



A Guide for Individuals and Families

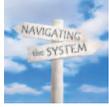
Division of Developmental Disabilities

"Supporting Tomorrow's Vision Today"



DEPARTMENT OF ECONOMIC SECURITY

Your Partner For A Stronger Arizona



Introduction

Fall 2014

Greetings!

I have the pleasure of talking with many people with developmental disabilities as well as their family members and stakeholders. It is clear from these conversations that people often experience confusion and frustration when working with multiple systems and processes to get their needs met. *Navigating the System* was developed to provide information in a clear way to aid in understanding how service systems and processes work, and where further information can be obtained.

This guidebook was developed through the efforts of many people including self-advocates and family members. It does not answer every possible question, but this book should help in finding answers to most questions.

Staff from the Division of Developmental Disabilities (the Division) review and update this guide periodically. All updates are posted on the Division's website at www.azdes.gov/ddd. If you do not have access to the internet at home or through your local library, you may call your Support Coordinator to obtain an updated copy.

If you have suggestions to improve future editions of the guidebook, I encourage you to share them with us by calling 602-542-6850 or 1-866-229-5553 (toll-free).

It is my hope that *Navigating the System* proves to be useful as a valuable source of information.

Cordially,

Dr. Larry L. Latham, Assistant Director
Arizona Department of Economic Security
Division of Developmental Disabilities



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An Overview of the Division of Developmental Disabilities

Why do I need this guidebook?

Life is complicated. Systems that help people with developmental disabilities are even more complex. This guide is intended to help people understand the many systems that may be encountered by people with developmental disabilities. Some of the information in this book may never be needed. If something does happen, easy access to information is available. This book provides information necessary to help “navigate” the system.

What is the Division of Developmental Disabilities?

The Division of Developmental Disabilities (Division), within the Arizona Department of Economic Security (ADES), is the state program that provides supports and services for eligible people who have at least one of the following diagnoses:

- autism;
- cerebral palsy;
- epilepsy;
- cognitive/intellectual disability; or
- under the age of six at risk of having a developmental disability

The term *mental retardation* has been changed to *cognitive disability* or *intellectual disability*.

Additional information about the Division may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

Division Website

Where is the website?

The Division's web site is at www.azdes.gov/ddd

What is on the website?

The site includes general information about the Division. The "Help for Individuals and Families" link has Online Tools, Division Guides and a variety of other topics. A link in the reference section leads to applicable laws, policies, and procedures. Other links include News and Events, Find a DDD Service Provider, and Apply for DDD Services. The site also includes information about becoming a Qualified Vendor and Published Rates.

The DDD Credo

To support the choices of individuals with disabilities and their families by promoting and providing within communities, flexible, quality, consumer-driven services and supports.

Our Vision

Individuals with developmental disabilities are valued members of their communities and are involved and participating based on their own choice.

The Division's Values

We Value:

- The development and fostering of personal relationships with family and friends.
- Consumer and family initiative in making choices and expressing preferences.
- Equal access to quality services and supports for all individuals.
- Consumers as welcomed, participating, and contributing members in all aspects of family and community life.
- The rights of all individuals and the preservation of their worth, value and dignity.
- Healthy relationships with people.
- Individual and family priorities and choices.
- Equal access to quality services and supports for all individuals and families.
- Partnerships and ongoing communication with individuals, family members, advocates, providers and community members.
- Developmental approaches – changing conditions that affect people rather than changing people who are affected by conditions.
- Individual freedom from abuse, neglect and exploitation with a balance between the right to make choices and experience life and individual safety.
- A diverse workforce that is motivated, skilled, and knowledgeable and uses the most effective practices known.
- An environment rich in diversity in which each person is respected and has the opportunity to reach their optimal potential.
- An individual's right to choose to participate in and contribute to all aspects of home and community life.

- A system of services and supports which are:
 - *Responsive* – timely and flexible responses to internal and external customers;
 - *Strength based* – recognizing people’s strengths, promoting self-reliance, enhancing confidence, and building on community assets;
 - *Effective* – ongoing identification of effective methods and practices and incorporation of those practices into operations; and
 - *Accountable* – to our customers and to the taxpayers.

Who is eligible?

To qualify for supports and services through the Division, an individual must:

1. Voluntarily apply;
2. Be an Arizona resident and lawfully in the United States;
3. Have been diagnosed with autism, cerebral palsy, epilepsy, or a cognitive/intellectual disability which was manifested before the age of eighteen (18) and is likely to continue indefinitely; and
4. Have substantial functional limitations in three or more of the following life areas that are directly attributable to the qualifying diagnosis:
 - a. Self-care: needing help with eating, hygiene, dressing, using the bathroom, etc.
 - b. Receptive and expressive language: communicating with others.
 - c. Learning: acquiring and processing new information.
 - d. Mobility: the skill necessary to move safely and efficiently from one location to another within the person's home, neighborhood, and community.
 - e. Self-direction: managing personal finances, protecting self-interest or making independent decisions which may affect your well-being.

f. Capacity for independent living: needing supervision or assistance on a daily basis.

g. Economic self-sufficiency: being financially independent.

Children under the age of six may be eligible for services when they are determined to be at risk for a developmental disability if services and supports are not provided.

Who determines eligibility for services through the Division?

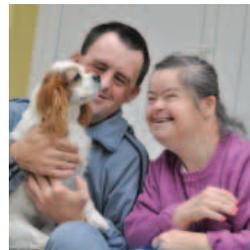
Specially trained intake staff of the Division will make the initial eligibility determination. If eligibility is uncertain, a committee that includes the Division's Medical Director will review the documentation and make the final determination.

Once eligibility is determined, will I always be eligible?

No. A person may meet the Division's eligibility at one point in time. Effective supports and services may later increase the person's abilities to the point that supports and services are no longer needed. That is why eligibility is re-determined at two set times in an individual's life.

When does eligibility redetermination occur?

Eligibility will be redetermined at the age six and again at age 18. A redetermination may also take place at any time if evaluations indicate that supports and services may no longer be needed.



What do I need to do?

It is important to get and keep copies of all evaluations, service progress notes, medical records, etc. Have these available for Division staff if they are needed.

Where can I get more information about eligibility?

Additional information about eligibility can be found in the DDD Policy Manual. The Manual is available on the Division's website at www.azdes.gov/landing.aspx?id=2844

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Eligibility for Arizona Long Term Care System

The Arizona Health Care Cost Containment System (AHCCCS) determines eligibility for the Arizona Long Term Care System (ALTCS). AHCCCS is Arizona's state Medicaid agency. AHCCCS pays for ALTCS services provided through the Division. AHCCCS is also the umbrella agency for other programs, including Kids Care, Medicare Savings Programs, and others.

What are the criteria?

1. A person may not have more than \$2,000 in cash or assets. Their monthly income may not exceed 300% of the federal benefit rate (e.g., Supplemental Security Income). A parent's income may be waived for a child under the age of 18.
2. A person must have medical and functional needs and be at risk for institutionalization. A Pre-Admission Screening (PAS) by AHCCCS makes this determination.

If you have any questions about ALTCS eligibility, contact AHCCCS at 602-417-4000 or 1-800-654-8713. Further information can be found at azahcccs.gov/applicants/application/ALTCS.aspx

What does it mean to be ALTCS eligible?

When a person is made eligible for the Division they must also apply to ALTCS. To be eligible for ALTCS you must meet financial and medical requirements. The Division receives federal funds to provide services for people who are also eligible for ALTCS. Arizona Long Term-Care System eligibility is required to receive most

services funded through the Division. If you are not eligible for ALTCS and over the age of three, only limited state funds are available.

How often will Arizona Long Term Care eligibility be reassessed?

If there is no change in the person's medical condition, ALTCS eligibility is only determined once. A person's financial condition is reviewed at least annually. Ask the AHCCCS staff making the Long Term Care eligibility determination when a reassessment will be made.

What do I need to do?

Complete the financial information form and cooperate with AHCCCS staff to provide answers to the Pre-Admission Screening determination. You will be interviewed, to help the AHCCCS staff gain a realistic picture of you or your son/daughter. The AHCCCS staff may request evaluations or other records. Providing these records will help the AHCCCS staff to increase their understanding of you or your son/daughter.

What happens if I am determined eligible for ALTCS?

Once a person is determined eligible for ALTCS, the Division becomes the program contractor that provides ALTCS services. Within five (5) days, a Support Coordinator will contact you to schedule an appointment to discuss the DDD ALTCS program.

What is the role of the Support Coordinator?

A Support Coordinator may play a variety of roles. The primary role of a Support Coordinator is to listen to the needs, goals and vision of the person and family in a non-judgmental manner. They ensure these needs and desires are respected. The Support Coordinator will assist the individual to include these needs and desires in his or her plan.

The role of a Support Coordinator may include:

- *Facilitator* – leading the team that develops and implements an Individual Support Plan.
- *Advocate* – advocating for the needs of the person as identified by the person and family.
- *Teacher/Modeler* - helping a person gain self-advocacy skills.
- *Coordinator* – coordinating supports and assessing for medically necessary services.
- *Mediator* – assisting with communication between a person, family, and other systems, with a focus on working together.
- *Information Source* – knowing about community supports, other systems, and supports from the Division.
- *Monitor* – monitoring the plan to ensure quality of supports and services, as well as progress towards reaching the individual's goal.

5 | Targeted Support Coordination

Targeted Support Coordination (TSC) is a program operated by DDD. It is for people who are enrolled in the AHCCCS Medical Benefits program, but not eligible for ALTCS. TSC does not provide Long Term Care services such as Respite, Habilitation, Attendant Care or Residential and/or Day Programs. For persons age 21 and under, Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services are covered. These services are provided by the person's AHCCCS health plan.

The most significant benefit of the TSC program is that people will receive professional Support Coordination services. Another benefit is that the person can determine the frequency and type of contact they would like to have with their Support Coordinator.

Who is Eligible?

AHCCCS determines who will be enrolled in the TSC program. Generally, a person is TSC eligible when they are *not* eligible for



the ALTCS program, but are eligible for AHCCCS Medical Benefits (acute care only). People who have Supplemental Security Income (SSI) are automatically eligible for AHCCCS Medical Benefits, and thus, DDD's TSC program.

How do I get Targeted Support Coordination?

Once AHCCCS determines the person is eligible for their Medical Benefit program, AHCCCS will automatically enroll them in the TSC program. Within five working days, a Support Coordinator will contact them to schedule a meeting to discuss the program. The Support Coordinator will provide assistance with finding community resources, accessing EPSDT services, etc.

Planning for Supports and Services

What are all these different plans?

The Support Coordinator, with team involvement, is responsible for developing and implementing a plan for services. The planning document identifies appropriate supports and services that are recommended for the individual. Feedback received from providers tells us how well the person is doing in meeting the outcomes defined in the plan.

The different plans are called:

- **Individual Support Plan (ISP)** – this plan is used for individuals over three years of age.
- **Individualized Family Service Plan (IFSP)** – this plan is used for children from birth to three years of age.
- **Person Centered Plan (PCP)** – This plan is more detailed and reflects the long term outcomes of the individual, as well as how the person is going to get there. Usually a PCP is not done until the individual is over age 18.
- **Behavior Plan (BP)** – This plan reflects the behavior of the individual, and the objectives and strategies needed to be more successful.

Why is planning important?

Planning creates a guide that describes the supports and services that will help a person in achieving his/her vision and priorities.

How does planning work?

The team meets and reviews an individual's strengths, resources, and capabilities, as well as areas where assistance may be needed. The person's priorities and vision of the future are detailed. The supports and services are based on the person's priorities and determining what resources are needed to move closer to achieving their vision. It is important to know that the plan is flexible and may be changed as needed.

Who participates in the planning process?

The Division and the individual or legally responsible person determine the team membership. The team must include at least the individual, the Support Coordinator, service providers, and the legally responsible person, if there is one. Other members may include therapists, family members, friends and advocates. The individual and legally responsible person should tell the Support Coordinator who they want invited to the team meeting.

How often do planning meetings happen?

The entire planning document must be reviewed once a year. It may be reviewed more frequently depending upon where a person lives and the services they receive.



What does a plan look like?

The plan is a written document developed by the team. It identifies the priorities for the individual and the supports and services needed to reach those outcomes.

Can I have a copy of my plan?

The Support Coordinator will provide a copy of the plan within 15 business days after the meeting.

Where can I find more information about support plans?

Additional information about support plans may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

What services are available?

Services are provided based on assessed need and medical necessity. Services also depend on availability of funding and the individual's eligibility for Arizona Long Term Care System (ALTCS). A summary of available services:

- **Attendant Care** – This service provides a trained direct care worker (DCW) to assist a person to create or maintain safe and healthy living conditions. They also assist with maintaining personal cleanliness and activities of daily living. The DCW might help with bathing and dressing. Training and testing of

direct care workers is required. For more information, see the website at www.azdirectcare.org/

- **Day Treatment and Training** – This service provides training, supervision, and activities as appropriate. It promotes skill development. This service is primarily offered in a community setting. It is intended to help people learn safety skills and socialize.

- **Employment Services and Supports** – These services provide people with the help needed to get and keep a job. Six different services are provided under Employment Services and Supports:



- *Individual Supported Employment* – This service provides on-the-job training to assist an individual in learning the job. The person is hired by the company that they work for. They are paid just like any other employee.
- *Employment Support Aide* – This service provides people with ongoing one-on-one support needed for them to remain in their job.
- *Group Supported Employment* – On-site supervision is provided to small groups of people working in an integrated community setting. Groups can range from two to six individuals. The person is normally paid by the Division's service provider.
- *Center-Based Employment* – Supervised work and vocational training are provided within a provider facility where most of the workers are persons with a disability. Workers are paid based on their productivity.
- *Transition to Employment* - This service provides a Division member with individualized instruction, training and supports to promote skill development for integrated and competitive employment.
- *Transportation* – This service provides transportation for people to and from employment locations.



- **Habilitation** – Methods and training to increase an individual’s abilities are provided. Typically considered a teaching service, Habilitation may be provided in a person’s home or in the community. It might include activities to help the person learn to become more independent (for example, learning to cook a meal or balance a checkbook). These services are specific to the person’s needs as identified in their ISP.
- **Home Health Aide** – The Home Health Aide provides provides medically necessary health maintenance, continued treatment or monitoring of health conditions in the person’s home. Services may include assistance with activities of daily living. A Home Health Aide serves as an assistant to the primary caregiver. The aide works under the supervision of a registered nurse, and follows a prescribed plan of care that is based on the person’s medical condition.
- **Home Modifications** – Some people who are eligible for ALTCS may receive some types of home modifications. These modifications remove barriers, making it easier for individuals to be more independent in their homes. This service covers only modifications to an existing structure. It does not cover adding on to the home. Modifications can be made to individually or family-owned homes where the person with a disability resides. If the home is rented, the owner must give written consent to modify the home. The owner may require that the renter restore the premises to the condition that existed prior to the modification.
- **Home Nursing** – Skilled nursing services are provided in the person’s home. Services may include care related to a specific condition or coordination of medical services. It also may include accessing other medical services. Education about medical needs and supports may be provided.

- **Homemaking** – This service provides supports for a variety of housekeeping tasks. It allows a person to have their home kept in a clean and healthy condition.
- **Intermediate Care Facilities for Persons with Intellectual Disabilities (ICF/ID)** – Health and habilitation services are provided to people with developmental disabilities. Services are provided at facilities in Maricopa County, and at the Arizona Training Program at Coolidge. Admission must be approved by the Assistant Director of the Division.
- **Medical Services** – Medical Services are provided to members who are eligible for ALTCS. It includes doctor visits, hospitalization, medications, hospice and other needed medical services. Dental services, diapers and hearing aids for children up to the age of 21 are covered.
- **Nursing Facility** – This service provides skilled nursing care, residential care and supervision to members who need nursing services on a 24-hour a day basis, but who do not require hospital care.
- **Residential Services** – A broad range of residential options are discussed in the *Residential Settings and Options* section of this handbook.
- **Respiratory Therapy** – This service provides treatment to restore, maintain, or improve breathing.
- **Respite** – This service provides a trained person to supervise and care for an individual. The purpose of respite is to relieve the caregivers.



Caregivers can go to a movie, out to dinner, take a vacation or even take a nap. Respite may be provided overnight. This service may be provided in the person's home or in the provider's home. When necessary, respite may be provided by a nurse. Training and testing of direct care workers is required. For more information, see the website at www.azdirectcare.org/

- **Therapies (Occupational, Physical and Speech)** – These services maintain or improve the functional abilities of the individual. Therapy services are not intended to be long term. Physical therapy is limited to 15 visits per year for an individual over age 21.
- **Transportation (non-emergency)** – Transportation to therapy appointments or day programs is provided. Ambulance services are not included in this service.

What supports and services can I have?

Supports and services are based on age, ALTCS eligibility, assessed need and medical necessity. All services are designed to meet the needs of the person and family. All individuals and families have different strengths and needs. Needs are determined through assessments and evaluations. The Support Coordinator assesses the individual for other needed services such as Attendant Care, Habilitation, etc. Natural supports, including family, community and other resources must be used to their fullest extent. Other information about assessment may be found in the DDD Policy Manual. The Manual is available on the Division website at azdes.gov/landing.aspx?id=2844

How are supports and service decisions made?

Decisions about what supports and services a person receives are based on a team process. Through the planning process the team reviews assessments and evaluations. The supports and services are based on

the person's priorities and determining what resources are necessary to move closer to achieving their vision.

Additional information about the planning process may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

Who provides the supports and services?

Supports and services may be obtained through an agency or an independent provider. One option is to use a friend, neighbor or relative as a service provider. This can be done through a provider agency or the state. Talk to your Support Coordinator before determining the best option for you.

Additional information may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

Who monitors the supports and services?

The primary monitors of quality are the person receiving the supports and the family. For people living at home, the primary monitor is the individual and family. People living independently may be their own best monitors. They are the best judge of whether the service is good.

Monitoring is done by a variety of people, depending on the support or service and the setting. When an individual lives in a group home, the home is licensed by the Department of Health Services. Group Homes are also monitored by the Division. Regardless of the support, service, or setting, a Support Coordinator will also monitor a person's plan.

Additional information about monitoring can be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

What if my needs change?

If needs change, you go back to the planning process.

Where can supports and services be provided?

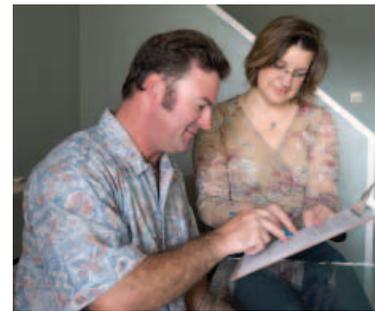
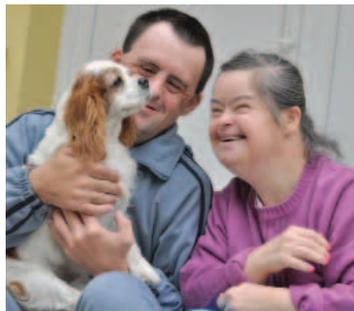
Services and supports may be provided in the person's home or in the community. In some cases, they can also be in the provider's home or in a provider's facility. The location depends on the support or service. For example, hourly habilitation cannot be provided in the provider's home.

Where can I get more information about supports and services?

The above information about services is intended to be brief. More information about services can be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

Who pays for the supports and services?

The state funded program is based on a yearly budget from the Legislature. The major source of funds is the Arizona Long Term Care System. This is the Medicaid funded program that covers services for people with developmental disabilities who meet the Long Term Care eligibility criteria. Other funding sources may include client contributions and grants.



Is there a charge for supports and services?

The Division may charge for a portion of the cost of support and services. This may be based on a person's or family's income and the services received. To determine if there is a charge for services, speak to your Support Coordinator.

The Early Years - Birth to Age 3

Parents or other individuals involved in a baby's life recognize that the first years are when the most significant development occurs. This is why it is important to know that supports and services are available to assist infants and toddlers from birth to age three. The following information describes early intervention and transitioning to preschool.

What is Early Intervention?

Early Intervention is a process in which a group of professionals, such as therapists and educators, work in partnership with parents and families of children with special needs to support the child's growth, development, and learning. Early Intervention uses a team approach to assist the family and to help support the needs of the child through everyday experiences and interactions with familiar people in familiar contexts.

How can it help my child and family?

The first three years of a child's life are critical years for learning. Early care and education have a long-lasting impact on how children develop. During a child's early years, it is important to focus on the child's developmental needs and to take advantage of the child's natural ability to learn through not only professionals but also by a supportive family.

Who is eligible for early intervention services?

Any child from birth to three years of age who has a developmental delay or an established condition may be eligible. To begin the eligibility determination process, contact Arizona Early Intervention Central Referral at 602-635-9799 or 602-635-9810 (bilingual line). You may also refer a child online, at www.azdes.gov/AzEIP. The Arizona Early Intervention Program (AzEIP) supports families of children, birth to three with disabilities or special developmental needs.

Who is eligible for early intervention services through the Division?

Any child who is eligible for AzEIP and also at risk for a developmental disability receives their early intervention services through the Division. A referral to the Division will be made during the AzEIP eligibility process, if appropriate. The Division and AzEIP work together to provide the needed services.

Can my child be eligible for early intervention and Arizona Long Term Care System (ALTCS) or Targeted Support Coordination (TSC)?

Yes, your child can be eligible for Early Intervention and an AHCCCS program (ALTCS or TSC) at the same time. These programs have different requirements and different services and supports that may be available. Your DDD Support Coordinator can explain these differences to you.

What is the role of a DDD Support Coordinator during these early years?

The DDD Support Coordinator will facilitate the development of an Individualized Family Service Plan (IFSP), and a transition plan for preschool services. The DDD Support Coordinator and the team will

meet regularly with the family in order to track progress and to make sure appropriate services are in place.

What is an Individualized Family Service Plan (IFSP)?

An IFSP is a written plan that describes the supports and services the child and family will receive to help with the child's growth and development. It is developed by a team, and identifies the family's outcomes based on child's and family's needs and priorities.

What kinds of early intervention supports and services are available?

Supports and services are planned to meet the needs of each child and family. This might include hearing services, home visits, nutrition services, occupational, speech or physical therapy, family counseling, vision services, or other services.

What if I disagree with the proposed supports and services?

For information, visit www.azdes.gov/AzEIP, or contact your Support Coordinator.



What is a Team Lead?

The Team Lead has expertise relevant to the child's needs and the outcomes on the IFSP. The Team Lead's focus is on coaching families as the primary strategy to implement outcomes in natural environments, with ongoing coaching and support from other team members. The Team Lead does not meet all the service needs of the child. The other team members support the Team Lead. They do this through regular team meetings and joint visits with the family.

What is a natural environment and why is it important?

Natural environments are settings that are normal for a child's age when compared to peers who have no delays or disabilities. Services and supports provided in natural environments are a part of the family and child's daily activities and routines. Natural environments promote integration of a child and family into the community.

What happens when my child turns three and is no longer eligible for early intervention?

When your child is between two and three years old, the team will begin the transition process to preschool. School districts have a responsibility to provide special education to all eligible children.



What is an Individualized Education Program (IEP) and how is it different from our IFSP?

The IFSP defines goals in developmental terms. The Individualized Education Program (IEP) defines goals in educational terms. Regardless of what the plan is called, all plans focus on a child's growth and development.

What will my child's school program look like?

A child's education will be based on the Individualized Education Program, which is the school's responsibility. The IEP will include all identified supports, services, and accommodations needed for your child.

The experience is different for each child. The education may be provided in a variety of settings. These will be discussed during the transition conference. It could be in a regular classroom with identified supports, or in a resource class or perhaps a self-contained class. Every member of a child's IEP team will help determine the most appropriate setting for a child to receive the identified educational supports and services.

What are some of the educational supports, services, and accommodations my child might receive?

These could include transportation, therapies, adaptive physical education, nursing, etc. The services provided will depend on your child's needs.

Where can I find more information about AzEIP?

Information can be found at azdes.gov/AzEIP, or by calling 602-532-9960, toll free 1-888-439-5609.

Where can I find information about special education laws?

You can learn about special education laws from a variety of sources, including:

- **The Arizona Center for Disability Law**
602-274-6287 or 1-800-927-2260
azdisabilitylaw.org
- **Raising Special Kids**
602-242-4366 or 1-800-237-3007
raisingspecialkids.org
- **Pilot Parents of Southern Arizona**
520-324-3150 or 1-877-365-7220
www.pilotparents.org
- **Arizona Department of Education Exceptional Student Services**
602-542-4013
www.azed.gov/special-education/
- **Wrightslaw**
www.wrightslaw.com
- **The Early Childhood Technical Assistance Center**
ectacenter.org/

The School Years

The years a child spends in school can be some of the most exciting and the most challenging. Children will have opportunities to learn new skills and experience new things. They will receive educational supports and services, and make new friends. The best thing that anyone involved in a child's life can do is become educated about a child's right to a free and appropriate public education.

There are federal requirements a school must meet to comply with the Individuals with Disabilities Education Act (IDEA). The Department of Education and the Division work in collaboration, but are two separate systems. The Division cannot provide supports that schools are federally mandated to provide. Children may get supports from the school and the Division.

What is Special Education?

Special education ensures that all children with disabilities have a free and appropriate public education. It must be designed to meet their unique needs. Special education is mandated by the federal Individuals with Disabilities Education Act (IDEA).



You can also learn more about Special Education from the following organizations:

- **The Arizona Center for Disability Law**
602-274-6287 or 1-800-927-2260
azdisabilitylaw.org
- **Arizona Department of Education Exceptional Student Services**
602-542-4013
www.azed.gov/special-education/
- **Raising Special Kids**
602-242-4366 or 1-800-237-3007
raisingspecialkids.org
- **Pilot Parents of Southern Arizona**
520-324-3150 or 1-877-365-7220
www.pilotparents.org

What is the role of the Support Coordinator during the school years?

They can coordinate the Individual Support Plan (ISP) with the student's Individualized Education Program (IEP). Support Coordinators can attend school meetings as their schedule allows, but they must be invited by the student or family to attend. Ask the school staff to notify the Support Coordinator as early as possible about upcoming team meetings.



What is an Individualized Education Program (IEP)?

The IEP is a plan developed by the school each year, with participation by all team members, including the family. It describes the goals for a child's education. It also includes specialized supports and services that will be provided to promote successful participation in school. The program should include a statement of the child's present level of performance, and measurable annual goals the child will be working on for the current year. It will include the amount and frequency of the supports and services to meet the identified goals. Ideally and/or when appropriate, the team may develop goals consistent with what the child is working on, in and out of the school day.

What is an Extended School Year?

Extended School Year refers to school services that an IEP team may consider to minimize a child's loss of important skills over the summer months. As part of each child's IEP, the need for additional school services over the summer must be addressed. Public schools will provide Extended School Year services if the IEP team determines:

1. The benefits gained during the regular school year would be significantly jeopardized if the pupil is not provided educational services during the summer session.
2. The pupil would experience severe or substantial regression if the pupil is not provided educational services during recesses or the summer months. Further, the regression would result in substantial skill loss of a degree and duration that would seriously impede the pupil's progress toward educational goals.

Participation in an Extended School Year program may impact the availability of summer programs through the Division.

As a child enters their teen years, how should planning for life after high school begin?

As with any child, planning for the adult years is very critical. Important areas to consider are employment, guardianship, living arrangements, and higher education. In addition, habilitation services are offered through the Division.

The Adult Years

At this stage of life, a person may have completed or will soon finish high school. They may be ready to meet the continuing challenges and adventures of life. This may mean deciding whether to explore a job, pursue higher education and/or live on their own in the community. In our society it is natural for young adults to want to move out of the family home. This may be a goal to discuss or explore.

Issues for family members to consider might include guardianship, wills, trusts and home ownership. Perhaps there is concern for what will happen to your family member when you are no longer able to care for them.

The Division's staff, including your Support Coordinator, are ready to assist you with addressing these issues.



What is the role of a Support Coordinator during the adult years?

Your Support Coordinator can help explore various residential options, as well as work or other day opportunities. This may include identifying resources for further skill development to enhance independence, or opportunities to have fun and make new friends.

I've been involved in groups for parents of children with disabilities. Are there any resources for adults with development disabilities?

There are several Independent Living Centers in Arizona that can identify resources for adults with developmental disabilities.

ABIL

5025 E. Washington St.
Phoenix, AZ 85034
602-256-2245 or 1-800-280-2245
abil.org

DIRECT Center for Independence

1023 N. Tyndall Ave.
Tucson, AZ 85719
520-624-6452 or 1-800-342-1853
directilc.org

Assist to Independence

P.O. Box 4133
Tuba City, AZ 86045
928-283-6261 or 1-888-848-1449
email: assist01@frontier.net

New Horizons

8085 E. Manley Dr., Ste. 1
Prescott Valley, AZ 86314
928-772-1266 or 1-800-406-2377
www.newhorizonsilc.org

SMILE

1931 S. Arizona Ave., Ste. 4
Yuma, AZ 85364
928-329-6681 or 1-855-209-8363
smile-az.org

Virtual Center for Independent Living

email: CyberCILmall@Cybercil.com

Planning is essential to ensure your child is provided for once you are gone. This may be in the form of a will, trust, special needs trust, or guardianship. It will vary for each family. Contact an attorney or financial planner for help in writing a will or establishing a trust.

As your child nears the age of 18, part of the annual planning process will include evaluating the need for a guardian. A person who is 18 years or older has all the legal rights of an adult, unless a legal guardian has been appointed by a court. Guardianship is not automatic just because an individual turns 18 years old. Even the

parent of an individual with a disability would need to be appointed as a guardian by the court, if a guardian is necessary.



What is guardianship?

Guardianship is a legal method used to ensure that a person unable to make decisions on their own has someone specifically assigned to make decisions on their behalf. A court appoints a guardian only after reviewing “clear and convincing evidence” that the appointment is necessary. Appointment of a guardian is a serious legal action, not to be taken lightly.

Do people with developmental disabilities have to have a guardian?

No. Not all people with a developmental disability need a guardian. Under Arizona law, an individual with a developmental disability is presumed legally competent. That means the person can give consent for things like medical treatment, contracts, program decisions and release of confidential information.

Who can be a guardian?

Any competent individual may be appointed as a guardian by a court, but certain people have priority for appointment over others. The individual's parents, adult siblings, or another family member such as a grandparent, aunt, uncle or cousin would be considered before a non-family member. Parents may designate a person in a will to be responsible to carry out this duty after them. This must be approved by the court.

Are there different levels of guardianship?

Yes. There are different levels of guardianship. Perhaps the person needs assistance to help make decisions in the management of money only, or assistance when making health care decisions. In those cases, perhaps limited guardianship is needed. There are other levels of guardianship that the court decides.



What are the duties of a guardian?

A guardian's duties are dependent on the type of guardianship granted by the court. A guardian must be involved in the development and monitoring of the Planning Document to ensure supports and services are appropriate and adequate. The court also requires periodic reports from the guardian regarding the welfare of the person.

Does a guardian need to live near the person?

A guardian must be willing and able to provide oversight of the individual's care and resources. Some guardians live out-of-state but are able to devote the necessary time to carry out their responsibilities. The Division staff can communicate with guardians through various electronic methods in order to keep them informed and involved.

Do I need the services of an attorney in order to pursue guardianship?

No. An attorney is not required. The Court Self-Service Centers have the required forms to file for guardianship without an attorney. Forms can be picked up from a Self-Service Center, completed and filed independently. Additional information may be found at the website, www.azcourts.gov



What rights does an individual lose when a guardian is appointed by the court?

Appointment of a guardian limits the rights of the individual. Some of the rights that may be lost include the ability to make independent decisions about residence, program involvement, and medical care. Day to day activities could be affected, including decisions about choosing friends or social events. A person with a guardian may not have the right to vote, hold a driver's license, choose a residence, invest money, and decide to take or not take medications. It is very important to carefully examine the extent or need for guardianship.

Why would I want a power of attorney? How is power of attorney granted?

In order to address needs in specific situations, a power of attorney may be established. Granting someone power of attorney does not require court action. Record the purpose of the power of attorney, such as assistance with health care decisions. The document must then be signed, witnessed, and notarized.

What if a medical emergency occurs and there is no appointed guardian?

Persons who lack the ability to make responsible decisions cannot consent to medical treatment for themselves. If a guardian is unavailable or one is not appointed, Arizona law allows other specific individuals to act as a substitute, known as a *surrogate*, to sign a consent for medical treatment. If an immediate and life-threatening emergency exists, the attending physician, after consulting with a second physician, may make a health care treatment decision without signed consent.

Is a conservator different from a guardian?

Yes. A *conservator* is an individual appointed by a court to manage the estate of another person. A person may have a guardian, a conservator, or both.

What is a public fiduciary?

When a parent, family member or close friend is unwilling or unable to act as guardian, a public guardian, known as a *public fiduciary*, can be appointed by the court. The county provides this service, and charges a fee to the person receiving the service.

What is a private fiduciary?

A *private fiduciary* is an individual or organization that performs guardianship duties for a fee. You select the fiduciary and can terminate your association with them if you are not satisfied.

What is a representative payee and how is that different from a guardian?

A *representative payee* is an individual designated by the Social Security Administration to manage Social Security payments on behalf of a person who has been determined to need support in handling their finances. A person can have both a guardian and a representative payee, or just a representative payee. Representative payees are responsible to manage and account for all income, both earned and unearned.

Who can I contact for more information?

The Arizona Developmental Disabilities Planning Council has prepared the *Legal Options Manual*, which describes available options for people over the age of 18. They can be reached at www.azdes.gov/ADDPC, or by calling 602-542-8978, toll free 1-877-665-3176.

Information about legal service organizations throughout Arizona can be found in the *People's Information Guide*, published by the Arizona Community Action Association. They can be reached at 602-604-0640, or by visiting azcaa.org.

I want to live at home. What supports are available to me?

When living at home, you may have services such as habilitation, work, day treatment and training, attendant care, respite, etc. These services are based on assessed need as identified in the Individual Support Plan.

I would like to move out of my family home. What options are there?

Planning is the key in addressing this important step. Needs and preferences of the individual are important when considering or planning a move. There are a variety of options available. These include independent living, developmental homes, group homes, and in some cases, assisted living. Your Support Coordinator can explain available options.

What is the process for obtaining a residential placement?

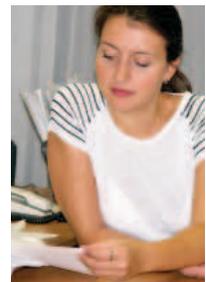
Once the need is identified, the individual and their team meet to complete a Placement Profile, to identify the most appropriate setting. The Support Coordinator will work with the Division Network staff to identify potential options. In most cases, the Network staff initiates a *vendor call*, to identify potential available residential providers. The individual and/or family will have the opportunity to choose the setting from available vendors who respond to the vendor call that best meet the person's needs. On occasion, a slightly different process may be followed. Consult with your Support Coordinator for further information.

Who provides these services? What are the qualifications? Are there background checks and training of staff who provide the supports and services?

Contracted agencies operate group homes and other supported settings. Support services may be provided by agencies or by individual providers for people living independently. Adult developmental homes are family homes that provide supports and are open to no more than three people.

Staff must be at least 18 years old, provide references from people other than family members, have knowledge, skills, and experience to meet the requirements of the job, and must obtain fingerprint clearance, which includes a background check. All staff must have cardiopulmonary resuscitation (CPR) training and First Aid certification, and be informed of the specific needs of each person in the home.

Other training requirements can be reviewed under Title 6, Chapter 6 of the Arizona Administrative Code, available at the Arizona Secretary of State website, www.azsos.gov You may also contact the Office of the Secretary of State at 1700 W. Washington St., 7th Floor, Phoenix, AZ 85007-2888, by telephone at 602-542-4285.



Who monitors these settings?

Routine monitoring is done by the Support Coordinator depending on the type of setting. Other Division staff also monitor contracted settings. Group homes and assisted living facilities are inspected and licensed by the Arizona Department of Health Services.

What are the licensing and monitoring standards for group homes?

Licensing rules may be found in Title 9, Chapter 33 of the Arizona Administrative Code, available at the Arizona Secretary of State website, www.azsos.gov You may also contact the Office of the Secretary of State for a copy of these rules, at 1700 W. Washington St., 7th Floor, Phoenix, AZ 85007-2888, or by telephone at 602-542-4285.

Is there a charge?

Yes. State law requires individuals receiving income or benefits to contribute to the cost of their residential support. This is called *residential billing*. An individual is billed up to 88% of benefits to offset room and board expenses. (The residential billing rate will be reduced to 70% beginning the summer of 2014.) The amount billed will not be more than the actual cost of room and board. Earned income is not billed. Only unearned income benefits received by the individual, which include



Social Security payments, Railroad Retirement, Veteran's Benefits, etc., are billed.

Can I tour group homes or other residential options?

Yes. This can be arranged through your Support Coordinator if a residential group home move is being contemplated.

Can I or my family member choose with whom I will live?

The Division makes every effort to accommodate this request, but it is not always an option. The Division does work with teams to ensure that people are as compatible as possible.

Can I or my family member meet the family members of other people in the home?

Absolutely! If the team finds an existing home and family members of the other people living in the home are willing, you may meet them.

11 | Employment Programs

How do I become involved with the Division's Employment Services and Supports?

The process begins with you and your planning team identifying an interest in employment. In some cases this will involve first going through the Rehabilitation Services Administration's (RSA) Vocational Rehabilitation (VR) program.

What is the Rehabilitation Services Administration and Vocational Rehabilitation?

RSA is a Department of Economic Security program that provides services for individuals who have disabilities that present a barrier to employment. Vocational Rehabilitation (VR) is the RSA program that assists individuals with disabilities to become employed.

You may be referred to the VR Program by the Division when:

- Your employment goal is consistent with the mission of the VR program;
- The type of employment you are looking for meets the VR program's definition of employment; and
- You are in need of VR services in order to attain your employment goal.



The Division must refer you to the VR Program for eligibility determination before it can begin to provide certain types of employment services and supports. Services provided by the VR Program may include but are not limited to Vocational Evaluation, Job Training, Job Search, Job Placement, Transportation, Job Site Modifications, Self-Employment and Entrepreneurial Activities.

The Division works closely with the VR Program. There are policies and procedures for information sharing, referral and joint planning activities. Ongoing on-the-job training supports upon completion of the VR Program may be provided by the Division to eligible individuals.

When can I become involved with the Division's Employment Services and Supports?

If you have already graduated from high school, you may consider employment at any time by contacting your Support Coordinator. If you are still in high school, you may be able to participate in employment or job training services after your regular school day is finished. You can also participate during school breaks such as summer vacation.

How are Employment Services and Supports funded?

The Division's Employment Services and Supports are funded through the Arizona Long Term Care System (ALTCS). Based on the availability of funding, people who are not ALTCS eligible may receive limited assistance with employment-related services.

What will happen to my Social Security, Long Term Care and other benefits if I get a job?

Social Security and Long Term Care Benefits are affected by income and assets. The amount of income earned may reduce your benefits. In most cases, work income will result in an overall increase in an individual's

income. To learn how your benefits might be affected, you may visit the Arizona Disability Benefits 101 website at az.db101.org.

What kind of jobs are available?

Job opportunities are based on work experience, education, abilities, interests, and the availability of employment within your local community. Your Support Coordinator and Employment Services Specialist will help you in exploring and identifying an appropriate job.

Are there a minimum number of hours that I am required to work?

No. There are no minimum or maximum number of hours.

What if I need extra training or education for the job?

You may be eligible for employment-related education and training through the RSA/VR Program. The Division also provides on-the-job training and supports.

How will I get to and from work?

Public transportation may be available, or you may need to rely on the assistance of family, friends, neighbors, co-workers, etc. Your planning team will help explore all available options, which may include transportation funded through the Division.



How much support will I receive when working?

Each individual receives the type and amount of support necessary to obtain and maintain successful employment. The team may also help to develop natural supports that can supplement or even replace funded services. This could be a friendly co-worker willing to act as a mentor at your workplace.

Can I choose to work full or part time?

Yes; both full and part time employment are options for you to consider based on your interests, skills and job openings.

How long will the Division provide job supports to me?

The Division will provide ongoing job supports as long as you need them to remain successfully employed. These supports are subject to regular review, and may be modified as your team deems necessary.

12 | Day Programs

What activities are available during the day?

Day activities may include volunteer opportunities and community experiences. They may also include other activities that are of interest. Day programs may be provided by the Division through contracted agencies. Day activities may be available through local community resources. For example, an individual may choose to participate in a local senior activity program.

Do I have the right to choose my day program?

Yes. It is your right to choose a day program based upon available options.

Is transportation provided to and from the day program?

The need for transportation would be identified through the planning process. It may include the use of public transportation.

Is there a charge for day programs?

There is no charge for an ALTCS-funded program for those individuals over the age of three. Community activities may have a charge. You will be given a choice of taking part in the activity or staying at the day program.

How do I find out more information?

Contact your Support Coordinator to discuss available options.

13 | Medical Services

This section provides information on medical services, including medically necessary equipment, aids and devices provided to people who are ALTCS or AHCCCS eligible. It also provides information on medical services for foster children who are not eligible for Long Term Care services.

What about my medical care?

If you are eligible for ALTCS, the Division provides medical care through contracted health plans or American Indian Health Plan. If you are not eligible for ALTCS, health care may be available through AHCCCS contracted health plans. Foster children who are not eligible for ALTCS receive medical care through the Comprehensive Medical and Dental Program (CMDP).

What if I have other medical insurance?



Other medical insurance must be used before ALTCS coverage. If that insurance requires co-payments, your ALTCS Health Plan will reimburse you the cost of those co-payments.

What is third party liability?

Third party liability describes resources, other than those provided by the Division, which may pay for care and services for the individual. It helps if you think of yourself as the first party, the Division as the second

party and any other payment sources, such as private medical insurance, as the third party. Private medical insurance may include Medicare, Tricare, or health maintenance organizations such as United Healthcare or Cigna. Although private medical insurance is called third party liability, or TPL, it is the primary payer. The Division is the payer of last resort.

How does TPL apply to me?

Your Support Coordinator will work with you to determine how TPL may apply to you. Once you provide the Division with information about insurance or settlements, the Division will take care of the rest.

If you have TPL, that insurance will be billed first. If you have other benefits or a monetary settlement as the result of an accident, these sources may also be billed for certain services.

Where can I get additional information about TPL?

Additional information about TPL may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

Who coordinates the medical care?

Everyone eligible for medical coverage through ALTCS or AHCCCS will have care provided and coordinated by a Primary Care Provider (PCP). Your PCP will make appropriate referrals for specialty care, prescribe medications or special equipment, and order certain services such as therapies.

What if I am unhappy with my medical care?

Talk to your PCP first. If you are still not satisfied, read the health plan or ALTCS member handbook to determine the next steps to take.

Are dental and vision services and hearing aids covered?

Dental and vision services and hearing aids are covered for children ages birth through 21, who are eligible for ALTCS or AHCCCS. These services are provided through the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program.

I'm going into the hospital. Is there someone I should notify?

You or your family member should notify your Support Coordinator. They will coordinate discharge planning with the Division's Health Care Services unit as needed, and can help to ensure continuity of care after getting out of the hospital.

What happens if I need nursing or equipment after I am discharged from the hospital?

Continuing needs should be addressed in the discharge plan, but be sure that you or your family member involve your Support Coordinator in that process. As part of the discharge plan, discuss any special things that may be needed at home to make it more efficient for receiving care. This may include determining which room in the house is most suitable for any specialized equipment.

What is durable medical equipment?

Durable medical equipment (DME) includes but is not limited to such things as wheelchairs, ventilators, and feeding pumps.

How do I get durable medical equipment?

Typically, your PCP or a doctor at Children's Rehabilitative Services (CRS) will identify the necessary equipment and make arrangements to obtain it. If training for you or your caregiver is needed, the equipment supplier will provide it.

Is there a charge for the equipment?

No. There is no charge if the equipment is approved by your health plan. However, if the equipment is not approved and you or your family feels it is needed, then you would have to pay for it.

What if I need different equipment or it needs to be repaired, or I don't need it anymore?

Contact your Support Coordinator, the health plan, or the supplier of the equipment.

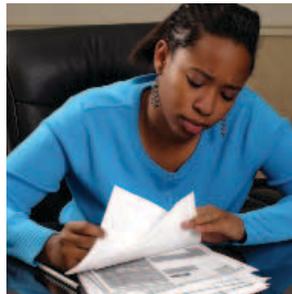
Where can I find additional information about durable medical equipment?

Additional information about durable medical equipment may be found in the DDD Policy Manual. The Manual is available on the Division's website at www.azdes.gov/landing.aspx?id=2844 You may also contact the health plan or physician.

What are adaptive aids?

Adaptive aids may include:

- Traction equipment;
- Feeding aids (including trays for wheelchairs);
- Helmets;



- Standers, prone and upright;
- Toileting aids;
- Wedges for positioning;
- Transfer aids;
- Augmentative communication devices;
- Medically necessary car seats; or
- Other items determined medically necessary by joint consultation of the Medical Director of your health plan and the Division's Medical Director.

How do I get adaptive aids?

Typically, your PCP or a doctor at CRS determines the need for the aids, and makes arrangements for you to obtain the equipment.

Who provides adaptive aids?

The health plan or the Division may provide the aids, or you may purchase them.

What are augmentative communication devices?

These devices enhance a person's ability to express wants and needs. Devices may range from simple picture boards to computerized devices.



Who is eligible for a device?

A person must be ALTCS eligible and must prove to be unsuccessful in his or her ability to communicate. Your planning team determines the need for a device, and the Support Coordinator makes the arrangements to obtain an appropriate device.

Who owns the augmentative communication device?

If the Division makes the purchase, the Division owns the device, which must be returned when it is no longer needed. Arrangements can be made with your Support Coordinator for its return. If your health plan buys the device, you must check with them to see who owns it.

Where can I get more information about augmentative communication devices?

Additional information about augmentative communication devices may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

What are Assistive technology devices and/or services?

Assistive technology (AT) devices are used to maintain or improve the functional capabilities of a person with a disability. Low-tech examples may include pencil grips, adapted spoons, adapted handles, etc. High-tech examples may be computers and augmentative communication devices.

Assistive Technology services assist a person with a disability in the selection, acquisition, or use of an AT device. Examples include wheelchair evaluations, device repairs, or training parents and family members in the use of devices.

Who do I contact for more information?

Your Support Coordinator can give you more information about Assistive Technology. You may also contact:

Institute for Human Development
Northern Arizona University
Arizona Technology Access Program
2400 N. Central Ave., Ste. 300
Phoenix, AZ 85004

602-728-9534 or 1-800-477-9921

602-728-9536 TTY

www.aztap.org

What is Children's Rehabilitative Services?

Arizona Children's Rehabilitative Services (CRS) is a program that provides medical treatment, behavioral health care, rehabilitation and related support services to AHCCCS members who have completed the CRS application and meet the eligibility criteria for enrollment. Qualifying medical conditions can be viewed on the AHCCCS website at azahcccs.gov/Commercial/CRS.aspx

Who is eligible for Children's Rehabilitation Services?

To be eligible for services through Children's Rehabilitative Services, a person must:

- Have a CRS eligible diagnosis;
- Be a U.S. citizen or qualified resident;
- Live in Arizona;
- Be enrolled in AHCCCS; and
- Be under the age of 21 at the time of initial enrollment.

How do I apply?

Anyone can fill out an application, including a family member, doctor, or health plan representative. Applications are available on the AHCCCS website, at azahcccs.gov/Commercial/CRS.aspx.

Along with a completed referral/application, you will need to send in medical records that document the CRS eligible condition. You should contact your doctor to help you collect the medical information that you need. If you need help completing the CRS application or getting information to send in with the application packet, call AHCCCS Member Services at 602-417-4545 or 1-855-333-7828.

Beginning Oct. 1, 2013, CRS members will be given a one-time option to stay in the CRS program when they turn 21. This is for members who are enrolled in CRS before age 21. AHCCCS will send an Advance Notification letter 60 days prior to the enrolled member's 21st birthday. This letter provides instructions for members to contact AHCCCS to choose to opt in to CRS.

What services are provided?

Physician services, medications, and outpatient services are a few examples of the services provided. Behavioral Health Services are also provided to CRS members. Contact CRS at one of the numbers noted



below or visit the website, azahcccs.gov/Commercial/CRS.aspx for more information.

What is the CRS Care Team?

Most of the care you will receive involves a care team who share your medical record information. Exactly who will be on your team depends on your special health care need. Medical providers on your team could be surgeons, medical specialists, primary care providers, behavioral health care service providers, and dental providers.

My child is ALTCS eligible. Why do we have to use CRS?

Using CRS is a requirement for children who are eligible for both DDD and ALTCS. You may use your other health insurance. If your health insurance will not cover the needed service, you must go through CRS.

Where are CRS services provided?

CRS members are able to receive care in the community or in a *multispecialty interdisciplinary clinic* (MSIC) that brings all specialties together in one location.

Phoenix

DMG Children's Rehabilitative Services

3141 N. 3rd Ave.

Phoenix, AZ 85013

Phone 602-914-1520 or 1-855-598-1871

Services available:

- CRS Specialty Care
- New primary care services
- Expanded behavioral health services

Tucson

Children's Clinic for Rehabilitative Services

2600 Wyatt Drive

Tucson, AZ 85712

Telephone 520-324-5437 or 1-800-231-8261

Services available:

- CRS Specialty Care
- New primary care services
- Expanded behavioral health services

Flagstaff

Children's Rehabilitative Services

at Flagstaff Regional Medical Center

1200 N. Beaver St.

Flagstaff, AZ 86001

Telephone 928-773-2054 or 1-800-232-1018

Services available:

- CRS Specialty Care

Yuma

Yuma CRS Clinic

Tuscany Medical Plaza

2851 S. Avenue B, Bldg. 25

Yuma, AZ 85364

Telephone 928-336-7095 or 1-800-837-7309

Services available:

- CRS Specialty Care

Who is eligible for Behavioral Health Services?

Individuals who are Title XIX (Medicaid) eligible and have certain behavioral health diagnoses may be able to benefit from medically necessary behavioral health services. An individual who is not Title XIX eligible, but has been identified as having a Serious Mental Illness (SMI), may still be eligible for services. Contact the Regional Behavioral Health Authority (RBHA) that serves your area.

RHBA	Area Served
Mercy Maricopa Integrated Care 1-800-564-5465 mercymaricopa.org	Maricopa County (Districts Central, West and part of East)
Cenpatico 1-866-495-6738 www.cenpaticoaz.com	Pinal, Gila, Yuma, La Paz, Cochise, Santa Cruz, Graham and Greenlee counties (Part of District East, part of District South, and Payson area of District North)
Community Partnerships of Southern Arizona (CPSA) 1-800-771-9889 www.cpsaarizona.org	Pima County (Part of District South)
Northern Arizona Regional Health Authority (NARBHA) 1-800-640-2123 narbha.org	Mohave, Yavapai, Navajo, Apache and Coconino counties

Who can make a referral and what happens after a referral is made?

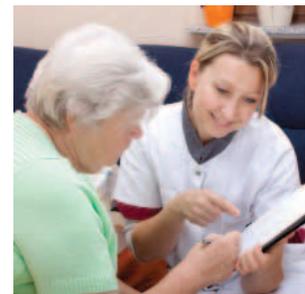
Anyone can make a referral. You may even refer yourself. A family member, your doctor, or a Support Coordinator may also make a referral. The person being referred must be in agreement and present when the referral is made.

An appointment for an intake interview will be made within seven days of the referral. If you are eligible for services, an appointment will be made within 30 days to begin planning and treatment.

What services are available?

Behavioral health services fall into three categories: Prevention, Evaluation and Treatment.

- *Prevention* services provide an individual with information and skills to help lead a healthy life.
- *Evaluation* services help determine what issues may exist and what to do about them.
- *Treatment* may include counseling, crisis response, medications, in-home supports, etc.



Is there a charge for services?

There is no charge for services if an individual is Title XIX eligible or eligible for the SMI program.

What if I am not happy with the decision regarding my eligibility or my treatment plan?

You can contact your RBHA's customer service department for assistance, using the numbers listed above. In situations where services are denied, you may file a service appeal. You can also contact your Support Coordinator for assistance.

What is the role of the Support Coordinator relative to Behavioral Health Services?

Your Support Coordinator can assist with the referral process. A Support Coordinator is responsible for being an advocate, coordinating care, and exchanging information with key individuals in the behavioral health system. If you are served through a behavioral health team (for example, Child and Family Team, Behavioral Health treatment team, Adult Clinical team, Adult Recovery team, etc.), your Support Coordinator will be part of that team.



Who can I contact for more information?

Your Support Coordinator can provide additional information. You may also contact the Arizona Department of Health Services/ Behavioral Health Services at 602-364-4558, or visit their website at www.azdhs.gov/bhs

15 | Safeguards

The health and safety of people with developmental disabilities is important to everyone involved in that person's life. Systems are in place to be sure that the rights of people with developmental disabilities are upheld. These systems are available to resolve concerns, get information or advocate for change.

Advocacy

Advocacy is active support for a cause or position. Parents and self-advocates know what it means...to strive to obtain what is right for an individual. Every individual is a powerful advocate. No one else can have the same passion for your cause.



Who do I contact for more information?

The Division has an advocate. The advocate can sometimes assist with situations requiring extra support. The DDD Advocate can be reached at 602-542-6850.

There are many advocacy and support organizations in Arizona. Below is a listing of other agencies that provide advocacy.

The Arc of Arizona

602-234-2721

www.arcarizona.org

Arizona Bridge to Independent Living

602-256-2245

www.abil.org

Arizona Center for Disability Law

602-274-6287 or 1-800-927-2260

azdisabilitylaw.org

Arizona Consortium for Children with Chronic Illness

602-997-2368

accci-az.net

Autism Society

480-940-1093

phxautism.org

Epilepsy Foundation of Arizona

602-406-3581 or 1-888-768-2690

www.epilepsy.com/arizona

Pilot Parents of Southern Arizona

520-324-3150 or 1-877-365-7220

www.pilotparents.org

Raising Special Kids

602-242-4366 or 1-800-237-3007

raisingspecialkids.org

Is there a charge?

Most advocacy agencies are free of charge.

Arizona Center for Disability Law

The Arizona Center for Disability Law (ACDL) is a non-profit public interest law firm dedicated to protecting the rights of people with a wide range of physical, psychiatric, sensory, and cognitive/intellectual disabilities.

What do they do?

As part of the nationwide protection and advocacy system, the Center provides training and free legal services under several major incentives:

- Protection and Advocacy for Individuals with Mental Illness;
- Protection and Advocacy for Individuals with Developmental Disabilities;
- Client Assistance Program;
- Assistive Technology Access Program;
- Housing and Urban Development/Fair Housing Initiatives Program; and
- Protection and Advocacy of Individual Rights.

Is there a charge?

No.

How can I contact the ACDL?

Phoenix

Arizona Center for Disability Law
5025 E. Washington St.
Phoenix, Arizona 85034

602-274-6287 or 1-800-927-2260

azdisabilitylaw.org

Tucson

Arizona Center for Disability Law
100 North Stone Ave., Ste. 305
Tucson, Arizona 85701
520-327-9547 or 1-800-927-2260
azdisabilitylaw.org

Developmental Disabilities Advisory Council

The Developmental Disabilities Advisory Council is a 17-member group of volunteers appointed by the Governor. Council membership includes people with developmental disabilities, family members, advocates, providers, and representatives from state agencies.

What does the Developmental Disabilities Advisory Council do?

The Council reviews and makes recommendations to the Assistant Director of the Division regarding:

- coordination and integration of services provided by state agencies and providers that have contracted to provide supports to people with developmental disabilities;
- the health, safety, welfare, and legal rights of individuals with developmental disabilities;
- the Division's plan for service delivery and improvement;
- establishment and review of Division policies and programs;
- the cost effectiveness of Division services;
- annual rate setting methodology;
- assessment of the Division's annual needs;
- selection of the Assistant Director of the Division; and
- monitoring of the Division's annual budget.

The Council also oversees and approves expenditures of monies from the Client Services Trust Fund. The fund was established after the sale of the former Arizona Training Program at Phoenix.

Who do I contact?

For information about the Developmental Disabilities Advisory Council, call 602-542-6850 or 1-866-229-5553.

Human Rights Committees

The Human Rights Committees are groups of local citizens that provide independent oversight in matters related to the rights of people with developmental disabilities who are served by the Division.

What do Human Rights Committees do?

Committees normally meet one time a month to:

- Review any incidents that may have involved neglect, abuse or denial of rights of individuals;
- Review programs that might infringe on the rights of individuals receiving supports such as the use of behavior modifying medication;
- Review any proposed research involving individuals receiving supports; and
- Make recommendations to the Division about changes needed to protect the rights of individuals receiving services.

Who serves on the Human Rights Committees?

Committee members are volunteers. They may include people who receive supports and their families, advocates, psychologists, physicians, nurses, attorneys, social workers, teachers, business people, and other community members committed to the rights of the people served

by the Division. Members are recommended by local Human Rights Committees and appointed by the Director of the Department of Economic Security.

What experience or training do Human Rights Committee members need?

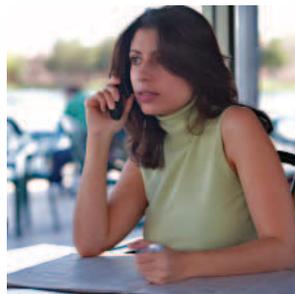
A sincere interest in the rights of the people served by the Division is the key requirement. Training is provided to prepare new members. All members receive ongoing training.

Who can raise an issue to the Human Rights Committees?

Issues can be raised by anyone who has a concern about a possible violation of the rights of an individual with developmental disabilities who is eligible for services from DDD. Contact the Division at 1-866-229-5553 for the name of the Human Rights Committee Chairperson. Concerns will be handled in a confidential manner in accordance with state laws and regulations.

What kind of issues should be raised to the Human Rights Committees?

Any suspected violations of rights of a person with developmental disabilities, such as mistreatment or discrimination, can be raised to the Committee. If the Human Rights Committee is not the best group to



handle the concern, you will be referred to the appropriate agency or entity.

What are some of the challenges of the Human Rights Committee?

In addition to dealing with a wide variety of individual issues, Human Rights Committees have been involved with many policy issues that relate to rights. These issues have ranged from matters of health and safety to personal power and choice. The committees make recommendations for action and raise awareness of the rights of people with developmental disabilities. The task of the committees is critical if the rights of the individuals served by the Division are to be respected.

How do I get involved or get more information?

Contact the Division at 1-866-229-5553 or visit the website at www.azdes.gov/ddd.

Incident Reporting

What are Incidents?

An incident is an event that could possibly impact the health, safety and/or wellbeing of a person enrolled with the Division. When an incident occurs, the Division is required to take some type of action.

The Division defines two types: Incidents and Serious Incidents.

An *Incident* includes inappropriate sexual behavior; theft or loss of the eligible individual's money (less than \$25.00); an error where the person was given the wrong medication. It also includes situations that pose a threat to health, safety, or welfare of eligible people—for example, the loss of air conditioning, water, or electricity for more than one day.

A *Serious Incident* is an extraordinary event involving an individual, facility or employed/contracted personnel. A Serious Incident poses the threat of immediate death or severe injury to a person. It also includes substantial damage to individual or state property.

Who can report an Incident?

Anyone who witnesses an incident may report it by calling the Support Coordinator, or the Central Reporting Line at 602-375-1403.

Will I be notified of the Incident?

All involved providers, Division staff, and individuals receiving services or their legal guardians shall be notified if a Fact Finding has been started. Notification occurs unless the District decides that such notification would compromise the Fact Finding process.

The general nature of an allegation shall be disclosed, when providing written or verbal notification. The reporting source is confidential.

What is a Fact Finding?

Fact Finding is a detailed collection and verification of facts. Its purpose is to describe and explain an incident. The Division conducts Fact Finding to confirm the details of the incident, and the need for any follow-up and/or corrective action. The process could include interviews with the individual, the provider and/or Division staff, and collection and/or review of individual and provider documentation. It also includes coordination with other agencies that might be investigating. The goal is to determine whether the alleged acts occurred, and if systemic issues might have contributed to the cause of the incident.

Who completes a Fact Finding?

Only a Division Incident Specialist or designee will conduct a Fact Finding. Representatives of the Division have the authority to visit and

inspect all regulated and contracted facilities. They may do so at any time and as often as may be necessary. Division representatives have the authority to interview employees or individuals. They may examine all records, books, accounts, the residential setting, and any vehicles used to transport individuals.

Who investigates incidents?

Law enforcement, Adult Protective Services, or the Department of Child Safety are agencies that may conduct investigations, as appropriate.

Can I have a copy of the results?

All requests for information about the Fact Finding must be submitted in writing to the Office of Compliance and Review. The request must include the requestor's name, address and phone number. It must also include the name of the individual served by the Division and his/her relationship to the requestor.

Where can I get more information?

Additional information may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844

Laws are passed by the Legislature (see *Legislative Process* later in this section). Laws define in broad terms what will happen. State agencies then develop *rules* that clarify laws by breaking them down to an understandable form.

Policies are developed from rules, and describe how a state agency will implement the laws and rules to provide guidance to staff, providers, and individuals with developmental disabilities and their families.

Where can I find laws, rules and policies?

If you know the number of the law, you may find it online at www.azleg.gov/ArizonaRevisedStatutes.asp. If you don't have the number, you may search that site for key words. Local libraries also have copies of Arizona laws.

Rules are available from the Secretary of State by calling 1-800-458-5842, or through the website at azsos.gov. Policies are available at all local Division Offices, or online at www.azdes.gov/landing.aspx?id=2844.

How do the laws, rules and policies apply to me?

All laws, rules and policies affect what happens to an individual who is eligible for services through the Division. Public comment is invited during the development of laws, rules, and policies.

Who do I contact with questions?

Call the Division at 602-542-0419, or toll free at 1-866-229-5553. You may also email us at dddweb@azdes.gov.

Legislative Process

Why would I care about the legislative process?

You can make a difference. Having a voice in our government is the responsibility of all of us. Listening to our voices is the responsibility of our legislators. Legislative decisions impact the supports and services the Division is able to provide.

How is legislation enacted in Arizona?

The process of enacting legislation is a complicated undertaking from the time a bill is drafted until it is finally passed and sent to the Governor. Legislation may be suggested by anyone—legislators, state agencies, advocacy organizations, legislative committees, lawyers, constituents (you), and others—for presentation to a Senator or Representative for introduction in the Senate or House.



How can I influence the process or have my voice heard?

You may write or call your legislator. You may also provide public testimony at hearings. Remember that your ideas are important.

Who can I contact for more information?

“Partners in Policymaking” is a course for individuals with disabilities and their families to help learn more about public policy and how to influence its development. Contact Pilot Parents of Southern Arizona online at www.pilotparents.org, or by phone at 520-324-3150, toll free 1-877-365-7220.

Current and historical information about bills, as well as a detailed description of the legislative process is available through the Arizona Legislative Information System (ALIS), at www.azleg.gov

17 | Issue Resolution

There may come a time in your relationship with the Division or providers when communication breaks down or you feel your needs are not being met.

Typically, your Support Coordinator will be the person best able to respond to issues, problems, or concerns. You are encouraged to discuss any issues with them.

If your Support Coordinator is not able to take care of your concern, you may want to contact the Support Coordinator Supervisor to assist you. There are also others who may assist, including the Area Program Manager and the District Program Manager. Your Support Coordinator can give you the name and phone number of the Area Program Manager or District Program Manager.

The Division has staff available to assist you if you still encounter

problems. Staff of the Division's Office of Family and Community Resources is experienced in resolving conflicts, and is available to you by calling 602-542-6850 or 1-866-229-5553, or by email at dddweb@azdes.gov

If you have a concern with your health plan, attempt to resolve the issue with your physician or with the member services representative.



What if my issue or concern is still not taken care of?

Most issues and concerns can be resolved using the methods described above; however, there are other options available to you.

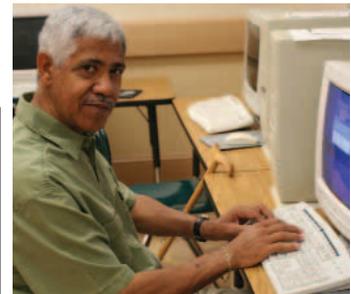
You may wish to file an appeal. Staff of the Division's Office of Compliance and Review will investigate your issue, research applicable laws, rules and policy, and make a recommendation to the Assistant Director of the Division.

The Assistant Director or designee will make a final written decision regarding your appeal. If you disagree with that decision, you may request a hearing (second level appeal). You will be given information about next steps when you receive the written decision on the first level appeal.

Where can I get additional information?

Additional information may be found in the DDD Policy Manual.

The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844



18 | Access to Records

Who can see my case file records?

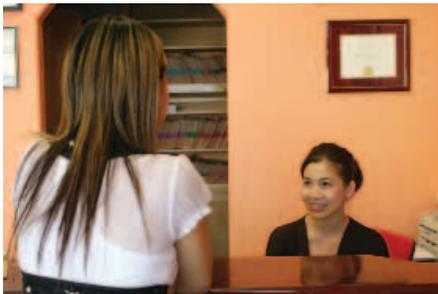
You may review your case file records. Other state agency staff may also see the case file records when needed.

When can I see my records?

Typically you may see your records when you request them, although it takes time to get the records to you. Requests for records should be made through the Division's Office of Compliance and Review. Typically, it takes about 30 days to get the records copied and to you. You will not be charged for the first copy you request in any year, but additional requests may carry a fee.

Where can I find more information?

Additional information about records may be found in the DDD Policy Manual. The Manual is available on the Division website at www.azdes.gov/landing.aspx?id=2844



Home and Community Based Certification

Home and Community Based Certification is a process that ensures individual and agency providers meet certain basic requirements, such as training in First Aid and cardiopulmonary resuscitation (CPR). Reference checks and fingerprint clearances are important parts of certification.

Why are providers certified?

Providers are required to be certified in accordance with state and federal requirements.

What is the process and what are the requirements?

The requirements vary according to the service to be provided. A complete description of the process and requirements can be found at your local office.

Can requirements be waived?

Requirements may not be waived; however, requirements for certain family members as providers are not as strict.

Many different types of training are available, provided by a variety of sources. For training provided by the Division, contact your Support Coordinator or view the Training Opportunities link on the Division's website, www.azdes.gov/ddd Other training is offered through the Exceptional Student Services program of the Arizona Department of Education. You can learn more about ESS at www.azed.gov/special-education

Anyone providing services funded through the Division receives training. At a minimum, all providers must complete First Aid, CPR and Article 9 – Managing Inappropriate Behaviors. Depending on the service, additional training will be required. Training requirements can be found at www.azdes.gov/ddd or by calling 602-542-0419.

Is there a charge for this?

Most training is free of charge.

University Centers on Developmental Disabilities

The Arizona University Centers on Developmental Disabilities (UCEDD) are programs established through a federal law entitled, "Developmental Disabilities Assistance and Bill of Rights Act of

2000" (Public Law 106-402). It is one component of a national program that includes the Councils on Developmental Disabilities and Protection and Advocacy systems. The goal of the UCEDDs is to bring the resources of universities to communities across the state to improve the lives of people with developmental disabilities and their families. The Arizona UCEDDs are part of a national network of UCEDDs based in every state and territory where a university is found.

What do they do?

The UCEDDs conduct university-based training for future and current professionals who work or who plan to work with persons with developmental disabilities and their families. These activities include courses and programs of studies that lead to a Certificate in Disability Studies.

The UCEDDs also provide a host of community-based trainings for continuing education and professional development. They also conduct research and evaluation to expand knowledge in the field of disabilities. The UCEDDs publish and disseminate the results of its activities. The results are available in text, electronic, and video formats.



How can I contact them?

Northern Arizona University

Institute for Human Development
Arizona University Center on Disabilities
P.O. Box 5630
Flagstaff, Arizona 86011-5630

928-523-4791

928-523-1695 TDD

nau.edu/ihd

Sonoran UCEDD

1521 E. Helen Street
Tucson, Arizona 85719

520-626-0442

sonoranucedd.fcm.arizona.edu

Developmental Disabilities Planning Council

The Developmental Disabilities Planning Council engages in advocacy, capacity building, and systemic change to increase inclusion in the community. The Council strives to promote self-determination, independence, productivity, and integration to support individuals with developmental disabilities and their families in all facets of life in the community of their choice.

What do they do?

The mission of the Developmental Disabilities Planning Council is to represent the interests and needs of persons with developmental disabilities. Particular attention is dedicated to persons who are not served or underserved through the State of Arizona.

How can I contact the Developmental Disabilities Planning Council?

Call the Developmental Disabilities Planning Council at 602-542-8970, or visit their website at www.azdes.gov/ADDPC

Acronyms

A list of acronyms you may encounter while navigating the system.

ADH	Adult Developmental Home
AHCCCS	Arizona Health Care Cost Containment System
ALTCS	Arizona Long Term Care System
APS	Adult Protective Services
AzEIP	Arizona Early Intervention Program
CD/ID	Cognitive Disability/ Intellectual Disability
CDH	Child Developmental Home
CES	Cost Effectiveness Study
CFT	Child and Family Team
CMDP	Comprehensive Medical and Dental Program
CP	Cerebral Palsy
CPS	Child Protective Services
CRS	Children’s Rehabilitative Services
DCS	Department of Child Safety
Division	Division of Developmental Disabilities
DDD	Division of Developmental Disabilities
DES	Department of Economic Security
EIU	Early Intervention Unit

EPSDT	Early and Periodic Screening, Diagnosis and Treatment
GMH	General Mental Health
HRC	Human Rights Committee
ICF	Intermediate Care Facility
IDLA	Individually Designed Living Arrangement
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
ISP	Individual Support Plan
ISP	Individual Service Plan (Behavioral Health)
OT	Occupational Therapy
PAS	Preadmission Screening
PCP	Person Centered Plan (Division)
PCP	Primary Care Provider/Physician
PRC	Program Review Committee (Division)
PT	Physical Therapy
QBHP	Qualified Behavioral Health Professional
RBHA	Regional Behavioral Health Authority
SMI	Serious Mental Illness
SPT	Speech Therapy
SSA	Supplemental Security Administration
SSDI	Social Security Disability Income
SSI	Supplemental Security Income
TSC	Targeted Support Coordination
VR	Vocational Rehabilitation



A Guide for Individuals and Families

www.azdes.gov/ddd

Equal Opportunity Employer/Program • Under Titles VI and VII of the Civil Rights Act of 1964 (Title VI & VII), and the Americans with Disabilities Act of 1990 (ADA), Section 504 of the Rehabilitation Act of 1973, the Age Discrimination Act of 1975, and Title II of the Genetic Information Nondiscrimination Act (GINA) of 2008; the Department prohibits discrimination in admissions, programs, services, activities, or employment based on race, color, religion, sex, national origin, age, disability, genetics and retaliation. The Department must make a reasonable accommodation to allow a person with a disability to take part in a program, service or activity. For example, this means if necessary, the Department must provide sign language interpreters for people who are deaf, a wheelchair accessible location, or enlarged print materials. It also means that the Department will take any other reasonable action that allows you to take part in and understand a program or activity, including making reasonable changes to an activity. If you believe that you will not be able to understand or take part in a program or activity because of your disability, please let us know of your disability needs in advance if at all possible. To request this document in alternative format or for further information about this policy, contact the Division of Developmental Disabilities ADA Coordinator at 602-542-0419; TTY/TDD Services: 7-1-1. • Free language assistance for DES services is available upon request. • Disponible en español en línea o en la oficina local.