It is also important to help your child to be an active participant in their own healthcare.

- Achievable Clinic <https://achievable.org/>
- Healthcare funding:
 - MediCal
 - Medicare
 - Employer Provided Private Insurance
 - Parent's Insurance
 - Insurance through IWDD's employer
 - Covered California <https://www.coveredca.com/>
- Healthcare Transition
 - Got Transition www.gottransition.org
 - Health Coverage Options for Children with Special Health Care Needs WHAT HAPPENS WHEN THEY AGE OUT OF CHILDREN'S PLANS



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https://www.lpfch.org/sites/default/files/ep-insur_age_out.pdf

Resources for Health Care Funding

- ◆ LA County Department of Public Social Services
<https://dpss.lacounty.gov/en/health/senior-disabled.html>
- ◆ California Health Advocates <https://cahealthadvocates.org/disabilities/medi-cal-medicare-for-people-with-disabilities/>
- ◆ Autism Insurance Resource Center <https://s3.amazonaws.com/disability-info/AIRC/pdf/Adult-Disabled-Dependents-102018-Accessible.pdf>
- ◆ Covered California <https://www.coveredca.com/>
- Healthcare Transition
 - Got Transition www.gottransition.org
 - *Health Coverage Options for Children with Special Health Care Needs What Happens When They Age Out Of Children's Plans* https://www.lpfch.org/sites/default/files/ep-insur_age_out.pdf

Higher Education

There are many options for higher education for IWDDs. In addition to 2- and 4-year degrees, there are certificate programs, adult school and programs specifically for people with disabilities. Some things to check out include:

- Open the Door to College <https://www.semel.ucla.edu/opendoors>
- Disability Rights California <https://www.disabilityrightscalifornia.org/resources/higher-education>
- Think College! <https://thinkcollege.net/>

Living Options

Although most adults with developmental disabilities live with family, there are other options. Even if an adult needs 24/7 care or supervision, they still have choices including living independently. The options include:

- Living Independently (with or without support)
- Group Homes



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- Community Care Facilities
- Intermediate Care Facilities
- Skilled Nursing Facilities
- Adult Family Homes

Resources for Living Options

- ◆ Autism Speaks <https://www.autismspeaks.org/housing-and-community-living>
- ◆ Regional Center of Orange County <https://www.rcocdd.com/consumers/description-of-services/residential-services/its-all-about-options/guide-to-living-arrangements-for-adults-with-developmental-disabilities-2/>

Recreation

There are many choices for recreation. There are specialized programs for people with disabilities as well as general programs in the community. Think about what your child likes to do and is interested in. This is a great way to get started. You can also talk with regional center and/or a Family Resource Center for local programs and resources.

- Regional Center - <https://www.dds.ca.gov/rc/listings/>
- Family Resources Centers <https://frcnca.org/get-connected/>

Regional Center Support

Regional Center becomes the primary service system after a person graduates or ages out of special education. They can provide a variety of services and also help people identify and access generic services. All services should be based both on a person's needs but also on their goals and interests. Each regional center has "service standards" or "purchase of service guidelines" that list the services and guidelines. In addition, regional centers should use person centered planning to help identify goals and needs.

- Person Centered Planning <https://www.dds.ca.gov/rc/ipp/> https://www.dds.ca.gov/wp-content/uploads/2019/03/RC_PersonCtrdPlanning_20190304.pdf
- Self Determination – is a different way of providing services and supports. It is more flexible and doesn't require using regional center vendors. <https://www.dds.ca.gov/initiatives/sdp/>



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Relationships and Social Life

People with developmental disabilities want relationships. This can include friendships as well as romantic relationships. Each regional center offers opportunities for relationships as well as resources for sexuality education. People also form relationships with people they meet through recreational and educational programs or people they interact with in the community. So involving your child in their community can support their social life.

- Family Resources Centers <https://frcnca.org/get-connected/>
- Regional Center - <https://www.dds.ca.gov/rc/listings/>
- Our Sexuality, Our Health: A Disabled Advocate's Guide to Relationships, Romance, Sexuality and Sexual Health <https://odpc.ucsf.edu/advocacy/sexuality-sexual-health/our-sexuality-our-health-a-disabled-advocates-guide-to>

Transportation

There are a variety of transportation options for adults with developmental disabilities. Some transportation options can be funded by regional center, others are self-funded. Check with your regional center or family resource center for transportation resources. Some of those options include:

- Driving on their own (regional center may be able to help with driving lessons)
- Taxis, Uber, LYFT
- Public Transportation (bus, metro)
- City run Senior/ Disability transportation programs (check with your city)
- Paratransit (e.g. Access)

Resources for Transportation Options

- ◆ DDS <https://www.dds.ca.gov/general/eligibility/support-services/>
- ◆ Family Resources Centers <https://frcnca.org/get-connected/>
- ◆ Regional Center - <https://www.dds.ca.gov/rc/listings/>
- ◆ National Center for Mobility Management <https://nationalcenterformobilitymanagement.org/states-at-a-glance/california/>



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