

Defining Intellectual and Developmental Disabilities

Developmental disabilities includes individuals with intellectual disabilities.

A person from birth through the age of nine years who has a substantial developmental delay or specific congenital or acquired condition

A diagnosis for intellectual or developmental disabilities can only be given by a PhD within their scope of practice and cannot be given by a psychiatrist.

may be considered to have a developmental disability without meeting three or more of the major life activities if the individual, without services and support, has a high probability of meeting those criteria later in life.

A **Developmental Disability (DD)** is a severe, chronic disability, including an intellectual disability, other than mental illness, which:

- Is attributable to a mental or physical impairment other than a severe emotional disturbance;
- Begins before the age of twenty-two years;

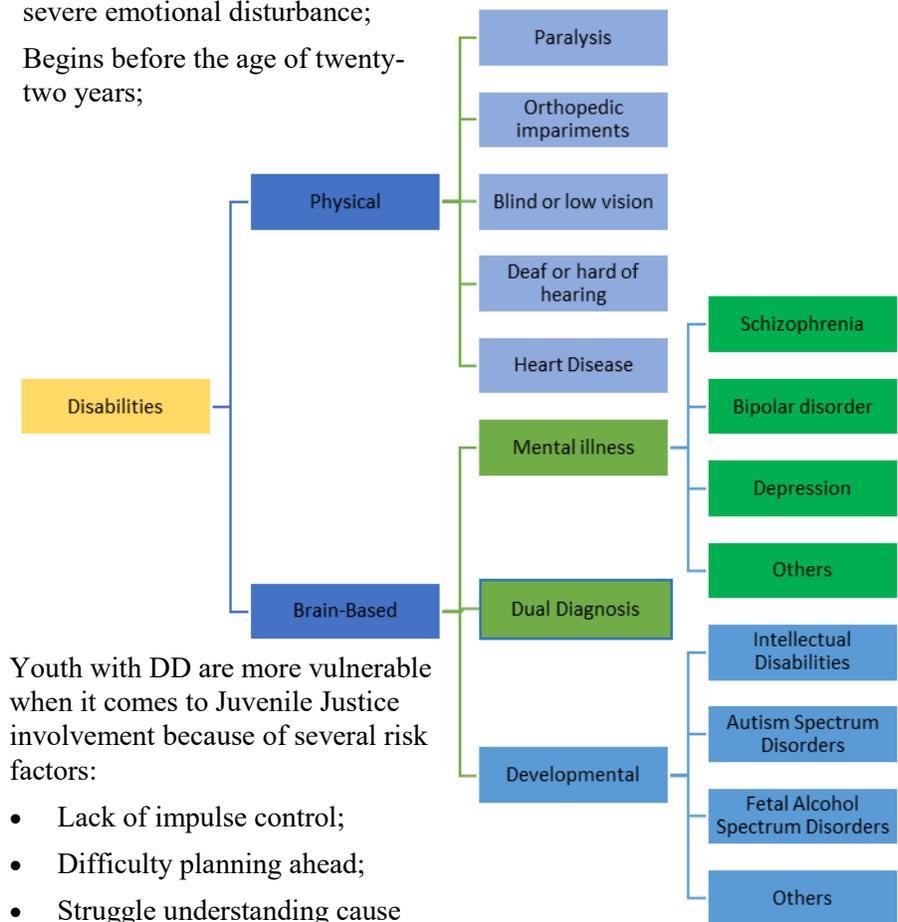
- Is likely to continue indefinitely;
- Requires special, individualized services or assistance for an extended time period; and
- Results in substantial functional limitations in one of each of the following areas:
 - Conceptual skills;
 - Social skills; and
 - Practical skills.

The Hidden Disability

The Justice system is not designed for early identification of individuals with special needs.

- Most individuals with DD do not look different from other people.
- They may fear rejection and resist disclosing their disability to others.
- Over time, many individuals learn how to fake understanding and “get by” without others understanding the extent of their disability.
- “Faking it” limits access to services, supports, and interventions necessary to prevent or divert their involvement in the justice system

These people are at a disadvantage when working with the courts because they may not understand what is happening and are highly vulnerable because of their disability.



Youth with DD are more vulnerable when it comes to Juvenile Justice involvement because of several risk factors:

- Lack of impulse control;
- Difficulty planning ahead;
- Struggle understanding cause and effect;
- Difficulty delaying gratification;
- Lack the skill to make good judgements;
- Tendency toward explosive episodes;
- Highly susceptible to peer influence;

- Becoming easily frustrated;
- Difficulty “unlearning” inappropriate behaviors;
- Elevated risk for a history of abuse and/neglect; and
- Difficulty communicating and expressing themselves.

Common Developmental Disabilities

Autism Spectrum Disorder

A Brain Disorder with onset in early childhood which impacts an individual's ability to interact, communicate, relate, play, imagine and learn.

Common features may include:

- Communication through pointing or gestures
- Repetition of phrases or words
- Repetitive body movements
- Difficulty regulating emotions
- Outbursts (distress, laughter, crying) for no apparent reason
- Sensory issues— aversion to touch, noise, lights or commotion.
- No fear of danger
- Self-injurious behavior
- Difficulty reading social cues
- Inability to interpret body language, tone or facial expressions

Youth with Autism Spectrum Disorder (ASD) have a higher risk of victimization and engagement in illegal acts related to their diagnosis.

For more detail view a brief article published in forensic Scholars Today 2016, Vol. 2, Issue 1 <http://online.csp.edu/wp-content/uploads/2016/08/FST-2.1-Special-Edition-Autism-Spectrum-Disorder-ASD-and-the-Criminal-Justice-System-An-Introduction-for-Professionals.pdf>

Fetal Alcohol Spectrum Disorders

A range of physical, mental, behavioral and/or learning disabilities occurring after fetal exposure to alcohol

Common features may include:

- Difficulty with learning
- Poor memory
- Poor coordination
- Hyperactive behavior
- Difficulty with attention
- Difficulty with school (particularly math)
- Speech and language delays
- Intellectual disability or low IQ
- Poor reasoning and judgment skills

Youth with Fetal Alcohol Spectrum Disorder (FASD) have a very high risk of criminal justice involvement with an average age of admission occurring by age 12.

Some data suggests up to 55% of people with FASD will be imprisoned, placed in a psychiatric facility or drug/alcohol treatment center; however, many will never socially mature beyond the level of a 6-year-old.

Dual Diagnosis: Co-occurring DD and Psychiatric Disorders

People with DD are at higher risk of psychiatric disorders than the general population.

Historically, there was a myth that one can have either an intellectual disability or a mental health diagnosis but never both. While this belief is no longer held as fact, there continues to be a disconnect between systems of care impacting an individual's ability to access the supports needed to adequately manage the co-occurring disorders.

It is estimated 30-35% of persons with DD are also diagnosed with a psychiatric disorder

MYTH: One can have either an intellectual disability or a mental health diagnosis but never both.

A co-occurring diagnosis can:

- Significantly impact educational and vocational involvement
- Disrupt family and peer relationships
- Complicate provider matching and service provision
- Contribute to placement disruptions

There are several factors impacting the over-representation of dually diagnosed individuals in the Justice system. These include:

- A lack coping skills needed to manage their diagnosis;
- A lack resilient social support systems; and
- Possible language difficulties that impact their ability to clearly express their thoughts and feelings to others.

Extra care must be taken to ensure services are provided to address both the developmental and mental health needs of these individuals

How Is a Developmental Disability Determined?

To qualify as having a developmental disability a person must have:

1. **A diagnosed, severe, chronic disability attributable to a mental or physical impairment**
2. **Significant limitations in each of the following areas of adaptive behavior: conceptual skills, social skills, and practical skills.**
3. **Have onset before the age of 22**

The IQ test is the primary means to measure intellectual functioning. This evaluates a person's capacity for learning, reasoning and problem-solving.

Classification	IQ Score	Estimated % of population
Highly Gifted	130 and above	2.1
Gifted	120-129	6.7
Above Average	110-119	16.1
Average	90-109	50
Below Average	80-89	16.1
Borderline	70-79	6.7
Extremely Low	69 and below	2.1

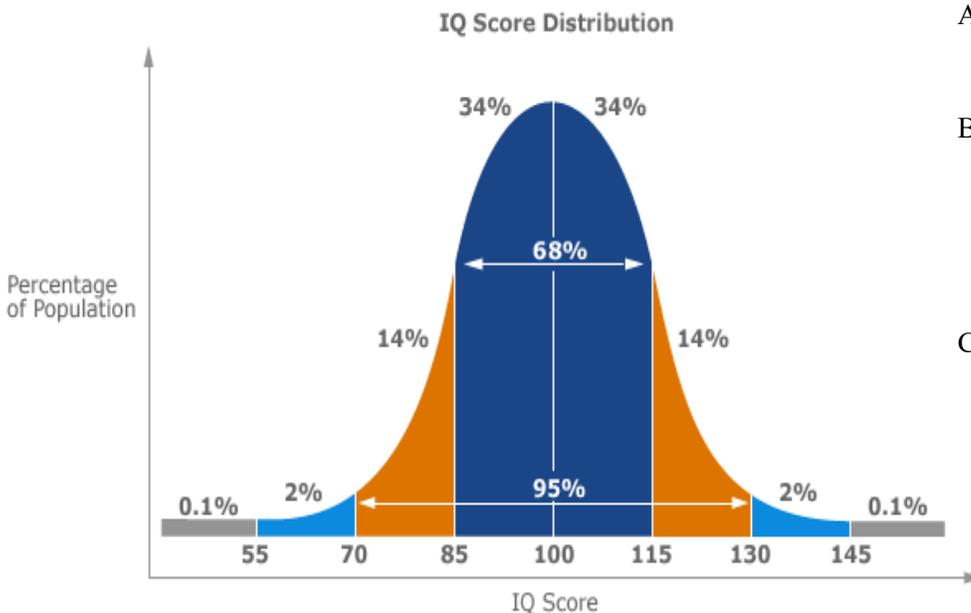
Classification	Range	Features
Below Average	80-89	Able to achieve normal independent functioning. Some data shows most violent crimes are committed by males from this range.
Borderline Intellectual Functioning	70-79	May have difficulty managing everyday demands. Able to achieve employment and independence but may require assistance.
Mild intellectual Disability	50-69	Able to care for self and obtain employment with supervision. Might live alone but do best with supports. May present as immature. Grade equivalent 3rd-6th
Moderate intellectual Disability	35-49	Noticeable delays (speech, motor...) Able to learn simple life skills and employment tasks with support. Require more supports for success
Severe Intellectual Disability	20-34	Able to learn some self-care but remain dependent on others. Basic tasks including language are difficult to learn.
Profound Intellectual Disability	19 and below	Heavily dependent on others. May struggle with learning simple tasks.

Evaluators must also consider other factors such as:

- Community environment typical of the individual's peer and culture
- Linguistic diversity
- Cultural differences in the way people communicate, move and behave

Adaptive functioning tests evaluate how the individual functions in their daily life in three skill areas:

- Conceptual skills**—language, literacy, money, time, number concepts and self-direction.
- Social skills**— Interpersonal skills, social responsibility, self-esteem, gullibility, naiveté, social problem-solving, and the ability to follow rules, laws and avoid being victimized.
- Practical skills**— activities of daily living, personal care, occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money and use of the telephone.



Accessing Services Through DHHS

The purpose of establishing a diagnosis of Intellectual Disability is to determine eligibility for :

- Special education services
- Home and community-based waiver services
- Social Services Administration benefits
- Specific treatment within the juvenile and criminal justice system

An **SSI disability verification** is an effective access point for Medicaid and some other DHHS services. Once SSI eligibility is obtained, a person is automatically eligible for Medicaid. The stipend provided by Social Security Income (SSI) can be used to pay room and board for residential services or program fees for day services.

A **Medicaid application** can determine eligibility for additional support for a single person with a disability. A family application for needs-based Medicaid will not trigger the verification process.

A separate **application for DD services** is necessary to access DD-specific supports. It is possible to be eligible for DD but not eligible for Medicaid. This program is administrated by the Division of Developmental Disabilities DHHS-DDD

Application for the DHHS-DD program is available online at www.accessnebraska.gov

DD Eligibility and Waivers for Funding of Services

Services from DHHS-DDD may occur over the lifespan, from birth (verification) to death. DD re-determinations are conducted at ages 9 and 18.

Funding for DD services is allocated by the legislature. Funding is extremely limited and not all persons who meet criteria are able to receive funding.

Once eligible, a person is placed on the Registry of Unmet Needs. There are approximately 4,300 people on this waiting list.

Nebraska Revised Statute 83-1216

addresses priority funding for persons who have been determined eligible with developmental disabilities.

When allocated, funding is provided to those who fall into pre-determined categories:

- 1) Persons in **immediate crisis** due to caregiver death, homelessness, or a threat to the life and safety of the person;
- 2) Persons that have resided in an **institutional setting** for a period of at least twelve consecutive months and are requesting community-based services;
- 3) Persons who are wards of the department or persons placed under the supervision of the Office of Probation Administration by the Nebraska court system who are **transitioning upon age nineteen with no other alternatives** as determined by the department to support residential services necessary to pursue economic self-sufficiency;
- 4) Persons **transitioning from the education system** upon attaining twenty-one years of age to maintain skills and receive the day services necessary to pursue economic self-sufficiency; and
- 5) All other persons by date of application.

Graduation before the age of 21 may create a gap in access to day services.

DD cannot fund any service which can be accessed by another source such as a school system, vocational rehabilitation or Medicaid.

- Public schools must provide day programs until a person graduates and turns the age of 21. Graduation before age 21 may create a gap in access to day services.
- The DD day services waiver is available to fund day services after the school's obligation is fulfilled. DD funding cannot be accessed for day services while school services are available.
- DDD cannot fund services provided in an institutional setting including hospitals, correctional or detention centers.

DD System Reform

There has been a move to change how society supports and treats individuals with DD. There is a move to increase the number of people receiving services within their community and reduce the reliance on institutional placements.

“It is pretty sad that you are put in prison because you have a disability.”
-Oregon self-advocate

Supporting Research

- People do better in community-based living
- Even people with multiple and profound disabilities can live in the community with the right supports
- Culture change is essential to support system change
- There is no evidence that community-based programs cost more than institutional options

Service Coordinator Roles

1. Ensure person centered planning
2. Encourage self direction and/or supported decision making
3. Identify what is important to and important for the individual
4. Monitor utilization of the individual budget (IBA)
5. Facilitate person centered planning meetings
6. Develop Individual Support Plans
7. Monitor service provision
8. Maximize usage of available formal and informal supports
9. Contact for families and providers if behavior or needs escalate
10. Access point for intensive services and priority one funding.

Service Coordinators are:

Person Centered helping individuals have choices in how and where to live and,

Family Centered partnering with families to meet the needs of their family member with disabilities

Legal Foundations of System Reform

The Courts have consistently upheld a person’s right to receive services in the least restrictive setting. In 1999, the Supreme Court ruled that “unnecessary institutionalization of people with disabilities constitutes discrimination under the ADA.” (Olmstead v L.C., 527 U.S. 581) The decision included the following language:

- Unjustified isolation, we hold, is properly regarded as discrimination based on disability.
- Institutional placement of persons who can handle and benefit from community setting perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.
- Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment.

This case initially focused on the transition of persons from institutional to community-based living. Subsequent cases have determined it also applies to people at risk of institutionalization, including those on a waiting list. Cuts in community services that would force a person into an institution violate the ADA.

LAWS IMPACTING REFORM:

Nebraska LB 1033– Olmstead Plan tasks DHHS with developing a comprehensive strategic plan to meet the needs of disabled individuals in the most integrated setting appropriate.

Individuals with Disabilities Education Act (IDEA)- Provides direction to ensure all children receive services <http://idea.ed.gov/explore>

Workforce Innovation and Opportunities act (WIOA)- Support for job seekers to access employment, education, training and support to succeed. <https://dol.nebraska.gov/EmploymentAndTraining/WIOA/Home>

The Role of the DD Service Coordinator

People eligible for services through DHHS-Developmental Disability are assigned a Service Coordinator. All DD services including service coordination are voluntary.

When working with Justice-involved youth, the Service Coordinator is an invaluable member of the family team. Their expertise in the development of Plans of Care specific to the DD population can help prevent the utilization of services not designed to meet the unique needs of these individuals and may open the door to an array of services and service providers skilled in working with this population.

The Relationship Between DD and Crime

Individuals with DD are over-represented in the justice system. Long term effects of justice involvement for youth with DD include continued involvement in the adult criminal justice system. Experts estimate up to 10% of the prison population are impacted by DD; however, they represent only 2-3% of the total population.

Contributing factors

Individuals with intellectual impairments are :

- More likely to be caught
- More likely to confess
- More likely to be convicted
- Less likely to be paroled

For youth, some studies show the estimated full-scale IQ of Justice-involved youth is 20 points lower than the mean full-scale IQ for the general population.

Any service that exists in the community that does not allow people with disabilities to make their own decisions, act on their own terms or that segregates or marginalizes them, is an institution.

Why is this important?

- DD impacts an individual's ability to engage fully in the legal system including participating in their defense
- These youth may not fully benefit from traditional interventions to reduce recidivism
- Failure in court-ordered services increases the likelihood of out-of-home placements
- Some see prison, detention and out-of-home placement as the "new institution" restricting the freedoms of disabled persons

Developmental Disabilities and Aggression

Most individuals with developmental disabilities are not aggressive. However, aggression is noted to occur at a higher rate than in the general population.

Effective Responses to Aggression

- Develop a Support Team
- Assess the Circumstances/ Triggers
- Develop a Positive Behavior Support Plan
- Set Realistic Goals
- ADAPT the Environment
- Teach Alternative Skills
- Reward Desired Behaviors
- Provide Parent Training and Support

Why? For individuals who struggle to communicate effectively with others, aggression can serve many purposes:

- A means for expressing frustration
- A learned behavior
- Attention seeking
- A desire to escape or avoid unwanted situations
- An expression of physical pain or acute medical problem
- A means of communication
- A signal of an acute psychiatric problem.

Individuals may develop aggressive patterns of communication over time in response to

- Stress
- Pain
- Grief/loss
- Changes in routine
- Novelty
- Developmental changes
- Growth in size or strength
- Puberty/hormonal changes
- Environment

Youth at Risk of Out-of-Home Placement

The Juvenile Justice System is in the midst of a similar reform, moving to community-based services as the best practice for reducing recidivism and meeting individual needs. Youth with DD continue to enter the system in response to impulsive and aggressive behaviors.

Our system focuses on intentional behaviors that need changed but the disability often takes "intentional"

out of the equation. As a community, we must decriminalize disability and recognize the need for specialized interventions designed for this population.

Justice placements are not the answer. These providers are ill equipped to work with the special needs of these youth and do not fully understand the complexities

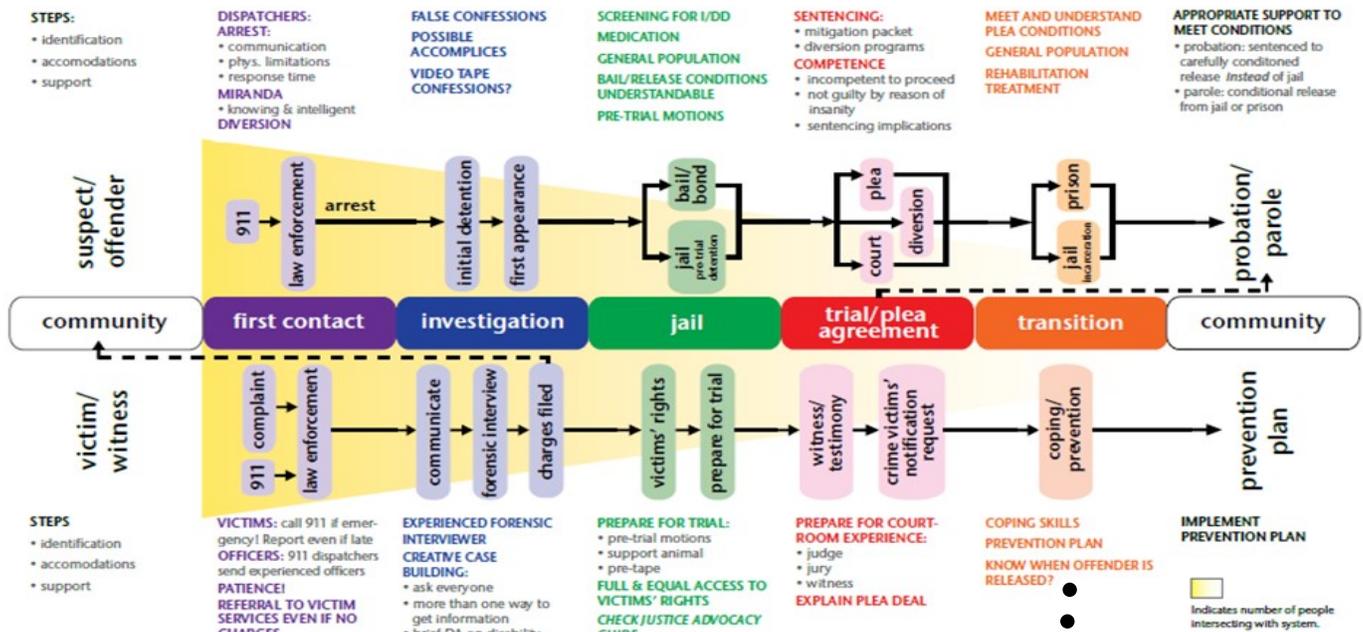
of their needs. We should seek to find sustainable solutions that increase community supports and impact their functioning across their lifespan.

Behaviors, including aggression, can be managed in the home with appropriate planning, skilled community supports, along with parent training and support.

The Pathways to Justice Model: A framework for discussion and solutions

The National Center on Criminal Justice and Disability (NCCJD) has developed the Pathways to Justice model to help identify and fill gaps that pull youth deeper into the system. System-wide training, family engagement and community based responses are essential to the development of strategies that will address the true needs of identified individuals

Pathways to Justice™ Model



Contributing Factors

- Misdiagnosis of disabilities
- Limited access to effective mental health services
- Inadequate or inappropriate school supports
- Behavior identified as noncompliant or willful
- Zero tolerance policies
- Higher rates of suspension and expulsion in school

Practical Solutions

- Developing parents as advocates for their youth
- Preplanning for individual needs:
 - At school, through an Individualized Education Plan (IEP) or Behavior Intervention Plan (BIP)
 - In the community, practiced responses with law enforcement, ID bracelet or card, monitoring online access
- Probation involvement in planning processes
- Advocacy and community resources

The most effective way to divert youth from the Juvenile Justice System is to ensure they are properly evaluated and being provided interventions to meet their individual needs using research-based supports.

Probation's Role at Intake, First Contact or PDI

Probation officers can assist in the early identification of individuals with DD and improve the utilization of targeted supports.



- Does the individual appear to understand the questions asked?
- Are they able to respond without delay?
- Do they seem eager to please?
- Are they able to explain their actions in their own words?

- Did they or are they currently receiving special education services?
- Do they receive Social Security Income (SSI) related to a disability?
- Does the person carry an identification card with the name of a support person or advocate you can contact?

- Family supports to evaluate the current plan of care
- School system including obtaining the Individualized Education Plan (IEP)
- Community resources to evaluate enhancement of supports
- Legal system to advise of any special needs identified
- Service coordinator if available
- Advocacy groups

The Impact of Learning Disabilities on Non-compliance

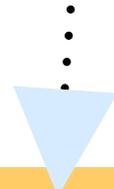
Probation officers are often the first call when a juvenile is acting out at home, school or in the community. Learning disabilities and cognitive impairments can be linked with an elevated risk for behavior problems. Many individuals are not properly identified and lack necessary supports increasing non-compliance, inappropriate behaviors and rule breaking. Undiagnosed learning disabilities contribute to frustration, anxiety, depression, substance abuse, and school failure.

Learning disabilities may impact an individual's ability to:

1. Understand and comply with expectations
2. Recall information or order of events
3. Express their thoughts and feelings
4. Generalize information
5. Plan and organize

As a result, these individuals may:

1. Be described as lazy, defiant or oppositional
2. Have difficulty explaining what they learned
3. Refuse to complete tasks or work
4. Engage in behaviors resulting in suspension as an effort to escape school



Probation's Role

1. Become involved in the IEP process
2. Ensure all youth are properly evaluated and identified
3. Assist in access to appropriate services
4. Utilize successful education modifications in other settings
5. Check for understanding
6. Analyze the impact of a disability on noncompliance

Utilize School-Based Resources

The public schools are the primary resource for day services for youth with special needs. Students are eligible for services to meet their educational and transitional needs as outlined in their IEP until age 21, or graduation, . Services may include a combination of educational, vocational, behavioral and life skills programming.

IEP

- **An Individualized Education Plan must include:**
- Present level of performance
- Annual educational goals
- Supports and services the school will provide
- Modifications- any changes in what a student will be taught or expected to learn
- Accommodations-tools or procedure changes provided by the school
- How and when progress will be monitored
- Transition planning for teens

FBA

- **Functional Behavior Assessment assumptions**
- Behaviors serve a purpose
 - 1. Obtain something desirable
 - 2. Avoid something unpleasant.
- Behaviors occur in response to an event
- Behaviors are managed by the responses they receive
- Behavior is a form of communication
- Some misbehavior might be "adaptive" or understandable given the circumstances

BIP

- **A behavior intervention plan will:**
- Describe the problem behavior
- Identify the reasons the behavior occurs
- Outline intervention strategies to address the problem behavior
- **To Maximize success**
- Interventions must be matched to the targeted behavior
- The plan must be monitored and adjusted over time

Vocational Rehabilitation

Nebraska VR provides support to help people with disabilities prepare for, find and keep employment.

Transition services are also available to youth with disabilities to prepare them for life after high school.

Services are available to youth with disabilities and may include

- Assessment of needs
- Work-based learning
- Education
- Training
- Employment opportunities

Individualized Plans for Employment (IPE) are developed to help youth

- Set personal employment goals
- Develop timelines to achieve goals
- Obtain services and supports necessary to obtain and maintain employment

Find a VR office near you
www.vr.ne.gov/offices/index.html

Transition Planning



A web based program to aid in transition planning for Nebraska youth and young adults with DD

http://dhhs.ne.gov/developmental_disabilities/Pages/RSG-HOME.aspx

Nebraska Planning Council on Developmental Disabilities

Six Regional Councils operate across Nebraska to address

- advocacy,
- capacity building
- system changes

To better serve individuals with disabilities living within the community. Participation is open to

any person living within the region.

Regional councils receive state funds to support activities related to public awareness, training and conferences.

Statewide plans are developed following the Needs Assessment Survey.

The statewide Council awards federally assisted grants to achieve the goals outlined in the statewide plan.

The current plan can be viewed at http://dhhs.ne.gov/developmental_disabilities/Pages/ddplanning_state_plan.5.yr.aspx

EBP for Treating Individuals with DD

Keys To Long Term Success

- Focus on individual strengths and needs
- Empower the individual and family to become a part of the solution
- Support relationship development
- Encourage personal choice
- Respond to behavior as communication
- Utilize pro-active strategies
- Adapt the environment to the individual
- Provide targeted skills training
- Link with community-based supports
- Identify support for caregivers
- Develop sustainable solutions

Behavior Modification (B-mod) Therapy is recognized by Medicaid as an evidence-based practice for treating individuals with developmental disabilities. B-mod can be funded by Medicaid up to age 21 across the service array from outpatient, to intensive outpatient, to day treatment. Day treatment is currently only available in Omaha at Monroe Meyer.

There are a wide variety of B-mod programs available to meet different needs. Models include:

- Applied Behavior Analysis (ABA)
- Intensive Treatment Management Services (ITMS)
- Multi-systemic Therapy (MST)
- Parent Child Interactive Training (PCIT)
- Parent Management Training (PMT)

Monroe Meyer in Omaha Nebraska is identified as the Center of Excellence when it comes to treating individuals with developmental disabilities, however they exclusively utilize Applied Behavior Analysis (ABA). Individuals are encouraged to explore different B-mod programs to find one that works for them.

Challenging Behavior Tool Kit



Autism Speaks has created a Challenging Behaviors Tool Kit.

While designed for youth with autism, this is a great resource for families and probation officers to assist in the process of identifying and planning around challenging behaviors regardless of diagnosis.

http://www.autismspeaks.org/sites/default/files/challenging_behaviors_tool_kit.pdf



In 2014, the Achieving a Better Life Experience Act was signed into law allowing individuals with disabilities to accrue more than \$2,000 in assets without losing their disability benefits.

An eligible individual can open an ABLÉ account at any time with money that is saved by or gifted to the qualified individual. This money is not taxed and can be withdrawn to pay for **Qualified Disability Expenses**.

Eligible individual:

- Is blind or disabled before the age of 26 and is entitled to SSI or Social Security Disability Insurance (SSDI) benefits, OR
- Has certification from a physician indicating that he/she has a marked or severe functional limitation that was diagnosed before the age of 26, which is expected to result in death, or is expected to last longer than 12 months or is blind.

For more information : www.enablesavings.com

Resources

National



Learn about specific diagnosis

<http://www.thearc.org/page.aspx?pid=2530>

Pathways to Justice video

<http://www.thearc.org/NC/CJD>

Disability Response Teams

<http://www.thearc.org/document.doc?id=5114>



The ASSET Network– Autism and Developmental Disabilities Services, Supports, Education and Training

<http://www.yapinc.org/asset>

10 Best Practices

<http://www.yapinc.org/Portals/0/Documents/Resources/Best%20Practices.pdf>



What probation officers need to know about Learning disabilities

<http://www.pacer.org/parent/php/php-c169.pdf>

Tips for Teens: Use your IEP Meetings to Learn How To advocate for Yourself

<http://www.pacer.org/parent/php/php-c149.pdf>

Students with Disabilities & the Juvenile Justice System: What Parents Need to Know

<http://www.pacer.org/jj/pdf/jj-8.pdf>

Nebraska



OMNI Behavioral Health SPECIALISTS IN COMMUNITY SERVICES

Education and Training

<http://www.omnibehavioralhealth.com/webinars/>



Support and information

<http://www.answers4families.org/>



Advocacy and support

<http://www.arc-nebraska.org/>



Resource List

http://dhhs.ne.gov/developmental_disabilities/Pages/aDDR.aspx

Nebraska Aging and Disability resource center

<http://nebraska.networkofcare.org/aging/>



Advocacy for and by people with disabilities

<http://www.peoplefirstnebraska.com/>



Parent information and support

<http://pti-nebraska.org/>

Apply



Administrative Office of Probation— Juvenile Services Division

• Julie A. Smith, Reentry Specialist

521 S. 14th Street, Suite 500
Lincoln, NE 68508

Phone: 402-314-8545

Email: julie.a.smith@nebraska.gov



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Nebraska Medicaid, Developmental Disabilities & Economic Assistance

<https://dhhs-access-neb-menu.ne.gov/start/?tl=en>



SSI: Benefits

Disabled Child Under age 18

<https://www.ssa.gov/disabilityssi/apply-child.html>

Disabled adult Over age 18

<https://www.ssa.gov/disabilityssi/>