

AFTER THE AUTISM DIAGNOSIS

**PROFESSIONAL RECOMMENDATIONS FOR TREATMENT
AND THE BARRIERS TO ACCESSING SERVICES**

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OBJECTIVES

Identify common
evidence based
treatment
reccommendations

Identify the barriers
caregivers face after
reciving an autism
diagnosis

Learn strategies for how
to bridge the gap
between reccommended
treatments and real-word
access

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WHAT'S THE POINT?

Increase the quality of life for the autistic individual and their family!

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EARLY INTERVENTION

- In some children, autism can reliably be diagnosed as early as 14 months
- Many well-documented benefits of EI
- FEDERAL LAW!
Individuals with Disabilities Education Act (IDEA): PART C
- Who is Eligible for EI?
 - Age 0-3
 - A delay in one or more areas of development
 - Informed clinical opinion
 - Known physical or mental conditions which have a high probability for developmental delays

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EARLY INTERVENTION

- Can and should be provided across contexts
- Individualized to each child's unique needs
Speech/language, occupational, physical, behavioral therapies, etc.
- CONNECT services at 1-800-692-7288.

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PRESCHOOL EARLY INTERVENTION

- Previously called DART in Allegheny County
- Who is Eligible?
 - ages 3-5
 - A delay in one or more areas of development (25%)
 - OR Any of the following physical or mental disabilities: autism/pervasive developmental disorder, etc.
 - AND In need of special education and related services.
- Developmental, speech/language, occupational therapy, physical therapy, vision, hearing, and family services.
- Provided through local IU/Head Start Classroom

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SCHOOL-BASED INTERVENTIONS & SUPPORTS

- Individualized Education Program (IEP)
 - FEDERAL LAW! Individuals with Disabilities Education Act (IDEA): PART B - 3 to 21 years
 - Goal-based
 - Family inclusion

Does not apply in the same way to private schools!

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SCHOOL-BASED INTERVENTIONS & SUPPORTS

- 504 Plan
 - Part of Section 504, Civil Rights Law
 - Must show evidence of a disability that requires accommodations
- An example of a 504 disability includes:
 - Receiving physician care for depression/anxiety/ADHD/other behavioral health challenges
- Not as rigorous as IEP
 - Accommodations rather than special education

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INTENSIVE BEHAVIORAL HEALTH SERVICES (IBHS)

Previously Behavioral Health Rehabilitation Services (BHRS) or “wraparound” services

3 categories of service:

01

Individual services

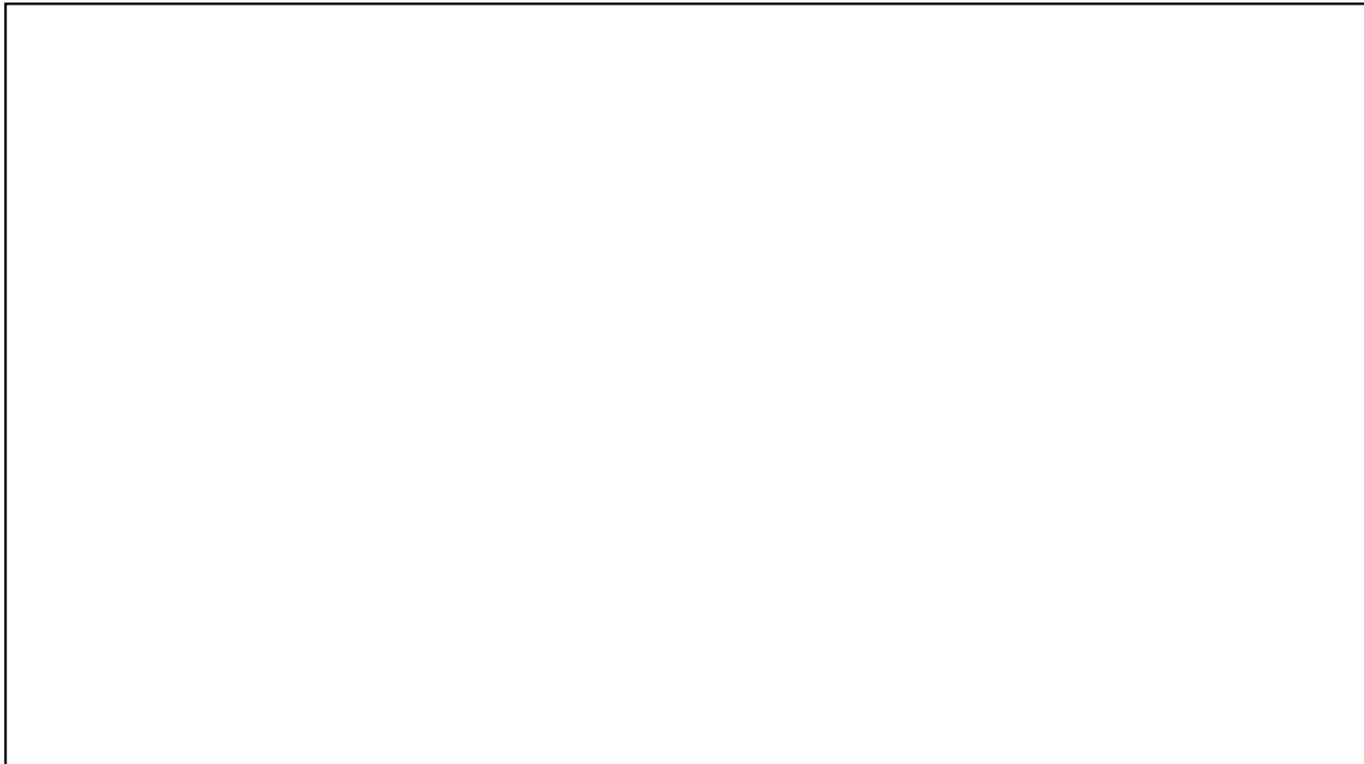
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Applied Behavior Analysis (ABA)

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Group services which are most often provided to multiple children at a specific place.

- Requires **WRITTEN ORDER** from physician/psychologist specifying **MEASURABLE GOALS**, support needs, and number of hours
- Services can be provided in the home, school or other community setting.
- Child must have Medicaid access card to access IBHS-ABA



IBHS-ABA

- Functional Behavioral Assessment (FBA)
- Behavior Analytic services
 - Behavior Consultation-ABA services (BCBA)
 - Assistant Behavior Consultation- ABA services (BCABA)
 - Behavior Health Technician-ABA services (BHT)
- Can be group based!

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PA CONSOLIDATED WAIVER - ODP

- Goal: to increase independent functioning at home and in the community
- Who is Eligible?
 - Individuals of any age with an intellectual disability (ID) or autism.
 - NEEDS BASED
 - Typically not prioritized until after high school graduation
- Specific Requirements
 - Dx of ID/autism/genetic condition
 - REQUIRES ADAPTIVE, COGNITIVE EVALUATION, APPROVED MEASURE FOR DIAGNOSING AUTISM
 - Medical evaluation

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INDIVIDUAL THERAPY

- Social skill building
- Addressing co-occurring mental health symptoms
- Anxiety, depression, OCD, emotion dysregulation, etc.
- Ideally provided by an individual familiar with autism
OR IN CONSULTATION with an autism expert
- Many evidence-based treatments require modifications for autistic individuals
- CADD or community practices

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GROUP THERAPY

SOCIAL SKILLS GROUPS

PEERS Curriculum at CADD (12 - 35)

Friendship groups at CADD (7 - 12)

WonderKids at Wesley Family Services (5-21)

Chatterbox Program at UPMC Children's Center for Independence

MINDFULNESS GROUPS

Open Up! Pittsburgh

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MEDICATION MANAGEMENT

- No medications treat the core symptoms of autism
- Medication management can be extremely useful for associated symptoms
- Hyperactivity/impulsivity, inattention, irritability, anxiety, depression
- Can support behavior/mood regulation to increase benefits from behavior therapies

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WHAT ELSE?

- Family-based mental health services
- Intensive outpatient programs
- Crisis supports
 - CACTIS through resolve
- Books/Web Resources
- Positive behavior strategies for caregivers to use at home
 - Visual supports
 - Reward systems
 - Coping skills

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THE PARENT PERSPECTIVE

Barriers to
Treatment

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OUR STORY

Born with bilateral clubfoot,
my son received PT 3x per week
Didn't meet developmental milestones until roughly
8 months - 1 year late per milestone
Involved in several forms of non-autism specific therapy

Help me Grow
Incredible Years
OT/PT/Speech
ADHD Diagnosis at age 4
Diagnosed with Autism at age 7
Fighting with schools to get IEP accommodations and SDI

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WHAT ARE SOME OF THE BARRIERS TO ACCESSING INTERVENTIONS?

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PROVIDER STIGMA

Autism stigma is primarily influenced by a public and professional understanding of autism in combination with interpretation of visible autistic traits.

Healthcare Microaggressions

“Treating children with autism is like navigating a minefield. You don’t know where the mines are buried and you don’t know if you will set one off.”

Marginalization

Some participants shared that their special needs patients come to the clinic on certain days, as their “special needs days,” due to attitudes of others working within their practice towards autistic children with significant behaviors

Preconceptions

A pediatric dental participant shared that, “A lot of times, unfortunately your teeth are not important. A lot of people don’t think it’s important. Especially parents of special needs kids. (It is) the last thing on their mind.”

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HOW DO WE BREAK BARRIERS?

Don't become a barrier!

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OTHER BARRIERS TO CARE FOR ASD

Overwhelming information - Deciphering between evidence backed treatment and more holistic approaches.

Long Waitlists - Years long waitlists for developmental pediatricians, therapy, psychiatry, social skills groups, and ABA/IBHS.

Financial Strain and time - Not all treatments are covered by insurance, and many times families already pay high out of pocket costs for sensory equipment and other increased costs experienced by kiddos on the spectrum.

Accessibility Issues - Services are concentrated in certain areas, families further outside of Pittsburgh cannot easily access them.

Navigating a Fragmented System - Health systems are difficult to navigate, even for the most educated and well informed. This turns caring into a special needs child a full time administrative job.

Confusion about legal rights and protections - FERPA, Civil Rights, and the IDEA law.

Impact on Family Dynamics - The divorce rate for families that have one autistic child is 36%.

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WHAT CAN YOU DO TO HELP?

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ADVOCACY

Many parents, and healthcare professionals, have the opportunity to serve on school boards, healthcare committees, and do advocacy work within their own communities. When you advocate for the needs of the marginalized, you make the world better for everyone.

Advocacy from parents and healthcare professionals has led to huge progress in Allegheny County and all of PA.

**Autism Surveillance Project
Autism in the Courts Taskforce
Proposed 2024-2025 Budget**

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NAVIGATING RESOURCES

It's hard to get help if you don't
know what's out there!

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NAVIGATING RESOURCES

Blended Service Coordination and Support Coordination

Office of Developmental Supports
Autism Connection of PA
Family Links

Family Peer Support

Not as widely available as it should be!
Not yet recognized as an independently billable
service
Parent2Parent of PA
Allegheny Family Network

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HELP A FAMILY KNOW THEIR RIGHTS

**Civil Rights
Procedural Safeguard Rights/IDEA
FERPA
HIPAA
US DHHS Autism CARES Act of 2019**

**Encourage families to reach out to
special education attorneys (usually
free to the family)**

**Acheiva
The Peal Center
Allegheny County School Based
Liasons**

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HAVE EMPATHY!

Caregivers are the experts on their children!

Take time to listen.

**Make appropriate suggestions and realistic referrals that meet
the needs of child yet also meet the families where they are.**

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WHERE ARE WE NOW?

Every weekday I get to go to work and use my lived experience as a mother to an autistic child with ADHD, Anxiety and ARFID to help other families navigate social systems and set goals towards resilience, empowerment and positive outcomes.

Grayson goes to an approved private school where he receives Autism specific services. He has friends, attends social skills groups, and has met most of his developmental milestones. He has hopes, goals and dreams for himself.

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QUESTIONS?