A Healthy Start for Children with Intellectual Disabilities and Developmental Delays

A toolkit to guide parents and caregivers to support the health and development of their children with intellectual disabilities and developmental delays

Special Olympics

Welcome to a community where all children and families are welcome and supported!

In this Healthy Start Toolkit, you will find information, resources and support to guide your child's journey following a diagnosis of developmental delay (DD) or intellectual disability (ID). This toolkit will help you discover your child's abilities and strengths and teach you some ways to support the ongoing progress. You will learn about your child's diagnosis, health, and educational needs. You will also find information about available services, from health care providers, therapists and teachers, and discover ways to access resources in your community. This toolkit will help you solve the problems you may encounter in your child's journey, while also supporting your own needs as a caregiver by building your confidence and supporting your well-being. Most importantly, you will hear from other families, connect into a diverse and inclusive community supported by Special Olympics and get a glimpse into your child's amazing potential and future.

How to Use the Healthy Start Toolkit

The Healthy Start toolkit includes four sections:

Understanding the Diagnosis	Plan of Care	Next Steps	My Child's Future
• Information about the diagnosis of developmental delay (DD) and intellectual disability (ID)	• Information about the medical, educational, and home care plans that can help guide for a healthy development for your child	• Information on creating a support team and action plan, and promoting the health and well-being of parents and caregivers	• Success stories and opportunities available in the community for adults with intellectual disability

Within each section, information is provided through text, resources, and links to specific topics. It may be helpful to discuss certain parts of the toolkit with your child's healthcare provider, teachers, therapists or family members.

This toolkit was designed to allow you to read it in any order. Based on where you are on your journey, you may choose to revisit different sections or come back to the information later.

Understanding the Diagnosis

The following section includes content covering the following areas:

Defining the Diagnosis

- Features, causes and general information about DD and ID

Reaching the Diagnosis

- Information about the psychological, medical and educational evaluation for diagnosing DD and ID in children

Processing the Diagnosis

- Information to help process and understand the diagnosis of DD and ID

Defining the Diagnosis

Learning about developmental delay and intellectual disability will give you the tools to better understand and support your child. This knowledge will also help you build a proactive partnership with your child's medical and educational team to build a plan of care.

DESCRIPTION OF DEVELOPMENTAL DELAY, INTELLECTUAL DISABILITY AND DEVELOPMENTAL DISABILITIES

Disclosure: While this toolkit will primarily focus on intellectual disability and developmental delay, the information and resources may also be relevant to children with other developmental disabilities. In this toolkit we will use the term Developmental Delay (DD) instead of Global Developmental Delay.

Children under the age of 5 who have delays in at least two areas of development, such as motor, language, cognition, social and adaptive functioning, are diagnosed with Global Developmental Delay (GDD). Within a year of the initial GDD diagnosis, a re-evaluation should be scheduled with a specialized physician, a psychologist, or other provider to monitor the child's development and progress.

Children with GDD have an increased risk for a later diagnosis of Intellectual Disability (ID). ID is defined by low intellectual and adaptive skills and is diagnosed between the ages of 5 to 18.

Intellectual disability, Cerebral Palsy and Autism Spectrum Disorder are part of the Developmental Disabilities group. Developmental Disabilities are disorders with ongoing physical, learning, language or behavior difficulties which start before the age of 22 and significantly impact daily functioning.

Criteria for Intellectual Disability

According to the American Psychiatric Association's 2013 DSM-5 diagnostic criteria, the diagnosis of ID requires the following three criteria:

- Low intellectual skills which are confirmed by an evaluation done by a psychologist and an IQ test score below 70-75.
- Low adaptive skills that impact at least one activity of daily living such as communication, social participation and independence. The daily living activities will require support in two or more settings, such as home, school, work, and community. Adaptive skills are evaluated and scored by a clinician based on reports from caregivers and providers who are familiar with the individual's performance.
- Evidence of low intellectual and adaptive skills before the age of 18 years

Types of Adaptive and Intellectual Skills

There are different types of intelligence, including reasoning, problem solving, planning, high-level (abstract) thinking, judgment, academic learning, and learning from experience.

Adaptive skills include daily activities which people perform by themselves and are expected within their community, culture, and age group. The three types of adaptive skills are conceptual, social, and practical.

- **Conceptual skills** include language, reading, and writing (literacy); knowledge of money, time, and numbers (mathematics); thinking; memory; independent functioning; and judgment in new situations.
- **Social skills** are defined by the ability to interact with other people and include communication with others, being compassionate, being able to make friends and to understand social situations. Social responsibility, self-esteem, being naive, and the ability to follow the rules and to avoid being bullied (victimized) may also be evaluated.
- **Practical skills** consist of activities to take care of oneself such as eating, dressing, mobility and being toilet trained. Following a schedule or routine, using a telephone, managing money, preparing meals, job skills, and abilities to use transportation and travel and to maintain health care, and safety may also be evaluated.

Severity Level of Intellectual Disability

Severity is based on the scores of adaptive functioning and will determine the level of support the individual will need. IQ scores are not used to determine the severity of ID.

GENERAL INFORMATION ABOUT DEVELOPMENTAL DELAY (DD) AND INTELLECTUAL DISABILITY (ID)

Occurrence of DD and ID

- ID has been reported to occur in all racial, ethnic, and socioeconomic groups. *According to the American Psychiatric Associations 2013 DSM-5 diagnostic criteria*, mild ID is 1.6 times more common in males and severe ID is 1.2 times more common in males.
- One in six children or 17.8 % of children aged 3-17 have one or more developmental disabilities, including ID and DD. Among these children, the prevalence of ID is 1.2%. This data was reported by the CDC, based on parent surveys collected in the U.S. from 2015-2018. e
- Based on data analyzed from a 2017 Global Burden of Disease study, an estimated 11.2% of all children and adolescents globally had at least one of the four disabilities measured (epilepsy, intellectual disability, vision and hearing loss). Among these children and adolescents, the prevalence of intellectual disability was 3.2%.
- According to a study published by Global Research on Developmental Disabilities Collaborators, it is estimated that about 53 million children under 5 years have developmental disabilities globally. The majority of these children live in low- and middle-income countries. Intellectual disability was found to be the largest contributor to years lived with disability.

Potential Impact on Development

- Children with DD/ID have delays in reaching developmental milestones, such as the ability to express themselves through words and to understand spoken language. Children with DD/ID who do not develop words may connect or communicate in other ways, such as facial expression, eye contact, gestures and sign language. These children may benefit from learning to communicate through augmentative and alternative communication, which includes communication through pictures, sign language and electronic devices.
- Children with DD/ID may have delays in developing fine motor skills, such as the ability to use their hands for different tasks, like holding a crayon, cutting with scissors, drawing and building with blocks.
- Gross motor skills, such as walking or running, may develop later in some children with DD/ID.

- Children with DD/ID may also need additional guidance in developing creative play and independence skills, like eating, toilet training, and getting dressed.

Supports for Children with ID/DD

- Most individuals with ID have a mild form and are often not diagnosed until school age. During school years, children may need additional support for learning to read, use numbers or writing. With support from parents, teachers, and other providers, all children with DD/ID will continue to learn at their own pace. Providing a positive environment with encouragement and recognition of a child's progress will help maintain the child's well-being, self-esteem and confidence.

- Early on caregivers and teachers need to start building independence skills in children. During school, the students receive transition planning to prepare them for life after graduation. Many of these students will be able to get training to prepare them to get a job or perform work in a supervised placement. As a result, more and more people with ID are employed today. Most individuals with ID will be able to live independently and need guidance only for complex decisions and tasks.
- A large number of people with ID are athletes, with millions worldwide participating in Special Olympics. Through training and team activities Special Olympics is one of the community programs which improves independence, leadership, and social skills of individuals with ID.

CAUSES OF DEVELOPMENTAL DELAY (DD) AND INTELLECTUAL DISABILITY (ID)

In most cases, it is unknown what causes DD/ID; however, in some cases a genetic or environmental factor can be identified. Among the known causes for ID/DD, a genetic factor is the most common. Abnormal brain formation and structure, brain tumors and metabolic conditions can also cause DD/ID. They can also be caused by a known environmental factor during pregnancy, around birth or shortly thereafter.

Genetic and Environmental Causes

The most common genetic disorders that cause DD/ID include:

- **Down syndrome** is the most commonly identified chromosomal condition associated with ID in both males and females. It occurs when an individual has a full or partial copy of chromosome 21. This extra genetic material causes the characteristics associated with Down syndrome. Children with Down syndrome are at a higher risk for certain medical conditions including congenital heart defects, hearing and vision loss, respiratory problems and increased susceptibility to infections. It is important to note that your child may not necessarily have all the medical conditions associated with Down syndrome and if he/she has any of the conditions, advances in medicine have rendered most conditions treatable.

- **Fragile X Syndrome** is the most common inherited genetic condition causing ID in males. It causes intellectual disability, behavioral and learning challenges, and various physical characteristics. Though FXS occurs in both genders, males are more frequently affected than females, and generally with greater severity. Life expectancy is not affected in people with FXS because there are usually no life-threatening health concerns associated with the condition.
- **Prader Willi syndrome** is a genetic condition caused by abnormalities in chromosome 15 that affects all sexes and races with equal frequency. It is recognized as the most common genetic cause of life-threatening childhood obesity and is also associated with intellectual disability and various learning disabilities.

Environmental factors that may cause DD/ID include:

- Factors impacting pregnancy, birth or shortly thereafter, such as infections, use of alcohol and certain medications.
- Factors affecting the baby around the time of birth, such as being born before term, low oxygen, infections, stroke, head trauma or bleeding
- Factors affecting the brain after birth, such as stroke, head trauma or bleeding, infection and certain treatments for cancer, decreased level of thyroid hormone, lack of oxygen, high lead level, malnutrition, or emotional neglect

Reaching the Diagnosis

Children are diagnosed with ID/DD through medical, psychological, and educational evaluations. These evaluations are usually performed by a team of providers from different disciplines.

Psychological Evaluation

Psychological evaluations include tests for intelligence, adaptive skills, and academic performance in reading, mathematics, written expression and spelling. Assessments for autism, anxiety, depression, social communication, learning, attention and other functions of the brain and behavior can be performed as needed.

Psychological evaluations can be performed by clinical psychologists and are for the purpose of getting the medical diagnosis of ID. In many cases the medical diagnosis is provided by a team, which may also include a physician, occupational therapist, and speech pathologist. A medical diagnosis is required by medical insurance for coverage for services and interventions provided outside school.

Psychological tests can also be performed by a school/educational psychologist for the purpose of getting an educational diagnosis, which is used to qualify for intervention services through school.

Educational Evaluation

Educational evaluations are performed by the Early Intervention program, for children aged 0-3, and by the school, for children older than 3. This evaluation is performed for the purpose of getting an educational diagnosis and to develop a specific intervention plan for each child.

The educational evaluation is performed by a multidisciplinary team and may include the following:

- Psychological evaluation is performed by the school psychologist for the purpose of receiving school services. This type of evaluation includes special tests for intelligence and adaptive skills, with additional testing for school age children such as: tests for reading, mathematics, written expression and spelling. Additional evaluation for autism, anxiety, depression, social communication, learning, attention, other functions of the brain and behavior may be performed.
- Speech and language evaluation is performed by a speech therapist and assesses the ability to understand, talk, communicate and have a conversation.
- Occupational therapy evaluation is performed by an occupational therapist and assesses the fine motor skills, such as the ability to use the hands to hold a pen or cut with scissors. Sensory processing, such as under or over reaction to sounds, sight, touch, taste, pain and movement, can be assessed.
- Physical therapy evaluation for gross motor skills assesses the ability to move and maintain balance and coordination when walking, running and jumping.

Medical Evaluation

Medical evaluations are usually performed by a physician specialized in development and behavior, such as a developmental behavioral pediatrician. The evaluation consists of medical, developmental, behavioral, educational and family history, as well as a physical examination. The physician will review previous evaluations and will also perform a developmental and behavior assessment. The medical evaluation can provide the medical diagnosis of DD/ID, as well as other behavioral and communication conditions that may occur together with intellectual disability, such as autism or Attention Deficit Hyperactivity Disorder (ADHD).

During these evaluations, children will also be assessed for medical conditions which can be seen more frequently in children with DD/ID, such as constipation, abnormal weight gain, hearing, vision, sleep and feeding disorder, pica (eating non-food items), seizures, teeth and gum problems.

Children with DD/ID may need to be referred for audiological (hearing) and ophthalmological (eye and vision) assessments. As part of the medical evaluation, the physician may recommend different blood tests, such as genetic testing, lead toxicity screening and thyroid function. In some children, a brain MRI (special picture of the brain) or EEG (a brain wave study to check for seizures) may also be done.

These are some of the specialists who may be helpful in evaluating and following children with DD/ID:

- Developmental behavioral pediatricians are physicians trained in assessing development, behavior and learning and can provide diagnosis and recommendations for treatment for DD/ID, autism, learning disability, ADHD.
- Psychologists are clinicians specialized in the diagnosis of DD/ID, autism, learning disability, ADHD, anxiety, and depression. Psychologists can provide behavior therapy, parent coaching, social skills training and counseling.
- Physicians specialized in genetics and genetic counselors perform an evaluation for a genetic cause or risk factor for DD/ID for the whole family.
- Neurologists are physicians specialized in disorders with abnormal structure or function of the brain and can evaluate for seizures or regression of skills.
- Psychiatrists are physicians specialized in the diagnosis and medication of mental health disorders, such as depression, anxiety, bipolar disorder, schizophrenia.

Additional Medical Tests

Some additional medical tests may be recommended for children with ID/DD, including:

- Blood lead levels should be checked every year in children who mouth or eat non-food items, or those who have been exposed to lead. Increased lead level may affect behavior and learning.
- Thyroid function is checked in all children at birth. It should be re-checked in children who have DD/ID or children with poor growth in height. Thyroid hormone, which is produced by the thyroid gland, affects development, behavior and growth.

- If the child loses skills, has seizures, or has certain findings on the physical and neurological exam, physicians may recommend pictures of the brain, such as brain MRI or a brain wave study such as EEG.

Processing the Diagnosis

After learning that your child has DD/ID you will have questions about the diagnosis, your next steps and what your child's future may look like. Understanding your child's diagnosis and needs takes time and is part of a continuous journey to create the most positive environment for your child to succeed. The good news is that every day you will learn something new that will help to build your confidence in supporting your child. Through this process, it is important to remember that, like everyone else, your child has both strengths and challenges. Children with DD/ID will reach milestones at different times and will make progress at their own pace. Learning about the diagnosis will help you better understand your child's development and behavior and support their ongoing developmental progress. It will help you make informed decisions and become a stronger advocate for implementing the plan of care in school and at home.

After your child has been diagnosed with ID/DD, start by reaching out to your family or to other caregivers with a similar experience. They can provide support, understanding and advice on developing the plan of care.

"What did you do right after learning about your child's ID/DD diagnosis?"

"Right after the diagnosis, I reached out to a parent support group and made a few good friends who were always ready to listen and help."

"My main goal was to keep my child happy during intervention and to allow him enough time to relax and enjoy fun activities with our family."

"I made therapy fun and normalized my child's life through art, dance as well as swimming through the Special Olympics."

"I kept a list of my child's strengths and celebrated any progress."

"Early on I talked to my family about my child's diagnosis and felt supported."

After the diagnosis, you will meet providers who will be able to support your child's and family's journey. For example, a physician (medical doctor) can explain the child's diagnosis and address medical and educational needs. The physician can also help you develop an action plan for care and will be able to update you on your child's progress. The physician can provide referrals for interventions at home, school recommendations and guidance for accessing community resources. Developing a positive relationship with your child's medical and educational providers will help you create a network of support and care for your child's development.

"How did you work together with your child's physicians and health providers?"

"Before the doctor's appointment, I made a list of questions to be discussed."

"I asked my doctor to give me written recommendations and specific information regarding my child's intervention."

"When talking to a doctor, I was not afraid to clarify what I did not understand or what did not seem like a good choice for my child."

"Keeping regular follow up appointments with my child's doctor kept me on track with the care plan."

"I looked for a doctor who talked about my child's strength and progress and recognized my effort. This gave me the energy to be able to go on."

Plan of Care

The following section includes content covering the following areas:

Medical Plan of Care	Educational Plan of Care	Health & Wellness	Plan of Care at Home
• Information about intervention and treatment of the medical, developmental and behavioral conditions frequently seen in children with DD and ID.	• Information about the educational programs, such as the Early Intervention Program, Special Education and therapies, for children with DD/ID.	• Information about the promotion of health and wellness to prevent medical and mental health conditions.	• Information about the interventions led by parents and caregivers through home activities.

Medical Plan of Care

Children with developmental delays (DD) and intellectual disabilities (ID) may require a variety of medical interventions and supports from medical specialists, on top of their regular well-child care with their primary care physician.

STEP 1: GETTING COMFORTABLE WITH GOING TO THE DOCTOR

The first step in your child's medical plan of care is ensuring they are comfortable with going to the doctor. Children with DD/ID may need to be prepared before a new experience, especially an experience that could feel scary, like going to the doctor. Here are some tips that may help your child with a medical appointment:

- Prior to the appointment, use social stories, books or videos to explain and show what happens during the medical visit
- Schedule the visit during the best time for the child
- Try to schedule the first appointment in the morning or after lunch break, to avoid stress related to waiting
- Bring another adult to care for your child during the visit to allow you time to talk to the provider
- Consider bringing the following items to the appointment:
  - Snacks and drinks
  - Bubbles, preferred toys, books, games, or iPad to entertain or distract the child during exam or visit

STEP 2: MAINTAIN WELL-CHILD CARE

It is important to maintain your child's well-child visits with your primary care physician. These visits include preventative regular checkups, vaccinations and health screenings for:

- Growth
- Vision
- Hearing
- Dental
- Nutrition
- Other health conditions

STEP 3: EVALUATION AND TREATMENT OF PHYSICAL HEALTH CONDITIONS ASSOCIATED WITH DD/ID

Children with DD/ID have a higher risk for developing certain physical health conditions that may require additional screenings, evaluation and treatment. Below you can find detailed information about these specific health conditions, prevention and plan of care.

Weight/Nutrition

- Areas of concern: overweight, underweight and unbalanced nutrition
- Possible secondary problems: heart problems, snoring, learning and behavior difficulties
- Signs or risk factors that could lead to weight issues:
  - Picky eater due to sensory processing difficulties related to taste, smell, and food textures
  - Poor diet due to chewing and swallowing difficulties
  - Not having enough exercise
  - Lack of awareness of body weight

If you notice any of these signs or see issues with your child's weight or nutrition, talk with your child's primary care physician. You may be referred to a nutritionist to evaluate and change your child's diet, or an occupational therapist to address sensory difficulties. The plan of care for weight issues may include a behavioral intervention and physical activity plan.

Additionally, there are many ways you can support your child's healthy weight development at home, including:

- Check your child's weight regularly

- Keep your child and family on a healthy diet
- Maintain a consistent schedule with meals at the same time each day
- Give plenty of water and avoid giving soft drinks to your child
- Ensure your child gets at least 60 minutes of daily physical activity
- Set a sleep schedule to ensure your child gets good quality sleep

External Resources:

- Healthy Active Living for Families, from American Academy of Pediatrics

Dental and Oral Health

- Areas of concern: teeth cavities, gum problems, infection, missing or abnormal position of teeth
- Possible secondary problems: trouble speaking, eating, learning and behavior problems due to tooth pain
- Risk factors that could lead to dental issues:
    - Lack of Vitamin D
    - Unbalanced diet
    - Medications
    - Sensory processing difficulties causing difficulties brushing teeth
    - Poor dental hygiene

If you notice any of these signs or see issues with your child's teeth, talk with your child's primary care physician or dentist. They may recommend teeth cleaning, treatment of dental cavities, teeth and gum disease, or braces for the abnormal position of the teeth.

Additionally, there are many ways you can support your child's oral health at home, including:

- Drinking tap water that contains fluoride
- Avoiding soft drinks and large amounts of sweets
- Brushing teeth for two minutes twice per day with fluoride toothpaste
- Visiting the dentist twice a year from the time the first tooth comes in
- Asking your child's dentist to apply dental sealants when appropriate

External Resources:

- Oral Health, from American Academy of Pediatrics
- Children's Oral Health Basics, from CDC
- Preparing for the Dental Visit, from Autism Speaks

Vision

- Areas of concern: vision and eye problems
- Risk factors: family history of eye and vision problems, eye infections and trauma, certain infections before the baby was born, infections of the brain after birth, head trauma, certain genetic syndromes and metabolic disorders, diabetes, high Blood Pressure
- Possible secondary problems: learning, motor coordination, social skills difficulties and low self-confidence
- Signs for possible vision issues:
    - Looking closely at objects
    - Bumping into things
    - Eyes that are misaligned (look crossed, turn out, or don't focus together)
    - White or grayish white color in the pupil
    - Eyes that flutter quickly from side to side or up and down
    - Eye pain, itchiness, or discomfort reported by your child
    - Redness in either eye that doesn't go away in a few days
    - Eyes that are always watery
    - Drooping eyelids
    - Eyes that often appear overly sensitive to light
    - Headaches

If you notice any of these signs or have concerns about your child's eyes or vision, talk with your child's primary care physician. Your child may be referred to an Ophthalmologist or Optometrist, who are medical providers specialized in eyes and vision. Treatment may include wearing glasses, eye patching, medication for eye infections or surgery on the eye.

Additionally, there are many ways you can support your child's healthy vision development at home, including:

- Decrease use of recreational home screens and electronics
- Allow good lighting during reading, drawing, and writing activities
- Schedule routine eye and vision check with your child's primary care physician
- Check results for vision screening done by school
- Monitor for eye infection or trauma

External Resources:

- Warning Signs of Vision Problems in Infants & Children, by American Academy of Pediatrics
- 20 Things to Know About Children's Eyes and Vision, by American Academy of Ophthalmology
- Blindness and Vision Fact Sheet, by the World Health Organization (WHO)

Hearing Conditions

- Areas of concern: conductive hearing loss, sensorineural hearing loss, mixed hearing loss
- Risk factors: family history of hearing problems, ear infections, snoring, large adenoids or tonsils, certain infections before the baby was born, infections of the brain after birth, medications, head trauma, certain genetic syndromes and metabolic disorders
- Possible secondary problems: speech, language, communication, social skills, learning, behavior and attention difficulties and low self-confidence.
- Signs for possible hearing issues:
    - Lack of response to sounds
    - Ignores when name is called
    - Lack of following instructions
    - Language delay
    - Unclear speech
    - Watches TV or listens to music at a very high volume
    - Speaks loudly

If you notice any of these signs or see issues with your child's ears or hearing, talk with your child's primary care physician. They may refer you to a hearing specialist (audiologist) or a physician that specializes in ear, nose and throat conditions (ENT). Interventions may include treatment of ear infections or nasal congestion, surgery for ear fluids, large adenoids or tonsils, or the use of hearing aid or implants.

Additionally, there are many ways you can support your child's healthy hearing development at home, including:

- Check results of newborn hearing screening
- Schedule routine hearing checks with a pediatrician
- Check results of hearing screening done by school
- Follow up the doctor's recommendations for the child's ear infections
- Avoid exposure to loud sounds such as loud music or TV

External Resources:

- Hearing Loss in Children, by CDC

Bones, Muscles and Joint Conditions

- Areas of concern: abnormal walking, muscles, back and joint problems
- Risk factors for bone, muscle and joint issues: delay in starting to walk, poor muscle strength and balance, brain and genetic disorders

- Possible secondary problems: difficulties with motor coordination, walking, and general ability to move
- Signs for possible bones, muscles and joint issues:
    - Limping
    - Back or joint pain
    - Delayed walking
    - Asymmetric walking
    - Difficulties or poor quality in performing gross motor activities: walking, running, climbing, jumping

If you notice any of these signs, talk with an orthopedist, who is a physician that specializes in bones, muscles and joints, or a physical therapist, who is a clinician specialized in walking, movement, muscles and joints. Interventions may include stretching or exercises, braces, casts, or surgery.

Additionally, there are many ways you can support your child's healthy movements at home, including:

- Maintain regular physical activity
- Consider stretching
- Use comfortable shoes

External Resources:

- Kids and Their Bones: A Guide for Parents, by the National Institute of Health

Sleep

- Areas of concern: difficulties falling asleep, waking up at night, restless sleep, short sleep duration, snoring, teeth grinding and sleep walking, night terrors
- Risk factors for sleep issues: anxiety, ADHD, autism, obesity, seasonal allergies, large adenoids or tonsils, genetic syndrome, low muscle tone, low iron and vitamin D
- Possible secondary problems: weight and growth problems, hyperactivity, short attention span, other behavior and learning problems. Children who snore may have apnea which are pauses in breathing that may cause decreased oxygenation of the brain with secondary lung and heart problems

If your child snores or has restless sleep, your primary care physician may refer you to an ENT physician for a sleep study and other tests. Interventions may include behavioral therapies, medication, or treatment for sleep apnea.

Additionally, there are many ways you can improve the quality of your child's sleep such as:

- Avoiding heavy exercise within 2 hours of bedtime
- Avoid use of caffeine drinks and electronics before bedtime
- No TV in the bedroom
- No access to electronics after bedtime
- Maintaining a comfortable room temperature
- Use of bed sheets with preferred texture
- Having a consistent daily sleep schedule
- Having a quiet bedtime routine, which could include: Stop using electronics 1 hour before bedtime, drink a cup of milk, take a warm bath or shower, brush teeth, get in bed and read a story or listen to quiet music to calm down

External Resources:
- Tips for better sleep, by American Academy of Pediatrics
- Sleep Strategies for Kids, by Sleep Foundation
- Sleep Tips for Family's Mental Health, by American Academy of Pediatrics

Constipation
- Areas of concern: infrequent bowel movements, straining when passing stool, passing hard stool
- Risk factors for constipation: having selective diet, low muscular tone, low thyroid hormone levels, abnormalities of the bowel movements and structure
- Possible secondary problems: weight, growth, behavior problems, delayed toilet training, soiling and infections of the bladder and kidney

If you notice any of these signs, talk with your child's primary care physician. Interventions may include changes in diet or exercise, behavior intervention, medications, or bowel cleansing. Additionally, there are many ways you can support your child to have healthy bowel movements at home, including:
- High fiber diet with whole grains, fruits and vegetables
- Drinking a lot of water
- Ongoing physical exercise
- Sitting on the toilet shortly after a certain meal, every day and at the same time

External Resources:
- Constipation in Children, by American Academy of Pediatrics
- Constipation in Children, by National Institute of Health

STEP 4: EVALUATION AND TREATMENT OF MENTAL HEALTH AND BEHAVIORAL CONDITIONS ASSOCIATED WITH ID/DD

Children with DD/ID are at risk for certain mental health conditions, which may be screened, evaluated and treated by your physician or specialists. Below you can find detailed information about these specific health conditions, prevention and plan of care.

Attention Deficit Hyperactivity Disorder (ADHD)

Children with ADHD have difficulties paying attention to non-preferred activities and/or are hyperactive and impulsive. These difficulties may become more apparent once children go to school. The symptoms of ADHD are seen both at home and in school and may affect one or more of the following areas: learning, behavior and interaction with other children and family members, participation in group activities, and performance of daily living skills, such as getting dressed or chores such as cleaning their own room.

Children with untreated ADHD are at risk for having difficulty making friends and underachieving in school. As a result, they may develop poor self-esteem, and even anxiety and depression. Sensory processing difficulties may increase hyperactivity and decrease attention.

Intervention:

- Increase one-on-one attention and hands-on activities, decrease distractions during homework, maintain a schedule, routines and structured environments for consistency, prepare for transitions, and provide immediate and positive feedback.
- In school, children can receive accommodations for ADHD under the 504 Accommodation Plan or under their Individualized Education Plan (IEP). Such accommodation may include extra time for tests, preferential seating in the classroom and during tests, increased one-on-one attention, and more.
- Your primary care provider can provide guidance for behavior interventions and prescribe medication for treatment of ADHD.
- Referral to a child psychologist for home behavior modification and parent coaching may be helpful.

External Resources:

- Understanding ADHD: Information for Parents, by American Academy of Pediatrics
- Protecting the Health of Children with ADHD, by CDC

Anxiety

Children with anxiety may display some of the following signs, including excessive worrying, difficulty separating from caregivers, easily overwhelmed, or difficulty being with large groups. Sometimes children may pull their hair, develop headaches, stomach aches or sleep problems, chew on objects, or pick on their nails or skin.

These difficulties are seen both at home and at school, and may affect learning, interaction with other children and family members, and participation in group activities. Children with untreated anxiety are at risk for under-achievement in school and may struggle to make friends. Sensory processing difficulties may increase anxiety.

Intervention:

- Parents and caregivers are encouraged to avoid triggers for anxiety. Additionally, consider using a visual schedule, routines, or highly structured environment to create consistency and prepare for transitions. Playing sports or engaging in other fun recreational activities, such as music and art, may also decrease anxiety.
- In school, children with anxiety would benefit from an IEP with accommodations, including a highly structured environment, use of positive feedback and preparation for transitions. These children may also receive counseling from a school counselor.
- Your primary care physician can provide guidance on medication and treatment. Your child may be referred to a child psychologist for behavior therapy and parent coaching or to a developmental behavioral pediatrician or a child psychiatrist for medication.

External Resources:

- Anxiety and Depression in Children, by CDC
- Understanding Childhood Fears and Anxieties, by American Academy of Pediatrics

Depression

Children with depression may display excessive sadness, loss of enjoyment in their preferred activities, self-isolation, aggressive behavior, irritability, lack of energy, change in appetite and sleep patterns, and suicidal ideation or plan and threats to hurt others.

Children with untreated depression are at risk for under-achievement in school, difficulty making friends, and hurting themselves or others.

Intervention:

- A child with depression would benefit from therapy with a school counselor or psychologist and may need medication from a child psychiatrist.

- If a child has suicidal ideation or a plan to hurt themselves or others, they will need an urgent psychiatric evaluation through the emergency room.

External Resources:

- Anxiety and Depression in Children, by CDC

Aggressive behavior

Aggressive behaviors towards others and oneself can be caused by difficulties with communication and sensory processing. They can also be associated with mental health conditions, such as anxiety, depression, ADHD, and genetic disorders. These behaviors can also be triggered by physical health issues, such as constipation, dental issues or undiagnosed pain.

Children with untreated aggressive behaviors are at risk for difficulties making friends and hurting themselves or others.

Intervention:

- A child with aggressive behaviors would benefit from a school and home behavior intervention plan, working with a psychologist, and may need medication from a developmental behavioral pediatrician or a child psychiatrist.
- In addition, these children would benefit from addressing the underlying cause for the aggression. For example, improving communication skills and adequate school services to match the child's needs, treating sensory processing difficulties, treating a medical cause for pain (e.g., dental problems, stomach aches) may prevent and decrease aggressive behaviors.

External Resources:

- Behavior or Conduct Problems in Children, by CDC
- Disruptive Behavior Disorders, by American Academy of Pediatrics

Wandering/Elopement

Wandering by children with autism is common and can be dangerous. It also puts tremendous stress on families and caregivers. It is important to develop a comprehensive safety plan which includes wandering prevention strategies.

Intervention

- Secure your home e.g., by using a home security alarm system and placing hooks on doors to prevent your child from wandering away unnoticed
- Consider a locating device or GPS tracking system that can be worn on the wrist or ankle to be used to track your child
- Consider an ID bracelet containing the parent/caregiver's name and contact information. It should also state that your child has autism and whether or not they are verbal
- Teach your child to swim and fence your home swimming pool if you have one

External resources

- Wandering Prevention Resources, by Autism Speaks

Educational Plan of Care

Education is a fundamental part of every child's life, with or without developmental delay (DD) and intellectual disability (ID). Going to school is a wonderful way for your child to learn new skills, make friends, and develop their own interests.

EDUCATIONAL RIGHTS

In the United States, there are many laws that protect the rights and needs of children with disabilities to attend school.

Individuals with Disabilities Education Act

In the United States, under a law called the Individuals with Disabilities Education Act (IDEA), every child has the right to "free appropriate public education" (FAPE). According to Part C of IDEA, families and children with DD/ID younger than age 3 can receive early intervention services. Individuals from ages 3 through 21 receive special education and related services under IDEA Part B. For information about educational services, contact your local school district and seek out your state parent training and information (PTI) center. Every state has PTI centers for families of children with disabilities that can provide support and train families to get educational services for their children.

Assistive Technology Act

The Assistive Technology Act provides assistive technology to individuals with disabilities so they can fully participate in education, employment, and daily activities. Assistive Technology is any item, device, or piece of equipment used to improve task performance, function, and skills in individuals with disabilities.

Here are some examples of Assistive Technology devices for different conditions:

- For limited vocabulary: Augmentative and alternative communication, such as Picture exchange Communication System (PECS), talking devices or iPad apps to communicate with others.
- For difficulties reading standard print: Text to Speech software (TTS)
- For hearing deficit and other auditory or learning problems: Assistive Listening Systems

Family Educational Rights and Privacy Act

The Family Educational Rights and Privacy Act (FERPA) is a law that protects the privacy of a student's school records. These rights are transferred to the student when they reach the age of 18 or attend school beyond the high school level.

External Resources

- About IDEA - Individuals with Disabilities Education Act
- Find Your Local Parent Center
- Assistive Technology | ACL Administration for Community Living
- Family Educational Rights and Privacy Act (FERPA)

THERAPY AND INTERVENTION SERVICES

There are multiple options for targeted therapies and interventions to help your child make progress in development, behavior, and social skills.

These interventions can be received through Early Intervention Programs for children under 3 and through the school district for children above the age of 3. In addition, children can receive intervention through your medical insurance. Some of the interventions that may be available to your child include:

- Infant stimulation programs to promote overall developmental and play skills
- Speech and language therapy for articulation and language problems
- Occupational therapy (OT) to address sensory processing difficulties and develop fine motor skills, hand motor coordination, and focus on activities like feeding and dressing
- Physical therapy (PT) to improve balance, motor coordination and gross motor skills.
- Cognitive behavior therapy (CBT), which is a behavior intervention for anxiety and depression
- Behavior modification and parent coaching for difficult behaviors

- Applied Behavior Analysis (ABA) for behavior and social communication difficulties in children with Autism
- Social skills training to improve social communication and the ability to make friends
- Family therapy to help family members understand the nature of intellectual disability, address their feelings, and develop coping skills
- Relationship-based therapies to help parents and caregivers to better read a child’s social cues and take a more reflective approach to behavioral intervention

EARLY INTERVENTION PROGRAMS

Early Intervention Programs (EIP) are agencies that offer evaluations and provide specialized home and center-based services for families with children ages 0-3 diagnosed with developmental delays. Through early intervention programs, the child will receive an Individualized Family Service Plan (IFSP).

The IFSP outlines when and what services, including those mentioned above, the child will receive. These services are typically free or available at a reduced cost. Early intervention services vary by state and more information can be found on your state’s early intervention program website. At the age of 3 children are transitioned to continue services through their school districts’ Special Education programs.

SPECIAL EDUCATION

Individuals With DD/ID ages of 3 to 21 attending public school in the United States will be eligible for an Individualized Education Plan (IEP). An IEP is a personalized document that outlines the goals and skills that your child will work towards that year. Your child will be evaluated every three years to update their education goals and intervention plan.

Every year you will meet with your educational team to review the annual goals for your child’s intervention.

EDUCATIONAL TEAM

Your child’s educational team may include some of the following providers:

- General education teachers who are often the first ones to notice that a student may have a disability.

- Special education teachers will participate in IEPs meetings and collaborate in writing the IEP goals and objectives. Special education teachers can provide additional instruction by working one-on-one with students.
- School psychologists are licensed to administer assessments to help determine a student's eligibility for special education and related services. They may provide consultation to classroom teachers for students who have problems with social, behavioral, and emotional issues.
- School counselors can provide counseling for students with disabilities that are struggling with social and emotional issues.
- Speech language pathologists work with students who have issues related to communication. They provide evaluations, help develop IEP goals and objectives, and implement intervention for articulation, language, communication, poor oral motor coordination, and feeding disorders.
- Occupational therapists work with students who have problems with fine motor coordination, such as using their hands to grasp objects or handwriting. They can also work on sensory processing differences, such as sensitivity to food, sound, texture, etc., feeding and independence skills.
- Physical therapists provide intervention for gross motor skills and coordination, such as abnormal walking, jumping, etc. They can help students who have low muscle strength and have difficulties with balance, posture, and movement.
- Audiologists help diagnose hearing problems. They can help determine if a student would benefit from a hearing aid or other devices.
- Paraprofessionals work under the direction of a teacher or an administrator to provide direct services for students with disabilities in school.

In addition, school administrators often provide indirect services for students with disabilities by ensuring proper implementation of policies, procedures, and financial responsibilities. School administrators range from the on-site principals to districtwide administrators.

Promoting Health & Wellness

Health and wellness are an important part of life, especially for children with DD/ID who are at an increased risk for certain health conditions. Health and wellness are affected by behavior, barriers to health care, and genetics. Healthy lifestyles begin by creating good habits from the start.

Every family needs to find the best ways to implement a healthy lifestyle by eating healthy foods and engaging in fun exercises. Learning about health risks could also help with prevention and the initiation of timely treatments.

SUPPORTING HEALTH AND WELLNESS INTERVENTIONS AT HOME

Healthy Diet

A healthy diet consists of nutritious foods that support growth and development. Some choices for healthy foods may include:

- Whole fruits
- Variety of vegetables
- Low-fat or fat-free dairy products after age 2
  - Note: children under 12 months should drink breast milk or formula, and children between 12 months and 2 should drink whole milk.
- Whole grains
- Protein, like beans, soy, seafood, lean meats, poultry, and unsalted nuts and seeds
- Drink plenty of water

In addition to consuming healthy foods, it is important to limit high sugar and high saturated fat snacks and drinks, as this will also help achieve a healthy diet. Learning about good food choices will help your whole family maintain a healthy diet and lifestyle.

External Resources:

- Start Simple with MyPlate, by U.S. DEPARTMENT OF AGRICULTURE
- Nutrition Resources, by American Academy of Pediatrics

Physical Activity

According to the CDC, children ages 3-5 should be active throughout the day and children ages 6-17 should have 60 minutes or more of moderate to vigorous intensity physical activity daily. There are so many ways to incorporate fun physical activities that will help your child reach the daily recommended amount of exercise.

Some examples include:

- Swimming
- Dancing
- Playing sports
- Walking the dog

- Biking

It is also important to limit the amount of inactive time, including watching television, playing computer games, or using the Internet. During schoolwork, your child may stand up and take short breaks for physical activity to promote their physical health and improve focus and learning. Based on the recommendation from the American Academy of Pediatrics, the use of screen time should be limited to 2 hours per day.

External Resources:

- Fitness, by American Academy of Pediatrics

Sleep

A healthy sleep routine includes: a bedtime routine, a consistent sleep schedule, sleeping through the night, and age-appropriate sleep duration (9-11 hours).

Strategies to improve your child's sleep:

- Set up a sleep schedule
- Have a regular time for going to bed and waking up all year long
- Keep your child's room quiet and dark
- Consider white noise or soft music
- No TV/electronics in the bedroom
- Maintain a comfortable room temperature and humidity
- Find comfortable bedding texture

Strategies to help your child better understand their sleep routine:

- Review what is expected, like falling asleep in their own bed
- Use a picture schedule or social story about their bedtime routine
- Ignore problem behavior, like requests to sleep in your bed or asking for a snack

Strategies to promote sleep safety:

- Put a lock, doorbell, or alarm on the child's door, if your child walks during sleep or is at risk of running away at night
- Use a baby monitor or window guards to ensure your child's safety while they sleep

External Resources:

- Sleep and Sleep Disorders, by CDC
- Healthy Sleeping Tips, by Special Olympics

Stress Management

Stress management can help prevent behavior difficulties in your child. Strategies to decrease stress are helpful in children who tend to be anxious, aggressive, get easily angry, and overreact during transitions or when asked to do a non-preferred activity.

Strategies to decrease stress include:

- Create a visual schedule made of pictures showing your child's activities throughout the day. This will prepare them for transitions.
- Adjust expectations to your child's developmental age.
- Use meditation, breathing exercises, or yoga
- Use techniques like deep breathing, counting, or taking a break
- Listen to calming music
- Perform a soothing activity
- Spending time with a dog, cat, or other pet
- Spending quality time with a parents, sibling, or friend

External Resources:

- Building Resilience in Children, by American Academy of Pediatrics

SUPPORTING HEALTH AND WELLNESS INTERVENTIONS IN THE COMMUNITY

Special Olympics Programs

One way to encourage physical activity and active play is by having your child participate in their local Special Olympics Program. Special Olympics has a number of programs for children of all ages that continue into adulthood.

Special Olympics provides children and adults with and without DD/ID with the opportunity to participate in various sports training and competitions. Being on a Special Olympics team has many added benefits outside of physical activity, including supporting leadership and teamwork skills, while developing friendships and connecting with the community.

Young Athletes (Ages 2-7)

Special Olympics Young Athletes is an early childhood play program for children with and without DD/ID, ages 2 to 7 years old. Young Athletes introduces basic sport skills, like running, kicking and throwing and offers families, teachers, caregivers, and people from the community the chance to share the joy of sports with all children.

Young Athletes provides children of all abilities the same opportunities to advance in core developmental milestones and supports development of a variety of skills, including motor, social, emotional and learning skills. Children learn how to play with others and develop important skills for learning. Children also learn to share, take turns and follow directions. These skills help children in family, community and school activities.

Sports and Unified Sports (Ages 8+)
Special Olympics operates sports training and competition programs for people with DD/ID across almost 200 countries around the world. Children and adults, starting at age 8, can participate in Special Olympics' sports programming in over 30 individual and team sports. Special Olympics athletes participate in regular training and compete in local, regional, national, or global competitions.

In addition to Special Olympics' traditional sports, Special Olympics Unified Sports brings people with and without DD/ID together to train and compete on the same team. Unified Sports is inspired by principles of inclusion and the belief that training together and playing together is a quick path to friendship and understanding.

Special Olympics sport and Unified Sports are easy ways to incorporate regular exercise and physical activity into your child's routine, while helping them improve in their self-confidence, teamwork and social skills.

Strong Minds
Strong Minds is an interactive learning activity focused on developing adaptive coping skills. This program is a part of Special Olympics and supports your child's emotional health and well-being. Through multiple activities which can be used at home or at school, individually or in a group, your child will learn how to cope with stress.

Special Olympics Resources:

- Find Special Olympics Near You
- Young Athletes Introduction
- Young Athletes at Home
- Special Olympics Sports
- Unified Sports
- Strong Minds Activity Guide

Parents and Family at Home

Children with developmental delays (DD) and intellectual disability (ID) will benefit from a supportive environment at home that helps them learn and develop. While therapies and interventions will be important for your child's development, there are many ways you can support your child's needs and development from home.

BUILDING A POSITIVE HOME ENVIRONMENT

At home, you can create an environment that encourages creativity and the exploration of new skills. Starting with your child's preferred activities and gradually expanding to other tasks as well as gradually increasing the task difficulty will maintain the child's interest and build confidence, support positive self-esteem, and improve motivation to learn.

Consider the following tips to help build a positive, supportive environment at home:

- Be patient
    - Allow your child to have additional time when solving problems or being presented with a difficult task
    - Break down difficult tasks into smaller steps
    - Be aware of your child's needs, but also challenge them to grow
    - Modify expectations according to your child's individual skills and support progress, big or small
    - Increase expectations as your child masters one skill to the next
- Be engaged in conversations and activities with your child
    - Talk and listen to your child
    - Ask for your child's thoughts and wait for the response
    - Teach instead of show
    - Follow the child's lead when they initiate play with you
- Create a positive environment
    - Focus on your child's strengths and interests, while supporting his or her weaknesses
    - Use unexpected events as a learning opportunity to teach your child new skills
    - Prioritize positive feedback when shaping your child' s development and behavior

EXAMPLES OF ACTIVITIES FOR PARENTS AND CAREGIVERS TO LEAD AT HOME

Here are some beneficial activities you can practice with your child at home:

- Talk, read, sing songs and engage in interactive and imaginative play for language development
- Encourage your child to draw, copy shapes, write and build with blocks, Legos or puzzles to improve hand function
- Walk, run, jump, climb on playground equipment, dance, swim, do gymnastics, martial arts, or any sport to improve strength of large muscles of the body and movement coordination
- Have interactive playdates with other children or siblings to teach your child to share their toys, help others, show compassion, and improve social skills
- Teach your child eating and dressing skills, self-hygiene (brushing teeth, washing hands, and taking shower), and developmentally appropriate household tasks (cleaning toys, making the bed, setting the table, feeding the pet) for independence skills

Addressing sensory processing issues may reduce behavioral difficulties and anxiety and improve attention, learning, and social engagement. Here are some suggested interventions:

- Wear noise cancelling headphones or avoid noisy environments may help children sensitive to noises
- Children with short attention spans may benefit from a break during homework to allow them to jump or move around
- Wear a weighted vest or providing a massage may calm a child who is anxious

Some examples of ways to help you improve your child learning new skills:

- Teaching one skill at a time
- Engaging the whole family in certain activities that will help the child learn
- Rewarding and acknowledging the child’s progress
- Employing different senses in the teaching approach such as hearing, seeing, and feeling.
- Modelling desired behavior for your child

CONNECTING WITH OUTSIDE RESOURCES

Providing care for a loved one with DD/ID can sometimes be overwhelming. Many resources are available within your local school district, early intervention services, social work services, primary care physician, or local department of mental health.

There are several resources which may be helpful to you:

Early Intervention Programs

- Organizations that coordinate services and support for those with developmental disabilities and provide case management (more information from CDC)

Respite Care

- Temporary care options that give primary care providers a break
- Options include in-home, out-of-home, adult day care, emergency respite, volunteer companion program
- Locate your state's Respite providers and programs

Home-based Services

- Medicaid mandates home health services which improve health conditions under the term "medical necessity"
- Speak with physician, social worker, or patient advocates to identify and pay for essential health benefits

Patient Advocates

- An individual or organization who helps patients navigate health systems, including insurance, appointments, and communication with medical professionals
- Can be provided by insurance companies, hospitals, or independent organizations like Patient Advocate Foundation
- For information about patient advocates, you can check with the local parent support group and the child's primary care physician

Parent Mentors

- Match with parents who have children with disability
- Help new parents navigate support systems and resources for their child
- For information about parent mentors, you can check with the local parent support group and the child's primary care physician

Parent Training

- Improve parents' ability to teach and engage with their children
- Technical Assistance Alliance for Parent Centers is a hub for parent technical assistance centers, which are funded under IDEA

Next Steps

The following section includes content covering the following areas:

Working with Your Health Provider	Parent Support Groups	Create an Action Plan	Taking Care of Yourself
• Information about how to work together with your child's health provider	• Information about the role of parental support groups and importance of collaborating with other parents	• Information about creating an outline for next steps following your child's diagnosis	• Information about the importance of self-care for parents and caregivers

Working with Health Providers

COMMUNICATION

Tips to improve communication with your child’s physician:

- Ask questions about your child's condition
- Ask for written information about your child's condition with specific web links, books, or handouts
- Clarify what you do not understand
- Make a follow up appointment
- Bring a list of questions and concerns about your child to discuss with your healthcare providers
- Ask for specific recommendations and referral for intervention
- Keep a copy of all medical evaluations and recommendations
- Create a passport with all the dates of diagnosis, treatments and contact information for providers and bring it with you when you go to an appointment

FINDING THE RIGHT PHYSICIAN

Qualities of a good physician for your child:

- Accessible for communication outside of appointments
- Provides options for communication: email, messages through online medical chart, phone
- Responds promptly to your requests
- Provides clear verbal and written instructions
- Asks for your opinion
- Creates a partnership in decision making
- Ready to listen
- Supportive, compassionate, and knowledgeable
- Provides timely copies of evaluations, referral and support letters
- Being able to advocate for your child
- Being able to collaborate and refer to another specialist
- Connecting with other team members such as teachers, therapists or other medical providers

ESTABLISHING A MEDICAL HOME

Children with DD/ID have ongoing and complex medical, educational and psychological needs and would benefit from having a medical home. The Medical Home is a way to provide care for all your child's needs by a primary care team and in direct collaboration with the patient and family.

The medical home can be provided by the primary care physician or by a medical specialist such as a Developmental Behavioral Pediatrician and may also include a nurse or social worker. It provides ongoing coordination of care, follow ups, and support for the family.

Parent Support Groups

Support groups can connect families to others with similar experiences. These groups can provide practical, emotional, and social support to individuals with ID, caregivers, and families. Support groups vary in scope and purpose. They can be specific to a location (i.e., local chapter of a larger organization, or an independent support group for a smaller community), or national organizations. Some solely seek to connect families, while others host events or advocate for their community. Some groups are specific to a diagnosis, while others are focused on a broader range of developmental disabilities.

A few examples of support groups include:

- *Special Olympics*: Educates, connects, and supports families through Family Forums and other connection opportunities.

- *Parent to Parent USA*: Provides emotional and informational support to families of children who have special needs, most notably by matching parents seeking support with an experienced, trained "Support Parent"
- *Family Voices*: A national network of state-based organizations focusing on family-centered care for children with disabilities and special needs.
- Diagnosis-specific support and advocacy groups that connect families.
  - *Autism Connection*
  - *Autism Speaks: Home*
  - *Autistic Self Advocacy Network*
  - *Brain Injury Association of America*
  - *The Arc*
  - *Prader-Willi Syndrome Association*
  - *My Child without Limits (part of United Cerebral Palsy)*

Create an Action Plan

After your child has received a diagnosis of ID/DD, it will help to create an action plan. Having an action plan that fits your child's needs and your priorities will empower you to navigate resources and develop an efficient intervention plan.

As you start building and implementing your action plan, it may help to remember that caring for a child with DD/ID is a marathon. Take it one step at a time and maintain your own pace to find what will help your child be most successful. View a sample action plan.

Taking Care of Yourself

While you are trying to give all the attention to address your child's needs, it is important to remember to take good care of yourself. Maintaining your own health will give you the strength to better support your child. A few ways to maintain your wellbeing may include: practicing mindfulness, exercising, spending time with your other children, spouse and friends, and taking time for yourself.

PRACTICING SELF-CARE

Self-care can look different for each person, but it is important to find activities that you enjoy and help manage your stress.

- Take quality time for yourself
    - Spend 30 minutes a day doing something for yourself (doing your hair, listening to music)
- Reflect on your day
    - Write in a journal
- Say daily, positive affirmations
    - Statements like "you can do this" or "today you did really great at…"
- Spend time doing your own hobbies
    - Running/sports, knitting, baking, fishing, etc.
- Get involved in your community
    - Volunteer in your community, join clubs (book clubs, Mommy & Me, etc.), spend time with friends and other adults
- Attend therapy or family support:
    - Talk to a professional, friend or family member when you are stressed
- Get enough sleep
    - The average adult should get between 7-9 hours of sleep a night.
- Eat well

  - A balanced diet will give you more energy, lower chances of diseases, like Type 2 diabetes and high blood pressure, and retain bone strength.
- Exercise regularly
  - Exercise helps a variety of different body functions, such as sleep, reduces anxiety and depression, and keeps you physically healthy
- Establish a good hygiene routine
  - Taking time to do your own personal hygiene each day will help you feel better and model good hygiene for your child
- Practice stress management techniques
  - Managing your stress can help decrease sleep problems, weight gain, and illness. You will live a healthier life and be ready to take on any challenges you may need to face
- Parental medical care:
  - Making sure you are taking care of your own personal medical needs and getting your annual check-ups will help you remain healthy, so that you can care for your child.

Consider more Self Care Tips for Families from Special Olympics Strong Minds.

MINDFULNESS

Mindfulness is when you focus on being aware of what you are sensing and feeling in the moment without interpretation or judgment. Some of the benefits of mindfulness are to reduce stress, anxiety, depression, and insomnia. Practicing mindfulness exercises can help you direct your attention away from negative thinking and more positively engage with the world around you.

Here are some simple ways to practice mindfulness:

- Pay attention to your surroundings when doing a task.
  - For example, when you are on a walk, make sure to look around and appreciate your surroundings. Appreciate the fresh air, the smell of flowers, and the warmth of sunshine.
- Live in the moment.
  - For example, when you are on your walk try not to use your phone and just enjoy the time with yourself.
- Accept yourself.
  - For example, when you are on your walk try to think of positives in your life.
- Focus on your breathing.

    - For example, when you are on your walk remember to take deep breaths and try to relax.

If you want to find more information about more structured mindfulness exercises, check out the Guide to Practicing Self-Care with Mindfulness.

MOTIVATION

Motivation is the driving force that can help you achieve your goals. Every parent must identify their own priorities and what motivates them to overcome challenges.

Tips for parents:

- Talk to a psychologist, friend, or family member to identify what motivates you to overcome any of life's barriers.
- Learn from other families on how they motivated themselves
- Everyday, identify a strength or success achieved by your child
- Remember that even a small home intervention can make a difference in your child's progress
- Remind yourself that you are the best advocate and expert in knowing and understanding your child's needs.
- Use of reflective parenting approaches

If you want to find more information about reflective parenting approaches, visit the Center for Reflective Communities.

Understanding My Child's Future

Individuals with developmental delay (DD) and intellectual disability (ID) can lead fulfilling lives. With the right preparation, many individuals with ID can attend school, live independently, work in their communities, and show us their unique perspective and experience of the world.

They can also accomplish great feats:

- John Lee Cronin owns a sock company with his father called John's Crazy Socks
- Zachary Valentine is a social media star on Tik Tok and Youtube
- Zack Gottsagen starred in the movie Peanut Butter Falcon
- Madeline Stuart is a Down syndrome model and has worked in New York and Paris Fashion Week
- Chris Nikic completed an IronMan, becoming the first person with Down syndrome to do so
- Rion Holcombe graduated from Clemson University
- Lucy Mayer - US Fund for UNICEF Spokesperson for Children with Disabilities

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