Adult Sibling Toolkit

A future planning guide for siblings of adults with intellectual and developmental disabilities in Washington State





Sponsors of this Project



The Arc is "the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families" thearc.org

Founded in 1950, there are now over 700 state and local chapters throughout the nation. The purpose for this guide is to provide individuals and families throughout Snohomish County with resources and information to aid in the decision making process of moving into the community and being connected to the resources and supports available.

The Arc of Snohomish County arcsno.org | 425-258-2459

"As the Community Inclusion Manager for Snohomish County, I applaud the many years of effort on the part of Arc, an organization that has labored tirelessly to ensure that individuals with intellectual and developmental disabilities and their families can fully realize their potential for happy and healthy lives. Just as we all seek to live in safe, convenient and vibrant neighborhoods and housing, so should people with disabilities be able to live comfortably in their communities of choice." (Putterman, Julie. *Community Inclusion Manage, Snohomish County-2012*)



The Washington Developmental Disabilities Council is a Federal-State partnership working to plan for and with people with developmental disabilities and their families

Washington Developmental Disabilities Council ddc.wa.gov | 360-586-3560

Using This Guide

Many siblings feel a great deal of anxiety when it comes to planning for their sibling's future. What will you need to know? What will your legal and financial responsibilities be? Many people find that making a plan with their family helps to alleviate some of that anxiety. Here's how this guide can help:

- Gather important people- Sit down with your parents, sibling, and other family members or important support people
- Be honest- Talk about and decide what everyone's role should be. You might want to identify one person who will take the lead and be the "go-to" support person for your sibling, or you might want to share responsibilities evenly. Try to be honest about what you are willing and able to do, and allow others to express themselves, too.
- Gather paperwork- Find important documents like guardianship paperwork, your sibling's identification, medical information, etc. You can keep copies of them or identify some way to keep them organized and know where they are. If documents are missing, make a plan to get them.
- Be thorough- Go through the guide together as a family and support network. You don't have to do it all at once, but try to fill out everything to the best of your ability. It might help to set a date once a year to go through and update information.
- Identify support- How did it feel to start this process? Probably a bit overwhelming, but hopefully you will feel better having a plan. Now's the time to identify what support you need as a sibling. You can find resources in each section of this toolkit to help get you started.



Understanding inclusive community opportunities and steps to become a successful self-advocate.

Citizenship:

It is important for individuals to be a part of their community, to access things within their community and participate in community events.

Voting

In the state of Washington, there are several accommodations available for individuals with disabilities including accessible voters' pamphlets, accessible voting units and assistance voting your ballot.

wei.sos.wa.gov/agency/osos/en/voters/Pages/voters with disabilities.aspx

Transportation

Locate accessible transportation in your area in order for your sibling to access hi/her community independently. wsdot.wa.gov/choices/accessible.cfm

Advocacy:

Being independent is a goal for many individuals with disabilities. A large part of independence is knowing how to handle situations, have self-confidence and know what your personal rights are. Self-advocacy guides individuals in knowing how to have a strong voice and stand up for themselves.

Washington State Self-Advocacy Groups:

- Self Advocates in Leadership (SAIL)
 sailcoalition.org
- Self Advocates of Washington (SAW)
 <u>sailcoalition.org</u> | 253-571-8665
- People First of Washington
 peoplefirstofwashington.org |800-758-1123
- Allies in Advocacy alliesinadvocacy.com



There are many different options for people with disabilities when it comes to a place to call home. What will work for your sibling will depend on a variety of factors, including their preferences, care needs, and support services.

Questions to ask:

 How independent is your sibling in terms of their daily needs? Consider these things:

Meal Preparation & Food Preferences
Cleaning
Transportation
Personal Hygiene
Would your sibling prefer to live with family? On their own? With roommates?
 What type of family support will be best for your sibling and the rest of the family? Will it be necessary for your sibling to move to a different area?

In Washington State, many types of living arrangements are possible. Your sibling's case manager can help you pursue possibilities that might be a good fit. Some of these options are paid for using state funding, family funds, by the residents themselves, or some combination of these.

Even though it might be difficult to talk about, it might be helpful to look into housing options before they become necessary. A slow and smooth transition into a different living arrangement is often easier on everyone.

Some types of housing options outside of living with family include:

- Adult Family Homes: These are homes in the community with support staff to assist with the daily needs of the residents. Some Adult Family Homes specialize in serving people with developmental disabilities. These homes are licensed by the state and usually serve a group of residents living together.
- Companion Homes: These homes function using an adult foster care model and serve only clients with a disability.
- Group Homes: Group homes are houses in the community that serve groups of residents with disabilities. They can provide a variety of levels of support to residents but usually provide 24-hour support.
- Residential Habilitation Centers: Formerly called institutions, these are state operated residential settings that provide 24 hour care to people with disabilities who are eligible. There are currently four RHCs operating in the state of Washington.
- Supported Living Services: Supported Living Services offer support to people with disabilities in their own homes. The level of support varies widely depending on the needs of the resident.

Housing Resources:

Housing & Urban Development hud.gov

Homechoice Program wshfc.org/buyers/homechoice.htm

Low Income Energy Assistance Program commerce.wa.gov

DDA Residential Services dshs.wa.gov/dda/consumers-and-families/residential-services



Many adults with disabilities enjoy and find employment to be beneficial to their lives. Employment can offer someone structure and routine, more opportunities to socialize, and the feeling of purpose and value. Businesses also benefit from adding individuals with disabilities to their workforce.

When thinking about a job or volunteer opportunity for your sibling, some questions to

١	What are your sibling's interests?
_	
١	What job skills do they have?
_	What kind of support does your sibling need to perform in a work
•	What kind of support does your sibling need to perform in a work environment? Maybe this includes a quiet workspace or break area, a reward system, a task list, or transportation.
_	

If your sibling is a client of DDA, their case manager can help connect them with an agency that can help them find a position that meets their needs, skills, and interests. Services are generally free for DDA clients and vary by county.

More information can be found at: https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential

Some employment opportunities for individuals with disabilities include:

Volunteer Positions

- A great way to build job skills
- Sometimes offer more flexibility than paid employment (e.g. more options for scheduling, more leniency for missed days or arriving late for those who find attendance challenging
- A job coach can provide environmental adjustments, skill teaching, and support to help the position be successful

Supported Employment Positions

- Paid positions integrated into the workplace
- A job coach can help with on the job coaching, supervision, and feedback, as well as adjusting things within the workplace (for example, lowering a desk or setting up a task list) that can help

Sheltered Employment Positions (Being phased out in Washington)

- A workplace that provides supervised work specifically for people with disabilities
- Criticized for segregating individuals with disabilities away from the general population

Employment Resources

DEVELOPMENTAL DISABILITIES ADMINISTRATION

Home and community-based services for children and adults with developmental disabilities, including: Medicaid Personal Care, Employment/ Day, Supported Living, Therapies and Respite. Waiting lists may exist for some services, depending on available funding.

dshs.wa.gov/ddd

DEPT OF SERVICES FOR THE BLIND (DSB)

Serves children, youth and adults who are blind or have low vision. dsb.wa.gov | 800 552-7103

DIVISION OF VOCATIONAL REHABILITATION (DVR)

DVR is a national leader in vocational rehabilitation through the empowerment of individuals with disabilities achieving greater independence through employment.

dshs.wa.gov/ra/division-vocational-rehabilitation | 1-800-637-5627



Employment History

Current Employer	
Supervisor or Contact	
Address	
Phone	_ Email
Job Title	
Duties/Responsibilities	
Job Coach Name (if any)	
Phone	_ Email
What type of support does he/she receive o	r need to perform their job?
What are your sibling's strengths at work?	
What are some challenges for your sibling at	t work?

Previous Employer		
Supervisor or Contact		
Address		
Phone	Email	
Job Title		
Duties/Responsibilities		
Previous Employer		
Supervisor or Contact		
Address		
Phone	Email	
Job Title		
Duties		



Managing and accessing health care and staying well- medical, mental health, behavioral health, developmental health, wellness, and nutrition.

Things to Think About:

- Do you understand and can you talk about your sibling's disability and special healthcare needs with others?
- What steps can your sibling take to manage their own healthcare?
- How does your family find adult health providers who will understand your sibling's disability and special healthcare needs?
- Does your sibling know the importance of healthy eating and regular exercise?
- Does your sibling understand and manage their reproductive health?

For Aging Siblings:

- Is your sibling staying as physically active as possible?
- Who understands your sibling's medical needs and is available if they need help communicating their needs to others?
- Are there disability-related health issues about growing older you should be aware of?
- Is your sibling learning about changes in their body and health as they get older?
- Who will help your sibling create end of life documents and make their wishes known for medical directives?
- Is your sibling eating healthy meals and snacks?

Diet & Exercise	
Does your sibling struggle with being overweight?	Yes or No
Have specific dietary needs?	Yes or No
Have a regular exercise programs?	Yes or No

Medical History

Does your sibling have any al If yes, list here	Yes or No			
Does your sibling have any fo If yes, list here	Yes or No			
Does your sibling have any ch (Please circle all that apply)	nronic health conditions?	Yes or No		
Lung Disease	Arthritis			
High Blood Pressure	Hepatitis			
Heart Condition	Blood Disorders			
GI Issues	Visual Impairment	Visual Impairment		
Cancer	Hearing Impairmen	Hearing Impairment		
Kidney Disease				
Any other Conditions?				
Has your sibling had surgery	or been hospitalized in the past	ten years?		
List the year and cause:				
	sychological/emotional difficulti	es?		
(Please circle all that apply Depression				
Self-Talk	Behavioral Issues			
Agitation	Memory Loss			

Physical Aggression

PTSD

OCD

Loss of Skills

Medication Information

Medication Name:	Medication Name:	
Medication Purpose:	Medication Purpose:	
Dosage:	Dosage:	
Prescribing Doctor:	Prescribing Doctor:	
Comments:	Comments:	
'		
Medication Name:	Medication Name:	
Medication Purpose:	Medication Purpose:	
Dosage:	Dosage:	
Prescribing Doctor:	Prescribing Doctor:	
Comments:	Comments:	
l		
Medication Name:	Medication Name:	
Medication Purpose:	Medication Purpose:	
Dosage:	Dosage:	
Prescribing Doctor:	Prescribing Doctor:	
Comments:	Comments:	

Medication Schedule

	Medication Name	Dosage	Condition Treated	Prescribed By	Special Instructions	Possible Side Effects
Early Morning						
Mid- morning						
Lunch						
Mid- afternoon						
Evening						

Other Notes:

Medical Professionals

Doctor	Specialty	Condition	Phone	Address	City, State & Zip

WA HEALTH PLAN FINDER

Find, compare and enroll in health insurance. wahealthplanfinder.org
WA State Healthcare Authority

Hca.gov

MWA Apple Health (Medicaid)

Hca.wa.gov/Medicaid | 800-562-3022

Healthcare for individuals with low income (formerly known as Medicaid)

WA PRESCRIPTION DRUG DISCOUNT CARD

Free to anyone who lacks prescription drug coverage.

hca.wa.gov/pdp/ | 800-913-4146

AUTISM CENTERS

University of Washington Evaluation, treatment, training, and research. Seattle 206-221-6806 Tacoma 253-692-4721 NW Autism Center (Spokane) Information and referral.

nwautism.org | 509-328-1582

FAMILY TO FAMILY HEALTH INFORMATION CENTER

Information and referral about special health care needs and insurance. familyvoices.org | 800-572-7368

Family Health Hotline **1-800-322-2588**

DIVISION OF BEHAVIORAL HEALTH & RECOVERY

Contracts with 11 Regional Support Networks (RSNs) to administer community mental health programs for Medicaid-eligible persons. **dshs.wa.gov/dbhr/**

WITHINREACH/PARENT HELP 123

A family-friendly clearinghouse, connecting families to resources, benefits, and services. withinreachwa.org | parenthelp123.org

BASIC FOOD

Monthly benefits to help low-income individuals and families buy food. **foodhelp.wa.gov**

UW CENTER ON HUMAN DEVELOPMENT & DISABILITY (CHDD)

A range of on-site clinical service programs that serve primarily children, with or at risk for developmental, learning, and behavioral problems. **depts.washington.edu/chdd**

UW DENTAL EDUCATION IN CARE OF PERSONS WITH DISABILITIES (DECOD)

A program of the School of Dentistry that treats persons with severe disabilities.

206-543-4619



Staying safe and secure- emergencies, well-being, guardianship options, legal rights & issues

 Things to talk about: What is the least amount of support your sibling needs to be able to function as an adult in their financial, medical, and legal affairs? What skills and abilities can be practiced now to help them to function more independently?
• Are there alternatives to guardianship that might be appropriate for your sibling?
If a guardian is necessary, who should it be? Who should be the back-up guardian?
 In what areas are your sibling's parents and loved ones most concerned about their safety? (for example, health care/medical, school, community access, etc.)
 Is your sibling able to stay home or be in the community alone or without additional support, and do they know what to do in case of an emergency (fire, home invasion, etc)?
For aging siblings: • What are your sibling's legal rights and protection as they age?

 Are they at risk of falling or other hazards?
 Are there modifications or technology that will help your sibling stay safe as they age?
 Does your sibling have legal documentation of their end-of-life wishes?
 Is supported decision making, a guardianship alternative, or guardianship in place to protect their rights as they age?

Alternatives to Guardianship

Washington State law requires that alternatives to guardianship be considered, and that full guardianship be used only as a "last resort." Many individuals with disabilities are capable of handling their own financial, medical and legal decisions, or require less support than full guardianship. Your family should identify what types of legal or financial needs your sibling has, what supports they need to accomplish these, and determine if less restrictive options can be used. These might include:

- Case management
- Durable power of attorney
- Healthcare Power of Attorney
- Living Trusts
- Living Wills
- Money Management Services, Direct Deposit, or Joint Accounts
- Representative Payeeships

More information about guardianship alternatives can be found at:

washingtonlawhelp.org/resource/alternatives-to-guardianships-for-adults?ref=6036h



Guardianship

A guardian is a person or agency appointed to manage the affairs of a ward, an individual who is not able to manage them him or herself. This person is court-appointed, but usually selected by the family. All guardians must complete a mandatory training. Guardianship is not supposed to inhibit the ward from caring for themselves in ways they can already do independently. It is tailored to cover what is necessary for each situation. Since guardianship involves contact with the court on a regular basis, many families use an attorney to help with guardianship. There are attorneys who have experience in legal issues for adults with special needs, and can help set up a comprehensive plan.

More information about guardianship: arcwa.org/library/guardianship

Selecting a Guardian

Many factors come into play when selecting an appropriate guardian. A guardian can be a relative or other person who can and is willing to provide care and management of the ward and their estate. Selecting a guardian is a personal family decision. If you are considering stepping in as your sibling's guardian, either now or sometime in the future, you might be worried about what responsibilities you would have. It's important to know that a guardian/ward relationship is different than a parent/child relationship. A guardian's primary responsibility is decision making- not necessarily direct care. However, guardianship is a legal responsibility that shouldn't be taken lightly. It's important to discuss this issue openly as a family. The discussion should continue regularly since guardianship needs might change as time passes, and an ideal guardian now might not be willing or able to provide these services down the road.

Letters of Intent

An important document to include in your sibling's future planning is a Letter of Intent. This letter specifies the family's wishes for the future of the sibling and can direct future caregivers or guardians. It can include many pieces of information, some of which is included in this guide, including likes/dislikes, friends, medical information, and goals for housing and employment.

Income

Many individuals with disabilities receive income from a variety of sources. These can include:

- Supplemental Income from Family
- Personal Income (from employment)
- Medicaid
- Supplemental Security Income (SSI) or Social Security

Since many services available have maximum income eligibility requirements, it can be difficult to juggle various sources of income and set up a long-term financial plan.

Trusts

A special needs trust is a trust set up specifically for a person with special needs. A trust is typically set up in order to ensure a person with a disability that receives SSI income can continue to do so even if they acquire other assets. If an individual receives SSI, they cannot hold more than \$2000 to their name (this includes savings, assets like property, or inheritance.) A special needs trust can hold assets and funds intended for the individual with special needs without being considered income that might impact their SSI. The trust can be managed by a parent or guardian. There are several different types of special needs trusts; a qualified professional can help determine which type best fits each family's situation.

One option available to families is the Developmental Disabilities Life Opportunities Trust (DDLOT). This is a state-supported special needs trust that is only for residents of Washington State.

More information can be found at: www.ddlot.org

Legal and Financial Resources

Disability Rights Washington disabilityrightswa.org | 800-562-2702

NW Justice Project
nwjustice.org | 211 (Inside King County)
888-201-1014 (Outside King County)

Washington Lawhelp Washingtonlawhelp.org

Legal Documents Checklist

The following documents are important for future planning. Although not all of them will apply to your sibling's specific situation, you can use this list to check off what documents your sibling already has and note their location. If applicable documents are missing, make a plan to get them.

1. Important Papers
Life insurance policies for parents and sibling Health insurance policies & ID cards Real estate holdings/deeds Social security cards and benefit records Birth certificate State ID or Passport
2. Guardianship
 ☐ Guardianship papers ☐ Power of Attorney- financial ☐ Power of Attorney- medical ☐ Letter of Intent (from family) ☐ Advance Directives
3. Financial
☐ Special Needs Trust/Attorney contact information ☐ Bank records/Rep Payee Information ☐ Federal, State, & Local Tax Returns/Accountant contact information ☐ Car insurance/title
4. Sibling's Documents
 Medicaid, Medicare, and other Health Insurance Cards Waiver information Bank account information Copy of last Individual Service Plan (ISP) Copy of medical records, psychological or other evaluations



Building friendships and relationships, leisure activities, personal networks, and faith community

Things to talk about:

- Is your sibling building friendships by participating in extracurricular activities in the community such as clubs and social outlets?
- Does your sibling use social media safely and responsibly? (Facebook, Twitter, Instagram, Snapchat, etc.) To connect with and maintain contact with friends?
- Is your sibling learning about sex and intimacy, including safe sex and sexual boundaries?
- Is your sibling involved with a youth or adult group in your faith community?

For aging siblings:

- Does your sibling have end of life wishes pertaining to their faith?
- Which technology can your sibling use to help him or her keep in touch with friends and family?
- What opportunities does your sibling have to make/maintain friendships?
- Does your sibling have friends that are close to their age and share their interests?
- What hobbies or interests is your sibling pursuing in their spare time?
- Are your sibling's beliefs and spiritual wishes being considered and respected?
- Does your sibling need extra support to fully participate in their faith community as they are aging?

organizations, events, TV shows, favorite stores, etc. below.
My sibling:
Likes to have a fairly consistent routine Prefers to be flexible

Leisure Time: What does your sibling like to do? List favorite activities,

Schedule: What does a typical week look like for your sibling?

	Early Morning	Mid-morning	Lunch	Mid- afternoon	Evening
Sunday					
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					

Resources

Washington Access Fund- Sports and Recreation Resources washingtonaccessfund.org/sports-recreation-resources-for-people-with-disabilities-in-washington-state

Special Olympics Washington specialolympicswashington.org

Outdoors for All- Outdoor Recreation for Individuals with Disabilities outdoorsforall.org

Center for Parent Resources and Information- Nationwide Hub for Resources for Individuals with Disabilities

parentcenterhub.org/repository/foradults/#rec

Activities: What activities does your sibling currently do? Think of clubs/organizations, community activities like parks or libraries, therapies, activities with their faith community, and fun like concerts or sporting events.

Activity	Address	City, State & Zip	Phone Number	Contact	Method of Transportation

Friends: Who does your sibling spend time with?

Name	Phone Number	E-mail	Address	City, State & Zip

Support Professionals: Who are the key professionals in your sibling's life? This can include case managers, job coaches, or others you want to list here.

Name	Title	E-mail	Phone Number	Responsibilities



Many individuals with disabilities receive benefits from a variety of sources. It can be complicated to keep track of all of these services and how they are accessed.

Developmental Disabilities Administration (DDA)

The gatekeeper to almost all of these services is the Developmental Disabilities Administration (DDA). If your sibling is already a DDA client, they have a case manager that is your primary resource for what services your sibling is eligible for, receives, and might receive in the future.

If your sibling isn't a client of DDA, you can request an assessment. In order to apply for DDA eligibility, your sibling must:

- 1. Be a resident of Washington State. If your sibling lives out of state, the process can't begin until they move, and eligibility in their current state will not transfer.
- 2. Have an eligible condition. You can find a list of qualifying conditions here: dshs.wa.gov/dda (click on Eligibility)

Once these conditions are met, you can request a determination of eligibility from your local DDA office or online. An application packet and list of locations can be found at dshs.wa.gov/dda (click on Eligibility)

Documents to have on hand:

- Verification of identity
- Verification of residency
- Proof of disability
- Guardianship or Adoption records

It's important to know that the waiting lists for some services are very long. It's best to start the process as early as possible.

Your sibling's services will be reassessed regularly with your case manager, and put into an Individual Service Plan (ISP). It might be a good idea to keep a copy of this plan for your records, or at least know where the original is kept. The ISP meeting, where the plan is developed and revised, is a great way for siblings to be involved and keep on top of an individual's services.

My Life Plan is an online app that can help you start to think about goals and support needed prior to meeting with your DDA case resource manager for an assessment and service planning, or for your own planning purposes.

mylifeplan.guide

Social Security

Many individuals with disabilities are eligible for Supplemental Security Income (SSI) through Social Security. These funds are intended to pay for basic living expenses. Additionally, eligibility for SSI can open the door to additional services, such as Medicaid. For more information, call 1-800-772-1213 or visit ssa.gov. Your DDA case manager can help you navigate Social Security, but it's also important to keep clear records of everything you send to Social Security, as well as any income records for your sibling, such as pay stubs.

Waivers and Community First Choice

Most services that DDA provides are accessed through a Home & Community Based Services Waiver. Waivers are granted based on a combination of eligibility and available funding- in other words, your sibling can be eligible for a waiver but will usually be placed on a waiting list until funding becomes available. Your family can ask to be added to the "waiver enrollment database," which is the official waiting list for waivers.

DDA has five waivers: Individual & Family Services (IFS), Basic Plus, CORE, Children's Intensive In-Home Behavior Support (for children ages 8-20), and Community Protection. Most adult individuals living at home with parents will be placed on an IFS or Basic Plus Waiver, which can give them things like personal care support, assistive technology, transportation, and support for community access. Individuals not residing at home and with more intensive needs will sometimes be placed on a CORE or Community Protection waiver, which gives them access to supported living services.

Community First Choice (CFC) is a non-waiver entitlement program that offers funding for personal care, assistive technology, skills acquisition training, and an electronic device that allows you to call for help in an emergency. Since this is an entitlement program, if your sibling meets the financial and eligibility requirements, they can receive it without being placed on a waiting list.

More information about waivers can be found at: dshs.wa.gov/dda/consumers-and-families/waiver-program

Other Possible Benefits

Basic Food- Formerly known as food stamps or SNAP, this monthly benefit can help low income individuals with food costs. food-new-norm | 877-501-2233

Washington Assistive Technology Act Program- A hub for assistive technology including communication devices, WATAP can provide information, referrals, training, and device loans. watap.org | 800-214-8731



Case Manager Contact Information

Name:
Pnone:
Email:
List of Current Benefits:
List of Benefits to Learn More About:
List of Documents and Location:
List of Documents Needed:



Supporting an individual can be challenging and draining. Participating in support groups is a great tool to learn, share and connect with other families in the same

WA State Sibling Connection

Washington State Sibling Connection (WSSC) strives to connect siblings of individuals with disabilities, creating a community of sibs who can support each other and share information and resources to address issues important to them and their families.

WSSC currently has bi-monthly meetups for adult siblings to connect and share. To ask questions or to get on the mailing list to receive ongoing information contact Kendall Appell Kendall@arcsno.org | 425-258-2459 x105

Sibling Leadership Network

Sign up using your email to receive monthly e-mails offering the latest news relevant to siblings.

siblingleadership.org

Facebook Groups

- Washington State Sibling Connection- for local sibs facebook.com/groups/washingtonstatesiblingconnection
- SibNet- very active and large group for all sibs facebook.com/groups/SibNet
- Sib20- geared toward sibs 18-30 facebook.com/groups/118970768514797

General Resources

General Resources

Community Services Office dshs.wa.gov/onlinecso | 877-501-2233

Informing Families
Informingfamilies.org

University Center for Excellence in Developmental Disabilities (UCEDD) depts.washington.edu/chdd/ucedd.html

Washington State Developmental Disabilities Council (DDC) ddc.wa.gov | 800-634-4473

Washington Connection washingtonconnection.org

Washington Access Fund washingtonaccessfund.org | 877-428-5116