

Starting Points

Often, LPs/Dwarfs may need to find resources beyond LPA. LPA is a primary source of support to chat with others to get ideas for adaptations, and for families to support your child by connecting them to peers and adult mentors. But for direct support with services and resources, many other organizations help people with disabilities and their families access healthcare, education, employment, and assistive technology services that are also applicable for LPs. Below is information on places to start when seeking out information. This is not meant to be an all-inclusive list of disability-related resources; rather, it is a list of places to call first as you try to find answers to questions. These are also organizations that you should connect to for local advocacy and to be tuned into broader issues that impact all people with disabilities.

Your local **Independent Living Center/Center for Independent Living** can assist with a variety of services including advocacy, independent living skills training, peer counseling, and information and referral to other agencies. ILCs are non-residential and are consumer-controlled- meaning that people with disabilities are the majority of their staff and board. They can provide information on assistive technology, equipment, and funding resources as well. Information and training regarding the transition from high school to adulthood is also typically available. ILCs can also provide more information on the other programs in this document. Location information is at: <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

Knowing Your Rights under the Americans with Disabilities Act (ADA)- **Regional ADA Centers** provides information, training, and technical assistance to employers, people with disabilities, and other organizations with responsibilities under the ADA. This includes public access and employment concerns. You can find your local center at the ADA National Network website: <https://adata.org/> as well as resources and webinars. Technical Assistance is also available at **1-800-949-4232**.

An **IEP** is a special education plan that helps students with academics, and not all children with dwarfism will need an IEP. Some kids may need a **504** plan to assist with accommodations to modify the physical space. If you have questions about IEPs, 504s, and/ or special education, reach out the Parent Information and Resource Center for your state. They help families obtain appropriate education and services for their children with disabilities; train and inform parents and professionals and resolve problems between families and schools. <https://www.parentcenterhub.org/find-your-center/>

Adaptations/ Assistive Technology: State assistive technology programs can provide information on a variety of items and software to help people be more independent, including grabbers/reachers, kitchen items, and mobility devices. Remember that Assistive Technology can also be “low tech” devices to assist with daily tasks. Also, there may be accessibility loan closets to try out things before purchasing. In some states, these are managed by Centers for Independent Living. <https://www.at3center.net/state-at-programs>.

Children and Youth with Special Health Care Needs (CYSHCN) funds **Family-to-Family Health Information Centers** that are focused on the complex health care needs of children with disabilities. If your child sees multiple specialists or frequents treatments and surgeries, they can help you learn more about accessing Medicaid as secondary insurance and other local resources and programs.
<https://familyvoices.org/felsc/whataref2fs/>

Another resource for legal advocacy is the **National Disability Rights Network** (<https://www.ndrn.org/about/ndrn-member-agencies/>) which is a network of state legal centers that advocate for the rights of people with disabilities. Check out the organizations in your state using this [link](#) to see what areas of focus they have.

Early Intervention includes services for children up to age 3 that are created through an IFSP (Individualized Family Service Plan) which can include in home therapies to work on developmental delays. EI services from age 3 to kindergarten are part of the school system and an IEP (Individualized Education Plan) is created. Both IFSPs and IEPs are goal based. You can contact your Birth to 3 program to learn more: <https://www.cdc.gov/act-early/early-intervention/contact-information-by-state.html>

Getting or keeping a job: **Vocational Rehabilitation** is a federal program that supports individuals with disabilities in getting a job, getting a better job, or keeping the job they have. Offices may have different names in your area, but they all provide assistance including training, career counseling, and job seeking services. Agencies may prioritize those with the most significant disabilities and have a waiting list. Learn more and find local contacts here:

<https://www.careeronestop.org/ResourcesFor/WorkersWithDisabilities/vocational-rehabilitation.aspx>

Assistance with Social Security (SSI/SSDI): If you are looking at going to work but want information on how that will impact your SSI/SSDI benefits, WIPA (Work Incentives Planning and Assistance) programs can assist you as well as provide a detailed analysis of options. Local contacts and more information can be found at: <https://choosework.ssa.gov/>. For parents looking for information to apply for SSI for their child, based on family income, information is available here: <https://www.ssa.gov/ssi/text-child-ussi.htm>

Planning for Ages and Stages

At points in your child's life, different resources may become important to consider. This is a broad overview of considerations. Keeping a Care Binder with important medical records, historical info, and journal articles specific to dwarfism to share during transitions can also be helpful. Connect with Allison for more information on examples of this and what to keep.

Ages 0-3/ 3-5

- Access Birth to 3 if development delays are being observed
- Learn about programs to assist with medical needs
- Find a Medical Home- a trusted pediatrician or specialist that you can partner with

Health Transition (12+)

- Continue to assist youth learn about their dwarfism to better advocate for themselves
- Transition making appointments and handling Rx refills to them
- Start looking into insurance options for adulthood

School (K-12)

- Prepare for school by determining need for 504 and/or IEP
- Consider any needed PE Adaptations
- Work with your school and child to determine any Physical Modifications

School Transition (14+)

- Consider what type of driving adaptations will be needed including public transportation
- Learn about Vocational Rehabilitation and determine if needed
- Plan for college and employment accommodations

*At all stages, continue to foster self-advocacy skills to prepare for adulthood.
Contact your local LPA Chapter to find mentoring, resources, and support.*