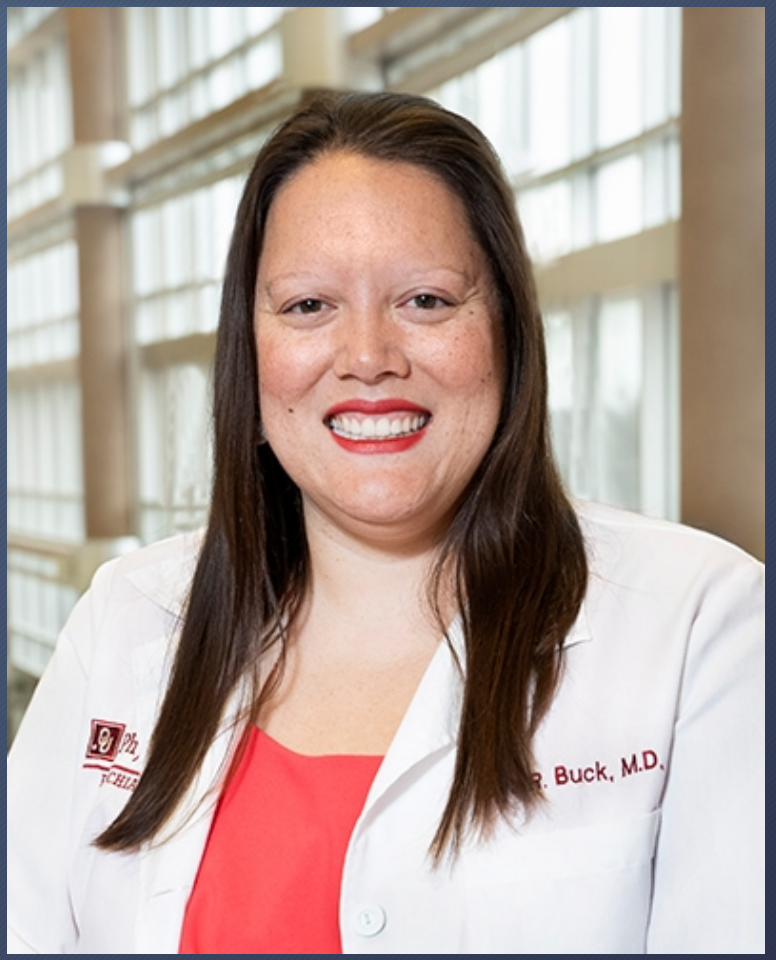
Working with children and families with developmental disabilities: Using a family centered and community based approach

Tara R. Buck, M.D.
Associate Professor
Child & Adolescent Psychiatry
OU-TU School of Community Medicine

Introduction-Dr. Buck OU Health

- Tara R. Buck, M.D.
- Associate Professor
- Program Director Child and Adolescent Psychiatry
- Core Faculty, Oklahoma LEND,
- Oxley Foundation Chair in Child & Adolescent Psychiatric Research



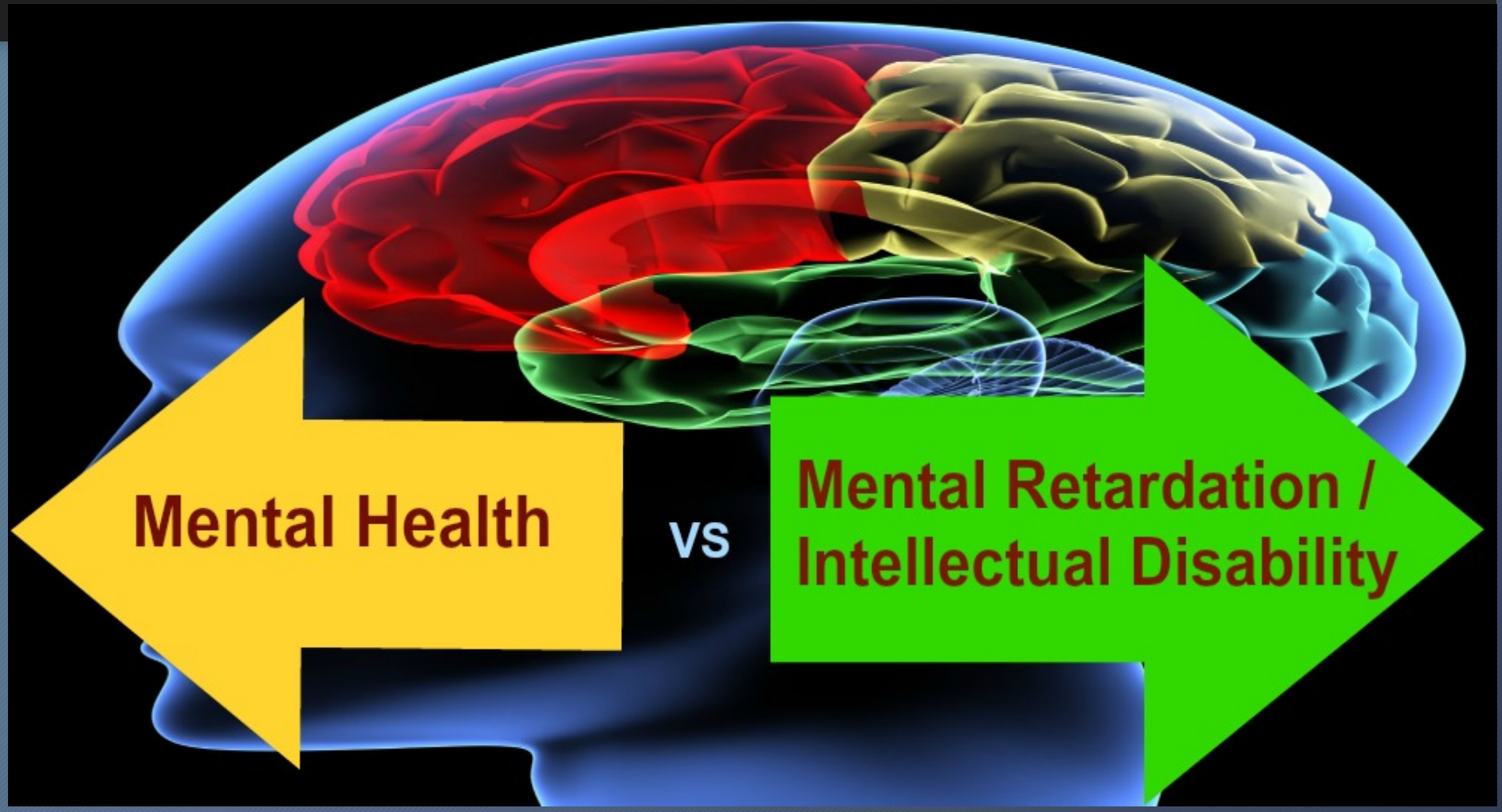
Disclosures

- I have no financial disclosures or conflicts of interest.

Objectives

- Recognize the utility of a dual diagnosis approach in treating mental health conditions in individuals with developmental disabilities
- Review common mental health disorders and how they may manifest differently in individuals with developmental disabilities
- Describe how community members can play an active role in the treatment and advocacy for individuals with DDs
- Review community resources for people with developmental disabilities in Oklahoma

Dual Diagnosis



Mental Health Disorders in Individuals with Developmental Disabilities

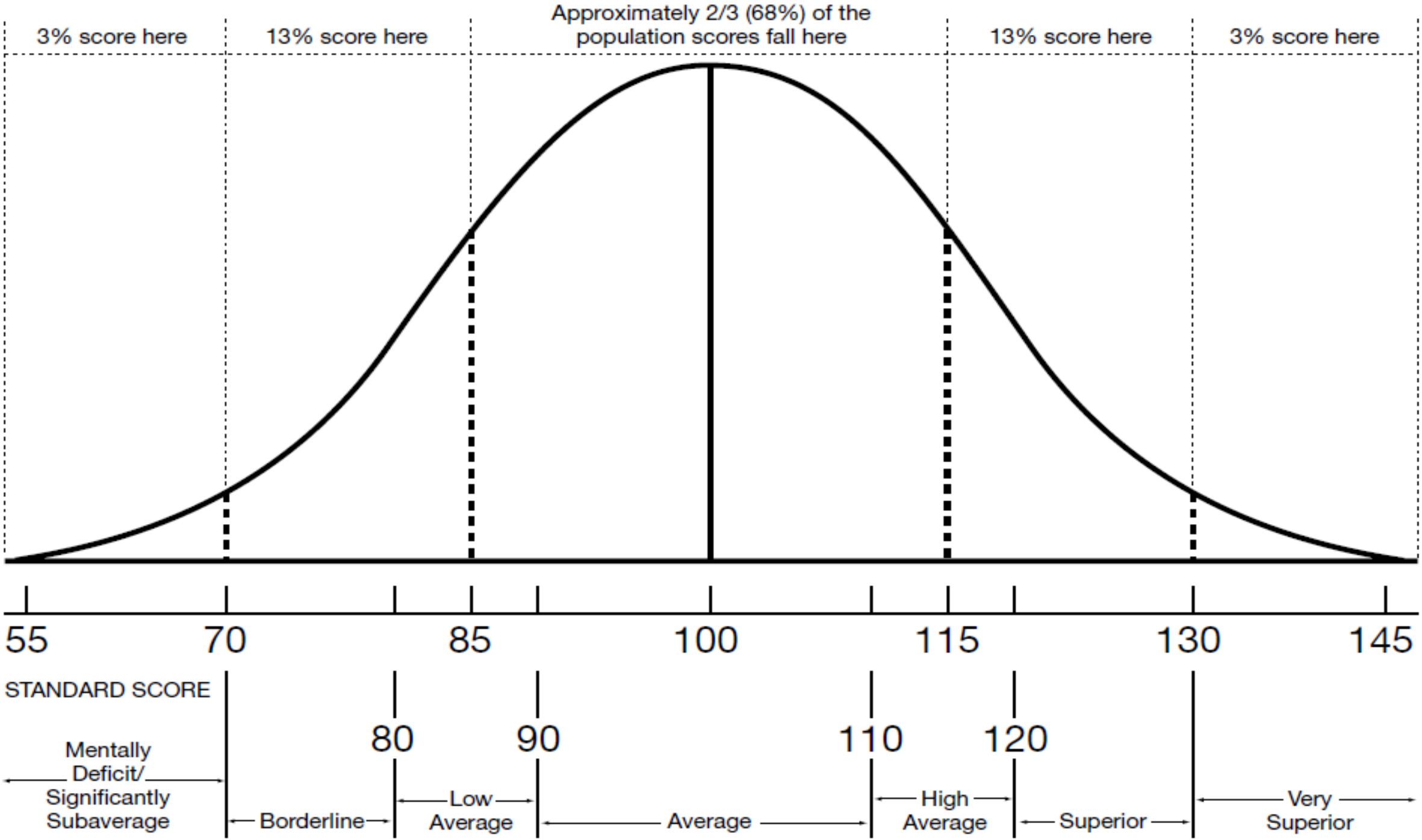
- Prevalence of mental health disorders in individuals with ID/IDD is 4-5 times higher than the general population (Rush et al, 2004)
- Psychiatric illnesses were present in 10-40% of individuals with ID (Rojahn & Tasse, 2002)
- Twenty to thirty-five percent of non-institutionalized individuals with ID have a comorbid psychiatric disorder compared to 15-19% of the general population (Graziano et al, 2002)

Co-occurring developmental disabilities

- Intellectual Disability/Intellectual Developmental Disorder
- Autism Spectrum Disorder
- Intellectual Disability + Autism Spectrum Disorder

Intellectual Disability (Intellectual Developmental Disorder)

- To make a diagnosis of Intellectual disability in DSM 5 (Intellectual Developmental Disorder), one must have 3 things:
  - Deficits in intellectual functions confirmed by clinical assessment and individualized, standardized intelligence testing, i.e. IQ score less than 70 (+/- 5 point margin of error)
  - Increased emphasis on deficits in adaptive living skills: social, practical, and conceptual domains.
  - Symptoms begin in childhood or adolescence.


3% score here
13% score here
Approximately 2/3 (68%) of the population scores fall here
13% score here
3% score here
55
70
85
100
115
130
145
STANDARD SCORE
80
90
110
120
Mentally Deficit/ Significantly Subaverage
Borderline
Low Average
Average
High Average
Superior
Very Superior

Adaptive Behavior

Domains and Index	Subdomain
Communication	Receptive Expressive Written
Daily Living Skills	Personal Domestic Community
Socialization	Interpersonal Relationships Play and Leisure Time Coping Skills
Motor Skills	Fine Gross
Maladaptive Behavior Index	Internalizing Externalizing Other

Severity Levels

Intellectual Disability	Approximated Developmental Age
Mild	9-12 years old
Skills for some self-support, needs assistance under stress	
Moderate	6-9 years old
Needs sheltered conditions, can reach ~2nd grade academic level	
Severe	3-6 years old
Minimal self-care, poor motor/ language development, full supervision needed, may form attachments to caregivers	
Profound	<3 years old
Needs 24/7 supervision, may form attachments to caregivers	

What is Autism Spectrum Disorder?

- Persistent deficits in social communication and interactions
- Restricted/repetitive interests or patterns of behavior
  - Symptoms must:
    - Be present during early development
    - Cause clinically significant impairment in functioning
    - Not be explained by intellectual disability or global developmental delay.
- Deficits range from mild to severe.

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5); American Psychiatric Association, 2013.

Examples of Social Skills Delays in ASD

- Doesn't keep eye contact or makes very little eye contact
- Doesn't respond to a parent's smile or other facial expressions
- Doesn't look at objects or events a parent is looking at or pointing to
- Doesn't point to objects or events to get a parent to look at them
- Doesn't bring objects of personal interest to show to a parent
- Doesn't often have appropriate facial expressions
- Unable to perceive what others might be thinking or feeling by looking at their facial expressions
- Doesn't show concern (*empathy*) for others
- Unable to make friends or uninterested in making friends

Examples of Communication Delays in ASD

- Doesn't say single words by 16 months
- Repeats exactly what others say without understanding the meaning (*often called parroting or echoing*)
- Doesn't respond to name being called but does respond to other sounds (*like a car horn or a cat's meow*)
- Refers to self as "you" and others as "I" and may mix up pronouns
- Often doesn't seem to want to communicate
- Doesn't start or can't continue a conversation
- Doesn't use toys or other objects to represent people or real life in pretend play
- May have a good rote memory, especially for numbers, letters, songs, TV jingles, or a specific topic
- May lose language or other social milestones, usually between the ages of 15 and 24 months (*often called regression*)

Examples of restricted, repetitive behaviors/interests/activities

- Restricted or fixated interests
- Insistence on sameness, routines or patterns of verbal/nonverbal behavior
- Stereotypic movements, use of objects (lines toys/spinning), or speech (echolalia/idiosyncratic speech)
- Sensory issues

DSM-5: ASD as a Continuum

- Levels 1 through 3: Social Communication and Restricted interests and Repetitive Behaviors

- With or without accompanying language impairment
- With or without accompanying intellectual impairment
- Associated with a known medical or genetic condition or environmental factor

Autism is on the rise…

- ASD affects 1 in 44 children in the U.S.
- Increase in prevalence since the 1990s
- Affects more than 5 million American adults-boys 4x more likely
- Average age of first diagnosis: 4.5 yo

MMWR Surveillance Summaries March 28, 2014 / 63(SS02);1-21 MADDSP: Metropolitan Atlanta Developmental Disabilities Surveillance Program

Autism and Developmental Disabilities Monitoring Network (ADDM)

- **Objective: To understand the magnitude and characteristics of the population of children with autism and related developmental disabilities**
- ▫Currently there are 11 funded ADDM sites, plus CDC/MADDSP
- ▫Autism prevalence among 8 year olds is monitored in all sites
- ▫Piloting autism surveillance among 4 year olds in six sites
- ▫Some sites track Cerebral Palsy (4) or Intellectual Disability (7)

Current ADDM Network Sites, Surveillance Years 2010 and 2012

Monitoring 8 year olds

Monitoring 4 and 8 year olds

Autism

Autism, Cerebral Palsy

Autism, Intellectual Disability

Autism, Cerebral Palsy, Intellectual Disability, Vision Impairment, and Hearing Loss

CS229603-A

ADDM = Autism and Developmental Disabilities Monitoring

AAP Screening Recommendations

- Well child visits for all children should include:
  - Developmental monitoring (informal probing about development and behavior at every well-child visit)
  - Developmental Screening: Autism specific screening when children are at 18 and 24 or 30 months of age
  - However, children should be evaluated at any age if a parent or professional has concern about the possibility of an ASD.

AAP Policy Statement on Developmental Screening (2006)
AAP Clinical Report on Diagnosis of Autism (2007)

Screening and Assessment Cont.

- Medical assessment of children with ASD should include a comprehensive physical examination, hearing screen, and genetics evaluation.
- Additional evaluations are warranted if there are unusual symptoms such as history of developmental regression, facial dysmorphology, staring spells/seizures, or family history of disabilities/genetic syndromes). [15]
- American Academy of Pediatrics Surveillance and Screening Algorithms for ASD: https://pediatrics.aappublications.org/content/120/5/1183

What can we do to support people and families with developmental disabilities?

Typical challenges someone with DDs may face

- Stress and Daily Life
- Multiple living environments
- Separation from families and communities at a young age
- Disrupted or unstable relationships
- Abuse, mistreatment, or neglect

Challenges in making a mental health diagnosis

- 1) Mental health and behavioral disorders can be difficult to diagnose.
- 2) There are systemic challenges.
- 3) Mental health issues are often overlooked.

Health & Social System Limitations

- Healthcare and support systems often fall short.
- Lack of providers with expertise in working with these individuals.
- Access issues
- Changes in residence or frequent hospitalizations can disrupt continuity of care.
- Budget issues may reduce or terminate services.

Overlooked psychiatric issues

- Many people overlook the need for mental wellness in people with developmental disabilities.
- Informed staff and professionals are needed to bridge the gap between mental health and disabilities' service structures.

Steps Towards Understanding

- Work to understand the **meaning or function** of the behavioral problems.

STEP ONE

Make a list of all the possible **reasons** for the person's challenges.

- Use family members and staff as part of the team.
- Think like a detective.
- Verify they have a primary care provider and are being evaluated medically on a regular basis.

Possible reasons for behavioral regression:

- Environment (new staff member/client, change in housing, change in routine, different expectations)
- Sleep
- Medical condition/sensory sensitivities
- Medication side effect
- Language deficit that can be addressed
- Trauma/abuse
- Treatable mental health condition such as anxiety or ADHD
- Puberty

Medical Comorbidities

- Assess for common medical conditions
  - Injuries
  - Tooth or ear infections
  - UTI
  - Allergies
  - Headaches
  - Reflux
  - Sleep disorders and disturbances
- GI problems 7-80%
- Epilepsy 8-30% (peak onset early childhood and adolescent)
- Genetic disorder specific medical problems

STEP TWO

- Consider the person's developmental level and goals and achievements appropriate to their developmental needs.

Severity Levels

Intellectual Disability	Approximated Developmental Age
Mild	9-12 years old
Skills for some self-support, needs assistance under stress	
Moderate	6-9 years old
Needs sheltered conditions, can reach ~2nd grade academic level	
Severe	3-6 years old
Minimal self-care, poor motor/ language development, full supervision needed, may form attachments to caregivers	
Profound	<3 years old
Needs 24/7 supervision, may form attachments to caregivers	

STEP THREE

- Consider the person's emotional development and how the person's experiences and history may impact the current situation.

Trauma & Abuse

- Children with disabilities are at least three times more likely to be abused or neglected than their peers without disabilities (Jones et al., 2012)
- Not all forms of disability carry the same level of risk, and not all children diagnosed with the same type of disability experience maltreatment equally.
  - For example, children with disabilities such as attention deficit/hyperactivity disorder, may be vulnerable to physical abuse by parents or caregivers who may become frustrated by their behavior.
  - Children who rely on adults for their care, as well as children who are nonverbal or hearing impaired, may be more likely than others to experience neglect or sexual abuse (Centers for Disease Control and Prevention, 2017).

Risk Factors for Abuse/Neglect

- Disabilities may result in feelings of isolation and powerlessness in children that prevent them from reporting abuse (Palusci, Datner, & Wilkins, 2015).
- Limited ability to protect themselves or to understand what maltreatment is or whether they are experiencing it (Lightfoot, 2014)
- Older youth with disabilities have higher rates of placement instability, longer stays in foster care, and decreased likelihood of reunification (Hill, 2012; Steen & Harlow, 2012).
- Children with disabilities may face increased risk of sexual abuse due to their placement in isolating environments (e.g., group homes, long-term-care facilities, hospitals) that allow easy access by others. (High staff turnover, decreased opportunity for staff to become familiar with the children and recognize changes in their behavior or demeanor indicative of maltreatment (Palusci et al., 2015).

Evaluate for Trauma/Abuse

- Look for gross signs of bruising on exam
- Inadequate hygiene/cleanliness
- Screen for inadequate community resources that may be leading to caregiver burnout
- Ask the individual themselves if possible. Interviewing alone may be needed.

Co-occurring mental health conditions

- Anxiety disorders
- OCD
- Attention Deficit Hyperactivity Disorder
- Insomnia
- Depression/Adjustment disorders
- Bipolar disorder/Psychotic disorders

- How has this current presentation deviated from their baseline functioning?

Behavioral Interventions

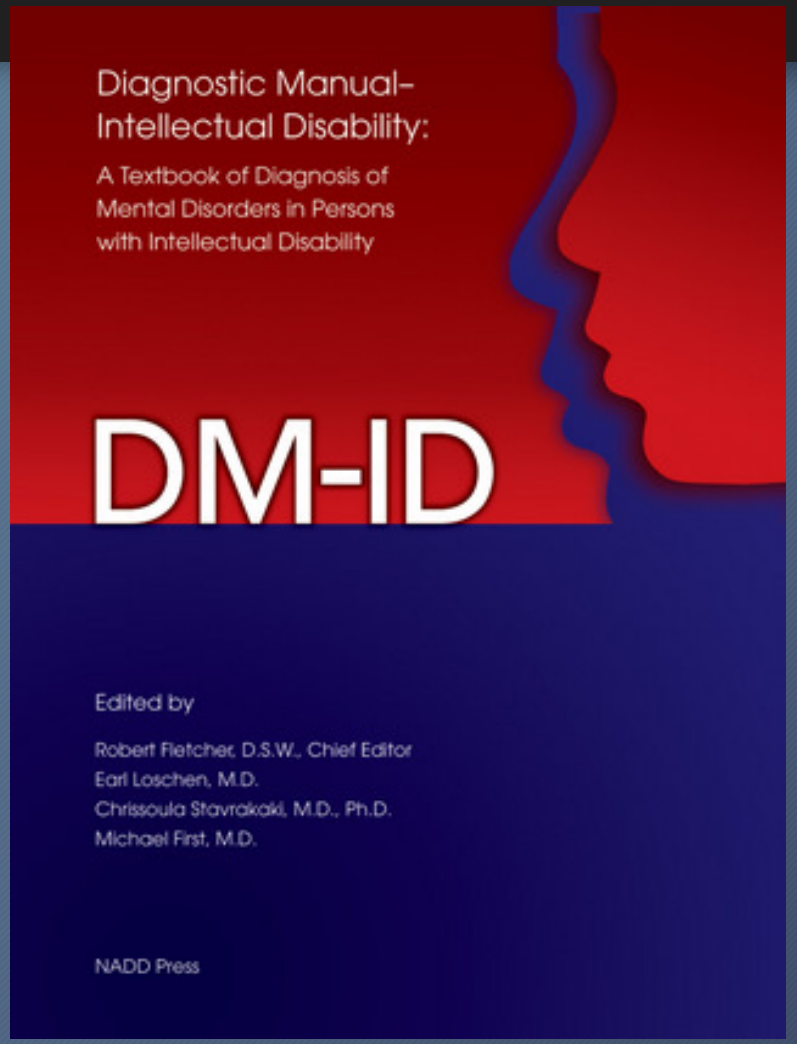
- *Social Skills & Social Cognitive Training:* Group or individual instruction by speech/occupational therapists and other providers can be used to treat children with ASD strategies to interact with others and strengthen understanding of others' perspectives.

- *Life Skills:* Daily life skills can be taught by occupational therapists and other providers. [12]

- *Cognitive-Behavioral Therapy:* CBT has shown efficacy for anxiety and anger management in high functioning youth with ASD.[1]

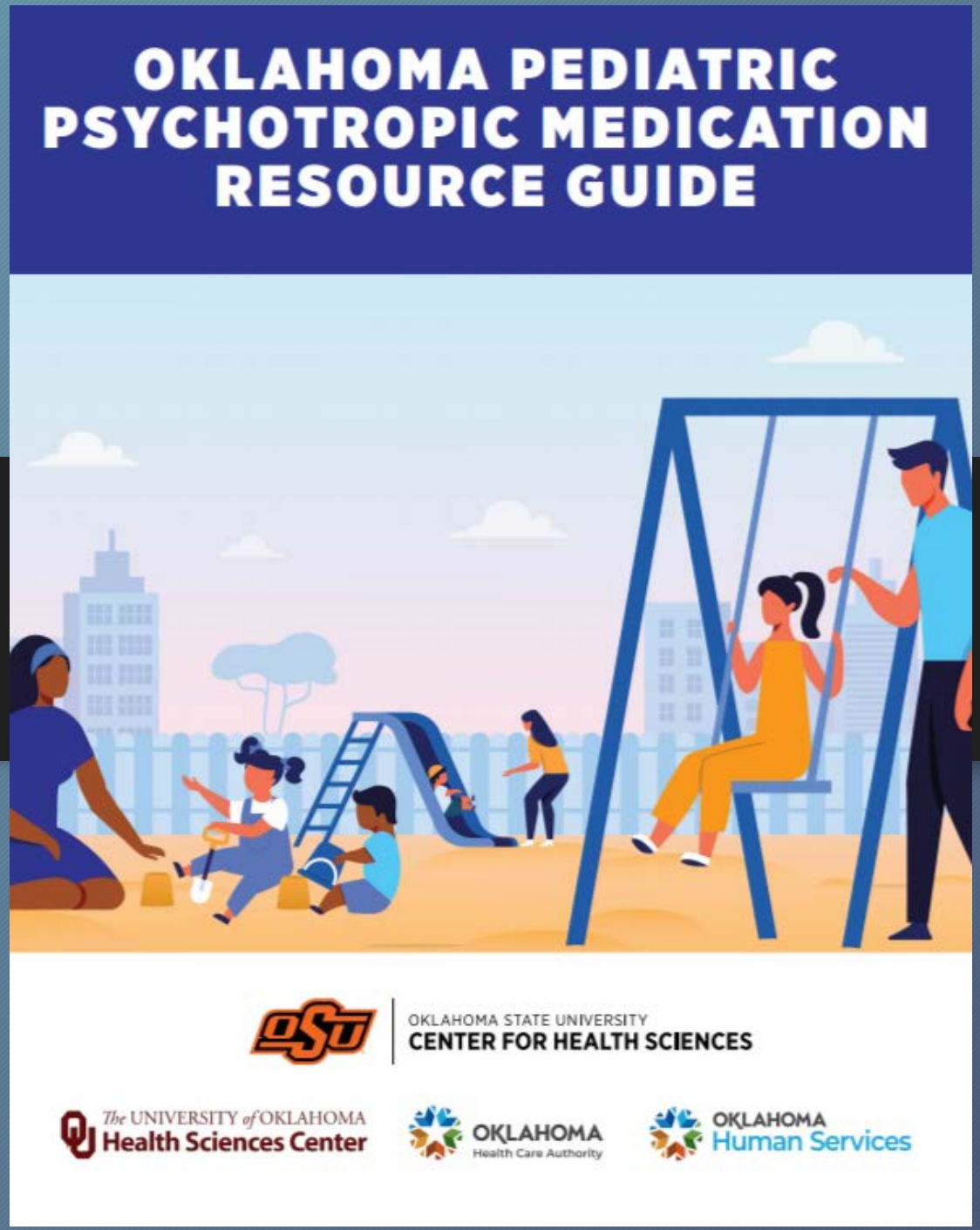
- *Parent-Child Interaction Therapy:* PCIT has shown efficacy for children under age 7 with ASD who also have inattention, hyperactivity, defiance, tantrums, and aggression. [8]

Co-occurring psychiatric conditions



Important Tips

- ****Do not confuse psychosis with autism features of self-talk, rehearsal of past conversations, soliloquy, fantasy or flashbacks as in PTSD***
- ***Especially important not to ask the patient leading questions***
- ***Obtain collateral information to establish validity***



https://medicine.okstate.edu/academics/psychiatry/documents/psychotropic-medication-guidelines-pages-final.pdf

STEP FOUR

- Use a person/family centered collaborative approach when diagnosing and treating conditions.
- Lots of collaborative problem solving and setting appropriate expectations!
- Focus on potential for caregiver burnout and community resources

Potential team members

- Client and family
- Primary care provider
- Mental Health/Behavioral Therapist
- Case manager
- Psychologist
- Psychiatrist
- School professionals (IEP/504)
- Occupational Therapist
- Speech Therapist
- Physical Therapist
- Community advocate
- Respite care

Verify their developmental disability diagnosis

- 1) Ask to review any developmental specialist assessments: educational assessment/psychological testing assessment
- 2) Verify that formal cognitive/achievement testing was completed to rule in or out Intellectual Disability/Learning Disabilities
- 3) Ask to see a copy of the student's IEP if available.
- 4) Ask about any developmental services being obtained such as speech therapy, occupational therapy, physical therapy, or ABA therapy.

When to refer to speech therapy?

-Ask the parents if they are concerned about their child's communication/language development.

-If so, encourage the family to ask their PCP for a referral to a SLP assessment

a) early intervention (Soonerstart)

b) outpatient clinic if insurance allows it

c) school's special education department (if the kid is older than 3)

Some pediatricians use standardized questionnaires (https://agesandstages.com/) at yearly check-ups so referrals can be made on time.

- "Also, a child with developmental disabilities at birth have probably been receiving services from a very young age, or at least they are on the PCP's radar for referrals. Another question behavioral therapists can ask the parent is whether their child has been receiving services and if the parents are satisfied with the services provided."

When to refer to speech therapy?

- CDC Pediatric Developmental Milestones https://www.cdc.gov/ncbddd/actearly/milestones/milestones-30mo.html
- ASHA Developmental Milestones https://www.asha.org/public/speech/development/chart/
- Example Video: https://www.youtube.com/watch?v=xiKYD9TSDhk

If expressive language is impaired:

- Engage in active listening.
- Reflect back to the speaker what they have said by paraphrasing or confirming that you understand.
- Summarize the message you heard from the person.
- Be patient and give the person time to express themselves.
- Don’t answer for the person.
- Don’t ask yes or no questions.
- Don’t get caught up in all the details, focus instead on the feeling.
- Be attentive to behavioral expressions.

If receptive language is impaired:

- Discuss one piece of information at a time. Then have the person repeat what was said in their own words.
- Use only examples that are familiar to the person.
- Use concrete language
- Use notes, pictures, cues, and symbols when communicating information.
- Encourage the person to keep a notebook with important information (notes, drawings, etc)

Language delays

- Assess nonverbal means of communication.
  - Sign language
  - PECS (Picture exchange communication system)
  - Proloquo/Tablet devices
  - Adaptive technology through AbleTech

Occupational Therapy

- OT is a therapy based on engagement in meaningful activities of daily life (such as self-care skills, education, work, or social interaction)
- Enables or encourages participation in these activities despite impairments or limitations in physical or mental functioning.
- Fine motor delays
- Sensory issues
- Social skills Training
- Social and emotional functioning basics
- Increasing independence with ADLs (Activities of Daily Living)

When to refer to occupational therapy?

- When a developmental issue or behavior is impacting the patient's ability to participate in anything they want or need to be able to do in their daily life!
- OTs can use CBT, task analysis, and other strategies to work on the barriers to daily occupations (including engagement in meaningful relationships)
- They use client history and contextual factors to determine what modifications and supports might help the individual.
- They can help with healthy routines, replacement skills, medication management, time management, etc.
- https://www.youtube.com/watch?v=YUdsgQGHSR8&t=260s

When to refer to physical therapy?

- A referral to Physical Therapy services may be warranted if:
  - Your child is not meeting motor milestones
    - https://www.cdc.gov/ncbddd/actearly/milestones/index.html
    - Not sitting by 10 months
    - Not walking by 15 months
  - Your child has trouble keeping up with peers on the playground
  - Your child has frequent falls or tripping
  - Your child walks on their toes frequently (greater than 50% of steps, at any age)
- https://www.youtube.com/watch?v=Ock2HTMkP9w&t=126s

When to refer to ABA therapy?

- Applied Behavior Analysis (ABA) is a therapy based on the science of learning and behavior
- Behavior analysis helps us to understand:
  - How behavior works
  - How behavior is affected by the environment
  - How learning takes place
- ABA therapy applies our understanding of how behavior works to real situations. The goal is to increase behaviors that are helpful and decrease behaviors that are harmful or affect learning.

What can ABA help with?

- ABA therapy programs can help:
  - Increase language and communication skills
  - Improve attention, focus, social skills, memory, and academics
  - Decrease problem behaviors
- The methods of behavior analysis have been used and studied for decades. They have helped many kinds of learners gain different skills – from healthier lifestyles to learning a new language. Therapists have used ABA to help children with autism and related developmental disorders since the 1960s.

What does ABA therapy look like?

- Applied Behavior Analysis involves many techniques for understanding and changing behavior. ABA is a flexible treatment:
- Can be adapted to meet the needs of each unique person
- Provided in many different locations – at home, at school, and in the community
- Teaches skills that are useful in everyday life
- Can involve one-to-one teaching or group instruction

Positive Reinforcement

- Positive reinforcement is one of the main strategies used in ABA.
- When a behavior is followed by something that is valued (a reward), a person is more likely to repeat that behavior. Over time, this encourages positive behavior change.
- First, the therapist identifies a goal behavior. Each time the person uses the behavior or skill successfully, they get a reward. The reward is meaningful to the individual – examples include praise, a toy or book, watching a video, access to playground or other location, and more.
- Positive rewards encourage the person to continue using the skill. Over time this leads to meaningful behavior change.

ABCs of Behavior: Antecedent-Behavior-Consequence

- An **antecedent**: this is what occurs right before the target behavior. It can be verbal, such as a command or request. It can also be physical, such a toy or object, or a light, sound, or something else in the environment. An antecedent may come from the environment, from another person, or be internal (such as a thought or feeling).
- A resulting **behavior**: this is the person's response or lack of response to the antecedent. It can be an action, a verbal response, or something else.
- A **consequence**: this is what comes directly after the behavior. It can include positive reinforcement of the desired behavior, or no reaction for incorrect/inappropriate responses.

Why A-B-Cs of behavior?

- Helps understand why a behavior may be happening
- How different consequences could affect whether the behavior is likely to happen again

- https://www.youtube.com/watch?v=7_ohTAaQON8&t=4s

When to refer to a psychiatrist?

- Many initial mental health concerns can be managed by primary care providers (Ex: anxiety, ADHD)
- Multiple mental health conditions (more complex presentations)
- If the patient only has partial response or no response to medication or therapy supports
- More severe mental health conditions (mood disorders, psychosis- most PCPs are not comfortable managing mood stabilizers/antipsychotic medications)
- When a patient has been stabilized in an acute psychiatric facility

When to refer to a psychologist?

- Psychologists can do both therapy and psychological testing assessments
- Comprehensive psychological testing (Cognitive/adaptive behavior)
- More complex patients that don't respond to transitional mental health therapies/interventions
- Psychologists cannot prescribe medications in the state of Oklahoma.

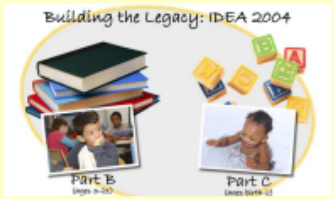
School Based Interventions

- Children with developmental disabilities can be served in school with 504 accommodation plans versus IEP
- Ask to review IEP or 504 plan
- Work to maximize parental engagement in educational settings and communication with school teams
- Get appropriate verbal releases so coordination can happen with teachers/para's, etc.
- Involve educational advocates when needed.

What is IDEA?

In 1975, the United States Congress passed legislation providing for the education and protection of children with disabilities in public schools. The law must be examined and reauthorized as the Individuals with Disabilities Education Improvement Act Amendments of 2004 (IDEA 04). It is also known as P.L. 108-446.

The law went into effect on July 1, 2004 and includes many changes designed to ensure that children with disabilities receive a high quality, free and appropriate education (FAPE).



http://idea.ed.gov/

On August 3, 2006 the final regulations implementing Part B of IDEA 2004 were made public.

Visit the OPC website:

www.OklahomaParentsCenter.org

Advocating for Children with Disabilities to

Mission Statement:

The Oklahoma Parents Center is dedicated to the equality of children and adults with disabilities. Our mission is to train, inform, educate and support parents, families, professionals and consumers in building partnerships that meet the needs of children and youth with the full range of disabilities ages birth through twenty-six.

IDEAs that Work

The contents of this brochure were developed, in part, under a grant from the U.S. Department of Education, #H328M100005.

However, those contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Greg Knollman.

This brochure is funded, in part, by a contract with the Oklahoma State Department of Education (OSDE). Views expressed in this brochure do not necessarily reflect the opinions of the OSDE.

EDUCATION

P.O. Box 512
Holdenville, Oklahoma 74848
www.OklahomaParentsCenter.org

Like us on Facebook at
https://www.facebook.com/OkParentsCenter/

Oklahoma Parents Center

Building Relationships…
Creating Successful Change!

Call us toll-free at
877-553-4332

Oklahoma Parents Center

Visit us at
www.OklahomaParentsCenter.org

What is the OPC?

The Oklahoma Parents Center (OPC) is a federally funded Parent Training and Information Center. We are funded through the US Department of Education, Office of Special Education Programs (OSEP) and Oklahoma State Department of Education (OSDE). We have been providing services to Oklahoma families of children with disabilities, their teachers and other professionals since 2000. Our PTI staff is here to help you navigate the Special Education Maze and provide you with the information and tools you need to be an informed and active participant in your child's education.

All services are provided <u>at no cost</u> to Oklahoma parents and families!

What is the Purpose of the OPC?

The purpose of the PTI project is to help Oklahoma parents and families:

- **<u>Better understand</u>** the nature of their children's disabilities and their children's educational, developmental, and transitional needs;
- **<u>Communicate</u>** effectively and work collaboratively with their child's educators and other professionals;
- **<u>Participate</u>** in decision-making processes, including those related to their child's Individualized Education Program (IEP);
- **<u>Understand</u>** about the range, type and quality of options, programs and services, technologies, practices and interventions that are based on scientifically-based research;
- **<u>Understand</u>** the resources available to assist their children at school and home;
- **<u>Understand</u>** their rights as provided under IDEA (the Individuals with Disabilities Education Improvement Act of 2004); and
- **<u>Participate</u>** in activities at the school level that benefit their children and to participate in parental involvement activities.

What Services do the OPC offer?

The OPC offers the following to parents, professionals, and consumers in Oklahoma:

- **Toll Free "Parent Info Line";**
- **Staff located throughout the state;**
- **Individual assistance with educational issues;**
- **Information and Referral; and**
- **Parent Education Workshops on a variety of subjects including:**
  - Writing an Effective IEP (Individualized Education Program)
  - Positive Behavior Supports
  - Effective Communication Skills
  - Transition to Preschool and Kindergarten Services
  - Transition to Adulthood
  - Basic Rights In Special Education
  - 504 - ADA
  - Bully Prevention and Solutions
  - And others, as requested

For more information or to schedule a workshop in your area:
Call toll free 877-553-4332

Email us:
info@oklahomaparentscenter.org

Oklahoma Department of Rehab

oklahoma.gov/okdrs.html

Registered Users Si... Home - University... Inteletravel Imported From IE Tulsa EMR CBT-NC COMAA -... Trial Retention Pape... Grants - All Docum... Nightmare Prevalen... SFMC Citrix

Translate

OKLAHOMA
Rehabilitation Services

Job Seekers Employers Students Independence Information Resource Guide Client Portal

Welcome to DRS

Oklahoma Department of Rehabilitation Services

OK Rehabilitation Services celebrates award winners' success at People with Disabilities Awareness Day

OKLAHOMA CITY – After a morning of visits with legislators at the state Capitol, 653 Oklahomans with disabilities, supporters and 93 volunteers convened for the 29th

DRS Services

- Transition planning assistance
- Vocational rehab assessments
- Summer programs: STEM camps, BEST STEP Summer Camps
- Assistance with Driver's Ed
- Stipends for comprehensive transition programs

What are we doing in Oklahoma to support families with developmental disabilities?

- Statewide programs: DDSD through DHS & Vocational rehab
- Social Security Disability
- SoonerStart
- SoonerSuccess
- Oklahoma Department of Mental Health and Substance Abuse
- Higher Education Institutions
- Legislative Advocacy

Developmental Disabilities Services Waitlist

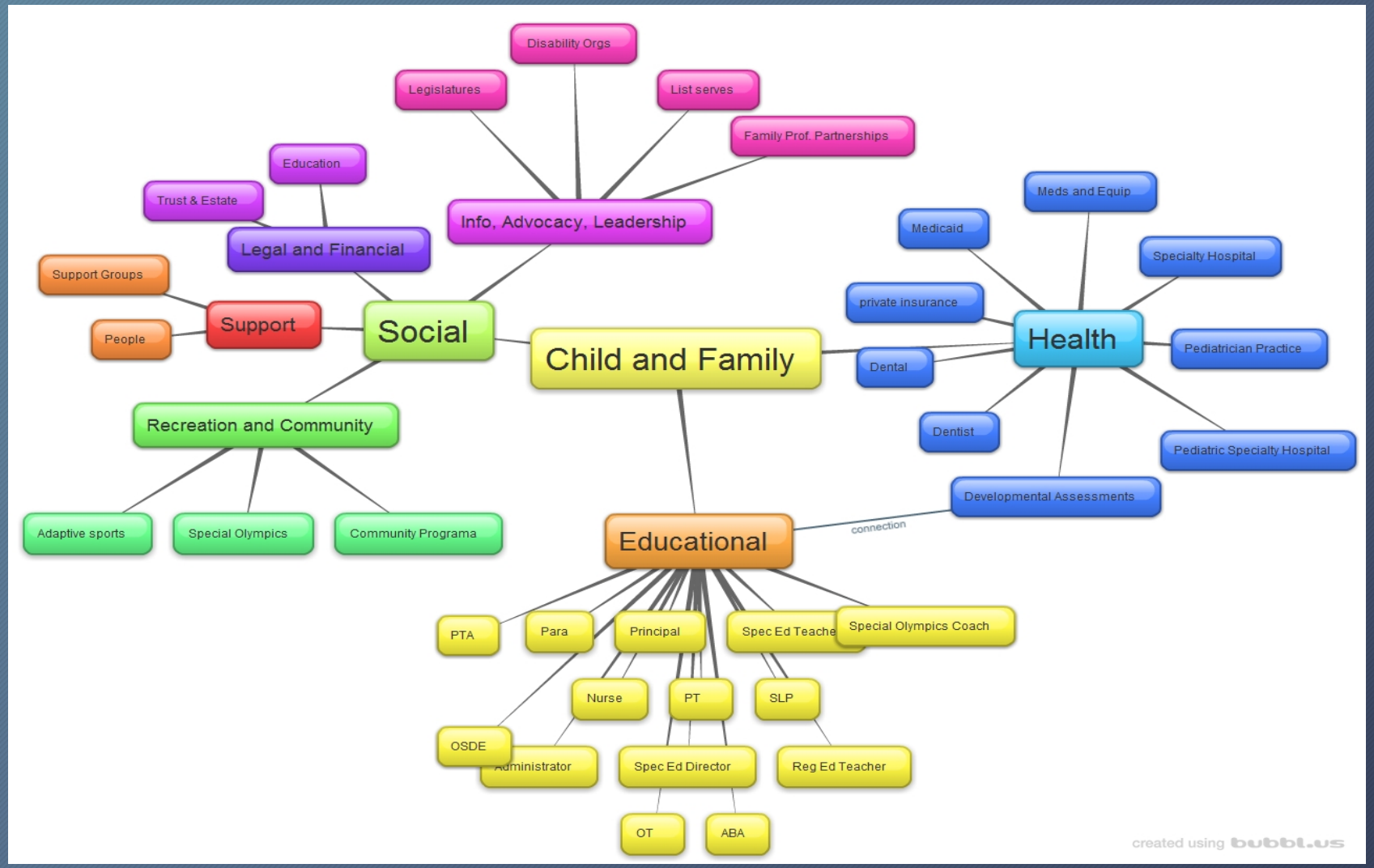
THE WAITLIST

In May 2022 there were over 5,100 families awaiting developmental disabilities services. The legislature appropriated $32.5 million to end the DDS wait list and increase provider rates. [Click here to read more about the budget agreement.]

The Arc's mission is to promote and protect the human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetimes. Services include:

Family Support
Self-Advocacy
Residential Monitoring
Advocacy & Public Policy
Support Groups

Sooner SUCCESS: helps navigate the healthcare system



Sooner SUCCESS Counties

Region 1:

- Blaine
- Canadian
- Kingfisher
- Garfield
- Major

Region 2:

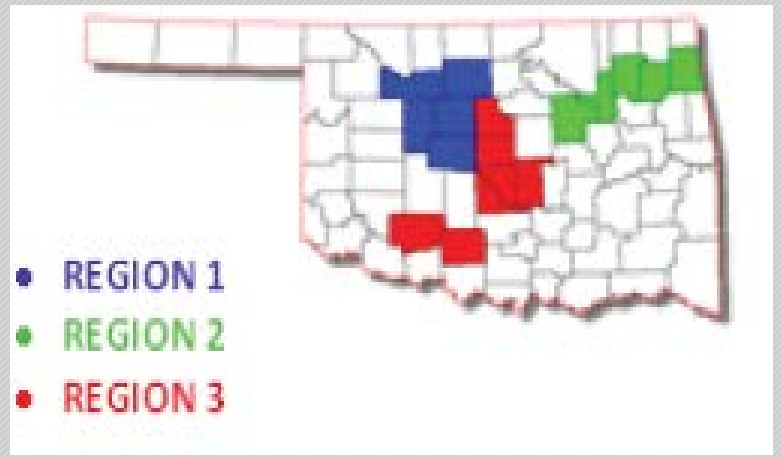
- Creek
- Delaware
- Mayes
- Rogers
- Tulsa

Region 3:

- Cleveland
- Comanche
- Logan
- McClain
- Oklahoma
- Pottawatomie
- Stephens

1-877-441-0434

soonersuccess.ouhsc.edu



SoonerSUCCESS:
Who we serve and What we do

- Serve families with children birth – 21
  - Developmental disabilities
  - Chronic/Special health care needs
  - Mental health needs
  - Abuse/neglect issues
- No “qualifying criteria”
  - No Income guidelines
  - No Insurance requirements
- Our services are free


CALL
OR
TEXT
988
MENTAL
HEALTH
LIFELINE
GENERAL TOOLKIT

988 is a direct, three-digit lifeline that connects you with trained behavioral health professionals that can get all Oklahomans the help they need.

GETTING HELP CAN BE HARD. SO WE MADE IT EASIER.

The mental health professionals on the other end of the line are here to help guide you.

1

CALL THE LIFELINE

It all starts when you call 988. You'll be connected to a mental health professional to talk you through what's going on and get the resources you need for either yourself or your loved one. About 80% of the time, things can get sorted out with just a phone call. But if you need more help, we got you.

2

IF NEEDED

CONNECT WITH A MOBILE CRISIS TEAM

If you or your loved one need more help after your initial phone call, the 988 call center will send a mobile crisis team to assess things and intervene if necessary. About 7 in 10 crises can be resolved at this touchpoint.

3

IF EVEN MORE HELP IS NEEDED

GET TRANSPORTATION

Some people need more in-depth care. If this is the case, transportation will be provided to help Oklahomans in need safely arrive at an Urgent Care and Crisis Center. In metro areas, transportation will be provided by law enforcement. If the closest center is more than 30 miles away, we'll connect you with a private transportation service to get you the help you need.

4

CHECK IN AT AN URGENT CARE AND CRISIS CENTER

For those of us that need higher touch help, an Urgent Care and Crisis Center has your back. These centers are staffed 24/7/365 with licensed local medical professionals, nurses, and peers who have been through it themselves. Every center accepts both drop-offs from first responders and walk-ins.

To learn more about how 988 works, visit **988oklahoma.com**

@988OKLA

Treatment Principles

- Children with DDs should be referred for treatment based on their individual needs.
- Treatments should be selected to address either core symptoms of their disability and/or co-occurring behavioral health concerns.
- Medical issues should always be ruled out before starting any treatment for emotional or behavioral problems.

Medication Treatments

- Though medications can be used to treat behavioral health symptoms and disorders in children with autism, no medication treats the core symptoms of autism.
- The goal of medication should be to improve the child's functioning and keep him/her in a less restrictive environment.
- **Children with developmental disabilities can be treated with psychotropic medications when there is a specific target symptom or co-occurring behavioral health condition.**

Treatment Principles

- Use an interdisciplinary mindset when treating individuals and families with developmental disabilities.
- No medication specifically addresses the core symptoms of ASD or ID. Children with DDs can be treated with psychotropic medications when there is a specific target symptom or co-occurring behavioral health condition.
- Oklahoma has many resources for people with developmental disabilities, but navigating them can be overwhelming for families.

Resources

State & National Resources:

- **Autism Focused Intervention Resources & Modules:** Free, online video training for use of evidence based practices with individuals with autism birth – 22. Includes parent guides.
- https://afirm.fpg.unc.edu/afirm-modules
- **Autism Speaks:** www.autismspeaks.org National advocacy organization for individuals with ASD providing helpful online resources and toolkits.
- **Autism Treatment Network Toolkits** https://www.autismspeaks.org/toolkit?resource_type[606]=606&article_type[2196]=2196&resource_type[606]=606&state[321]=321
- **OHCA Behavioral Health Provider Directory:** http://apps.okhca.org/providersearch/

QUESTIONS?

References

- Centers for Disease Control and Prevention. (2017b). Childhood maltreatment among children with disabilities. Retrieved from https://www.cdc.gov/ ncbddd/disabilityandsafety/abuse.html
- Danial JT, Wood JJ. Cognitive behavioral therapy for children with autism: review and considerations for future research. J Dev Behav Pediatr. 2013 Nov-Dec;34(9):702-15. doi: 10.1097/DBP.0b013e31829f676c. Review. PMID: 23917373
- Hill, K., Lightfoot, E., & Kimball, E. (2010). Foster care transition services for youth with disabilities: Findings from a survey of county service providers. Child Welfare, 89(6), 63–81.
- Hirsch LE, Pringsheim T. Aripiprazole for autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2016, Issue 6. Art. No.: CD009043. DOI: 10.1002/14651858.CD009043.pub3.
- Jan, J., & Freeman, R. (2004). Melatonin therapy for circadian rhythm sleep disorders in children with multiple disabilities: What have we learned in the last decade? Developmental Medicine and Child Neurology., 46(11), 776-782.
- Jesner OS, Aref-Adib M, Coren E. Risperidone for autism spectrum disorder. Cochrane Database of Systematic Reviews 2007, Issue 1. Art. No.: CD005040. DOI: 10.1002/14651858.CD005040.pub2.
- Johnson CP, Myers SM; American Academy of Pediatrics Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics. 2007 Nov;120(5):1183-215. Epub 2007 Oct 29. Review. PMID: 17967920
- Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy,

References

- Lightfoot, E. (2014). Children and youth with disabilities in the child welfare system: An overview. Child Welfare, 93(2), 23–45.
- E., Eckley, L., . . . Officer, A. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. Lancet, 380, 899–907. doi: 10.1016/S0140-6736(12)60692-8
- Mahajan R, Bernal M, Panzer R, Whitaker A, Roberts W, Handen B, Hardan A, Anagnostou E, Veenstra-VanderWeele J. Clinical Practice Pathways for Evaluation and Medication Choice for Attention-Deficit/Hyperactivity Disorder Symptoms in Autism Spectrum Disorders. Pediatrics Nov 2012, 130 (Supplement 2) S125-S138; DOI: 10.1542/peds.2012-0900J.
- McCracken JT, McGough J, Shah B, et al. Risperidone in children with autismand serious behavioral problems. N Engl J Med. 2002;347(5):314–321
- Mcneil, Cheryl & Quetsch, Lauren & Anderson, Cynthia. (2018). Handbook of Parent-Child Interaction Therapy for Children on the Autism Spectrum. 10.1007/978-3-030-03213-5.
- Ming, Xue & Gordon, Emily & Kang, Ning & C Wagner, George. (2008). Use of Clonidine in children with autism spectrum disorders. Brain & development. 30. 454-60. 10.1016/j.braindev.2007.12.007.
- Palusci, V. J., Datner, E., & Wilkins, C. (2015). Developmental disabilities: Abuse and neglect in children and adults. International Journal of Child Health and Human Development, 8, 407–428.
- Reichow B, Hume K, Barton EE, Boyd BA. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2018, Issue 5. Art. No.: CD009260. DOI: 10.1002/14651858.CD009260.pub3.
- Scahill, L., McCracken, J., King, B., Rockhill, C., Shah, B., Politte, R., . . . McDougle. (2015). Extended-Release Guanfacine for Hyperactivity in Children With Autism Spectrum Disorder. The American Journal of Psychiatry., 172(12), 1197-1206.
- Siegel, M. & C. Erikson, et al. Autism Parents' Medication Guide Work Group. Autism Spectrum Disorder: Parents' Medication Guide. American Academy of Child & Adolescent Psychiatry, 2016.

References

- Sturman N, Deckx L, van Driel ML. Methylphenidate for children and adolescents with autism spectrum disorder. Cochrane Database of Systematic Reviews 2017, Issue 11. Art. No.: CD011144. DOI: 10.1002/14651858.CD011144.pub2.
- Vasa, R.A., Carroll, L.M., Nozzolillo, A.A. et al. A Systematic Review of Treatments for Anxiety in Youth with Autism Spectrum Disorders. J Autism Dev Disord (2014) 44: 3215. https://doi.org/10.1007/s10803-014-2184-9
- Volkmar, Fred et al. (2014) Practice Parameter for the Assessment and Treatment of Children and Adolescents With Autism Spectrum Disorder. Journal of the American Academy of Child & Adolescent Psychiatry, Volume 53, Issue 2, 237 – 257.
- Williams K, Brignell A, Randall M, Silove N, Hazell P. Selective serotonin reuptake inhibitors (SSRIs) for autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2013, Issue 8. Art. No.: CD004677. DOI: 10.1002/14651858.CD004677.pub3.
- Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., … Schultz, T. R. (2014). Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder. Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.