After Diagnosis: Top 12 Things Families and Providers Need to Know

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Objectives

• Participants will identify 2 categories of impairment required for diagnosis of ASD.
• Participants will identify 3 key areas of support for children with ASD.
• Participants will identify 3 commonly co-occurring conditions.
• Participants will name 3 potential resources for supporting a child with a new diagnosis.
Who are you? Who am I?
Who is this training for?
Every Individual is Unique

• Every child is unique

• Every parent is unique

• Every family is unique
1. Possible Reactions After a Diagnosis

Parents’ feelings will vary but can include:

- Fear
- Anger
- Self-blame/Guilt
- Overwhelm
- Relief
- Defensiveness
- Confusion
- Grief
Possible Reactions After a Diagnosis

Actions:

- Telling everyone
- Telling no one
- Numbing out
- Searching for information
- Arguing
- Seeking a second opinion
- Sorting out priorities
Family Challenges

• Operating in “survival mode”
  ➢ Simple, everyday tasks take planning, effort, risk
  ➢ Childcare challenges
• Functioning as case manager/therapist
• Researching & selecting interventions
• Safety concerns
2. Two Areas to Meet Diagnostic Criteria

- Deficits in social communication and social interaction (3):
  - Social-emotional reciprocity
  - Nonverbal communication
  - Relationships

- Presence of restricted, repetitive patterns of behavior, interests, or activities (2):
  - Stereotyped or repetitive motor movements, speech, use of objects
  - Inflexible adherence to routines
  - Restricted, fixated interests
  - Hyper- or hypo-reactivity to sensory input
Levels of Functioning

- Levels of support
- With or without
  - Cognitive impairment
  - Language impairment
- Changes over time
- Under- or over-estimation
3. Risk Factors and Causes

- No single gene/cause
- Born with it: roots in early brain development
- Parents didn’t do anything to cause it
- 2-18% chance of having a second child with ASD
- Can generally be diagnosed around 2 years old
- Broader autism phenotype
4. Co-Occurring Conditions

- **Sleep** *(chronic problems in over half, 4/5)*
- **Eating** *(70%, 36% severe)*
- **GI Disorders** *(8 times more likely)*
- **Epilepsy** *(20-33 % vs. 1-2 %, more common with ID)*
- **Nearly 1/3 overweight** *(increases with behavioral medications)*
- **Safety concerns** *(1/2)*
Autism and Mental Health

- 54-70% of people with ASD also have one or more other mental health conditions
- ADHD (30 to 61%, vs. 6 to 7%)
- Anxiety (11 to 42% vs. 3% children, 15% adults)
- Depression (7% children, 26% adults vs. 2% and 7%)
  ➢ Increases with age and IQ
  ➢ Increases with co-occurring medical conditions
- Schizophrenia (4 to 35% of adults)
  ➢ Similar genetic risk factors
- Bipolar Disorder (6-27% of people vs. 4%)

AUTISM AND HEALTH: A SPECIAL REPORT BY AUTISM SPEAKS, 2017
5. Evidence-Based Practice

Evidence-Based Practice

Clinical Expertise

Best Research Evidence

Individual/Family Values, Perspectives and Preferences

Individual/Family Values, Perspectives and Preferences
Evidence-Based Practice

- What is available in your community?
- What will your insurance cover?
- What are evidence-based practices?
  - http://autismpdc.fpg.unc.edu/evidence-based-practices
6. Functional Communication

- Way to refuse, obtain, connect socially
- Expressing wants & needs
- Asking for help
- Directed to another person
- Back and forth conversation
- Sharing information
- Nonverbal communication
7. Self-Regulation

• Ability to control our own behavior/responses
• Prerequisite for learning
• Arousal and alertness
• Sensory regulation/dysregulation:
  ➢ Sensory overload (*fight, flight, freeze*)
  ➢ Sensory defensiveness
  ➢ Self-stimulation
  ➢ Self-injurious behavior
• Intertwined with emotional development
  ➢ Social communication and understanding
  ➢ Response to change
8. Visual Supports

- Strategy for communicating with child using objects, pictures, drawings, instead of words
- Visual boundaries
- Visual schedules
- Choice boards
- First/then
- Visual timer
Visual Supports

MY MORNING SCHEDULE

wake up  make bed  get dressed  breakfast  medicine
brush hair  brush teeth  lunch bag  backpack  wait for the bus
9. Lifelong Journey

- Thinking about the future
- Predictions for self and others
- Will they ever ___?
- What happens when I die?
10. Talking to Others

• Talking to family
• Talking to friends
• Talking to people in the community
• Talking to siblings
• What do I tell my child with autism and when?
• Timing is everything!
How do I respond to other people’s reactions?

- Information
- Empathy
- Boundaries
- Humor

Laurel and Williams, Our Hearts’ Desire, 2013
11. Thinking About Priorities

• What’s important to your family?
• What is developmentally appropriate?
• What skills does my child need?
• What type of supports does my child need from school?
• Are there challenges that get in the way of everyday life?
• What can your family realistically handle (cost, time, effort)?
Thinking About Priorities

• Seeking intervention and support
• Thinking about school
• Thinking about community activities
• Thinking about family events
• Thinking about family roles and relationships
Social Validity

- Is the intervention appropriate for the child and family?
- Is it a priority?
- Does it make sense?
- Is it effective?

Without these elements, intervention is less likely to be implemented and generalized!
12. Resources

- Talking with the primary care physician
- Learning about insurance benefits
- Sharing reports
- Talking with your child’s school
- What is available in your community?
- Contacting resource providers
- Connecting with other families
What do I need?

• Find your team (advocate, family therapist, care coordinator...)
• Who is going to support your family?
• Who can support you?
• Who can listen?
How do I find resources?

• Autism Family and Provider Resource Team
  • (505)272-1852, toll free (800)270-1861

• CDD Information Network Library
  • (505)272-0281, toll free: (844)231-5003

• Medicaid Care Coordinator
  • Contact your MCO

• New Mexico Autism Society
  • (505)332-0306

• Parents Reaching Out
  • (505)247-0192, toll free: (800)524-5176
Resources: Websites

• CDD Autism Programs
  • http://cdd.unm.edu/autism/index.html

• Autism Portal
  • http://cdd.unm.edu/autism/portal/index.html

• Autism Society of America
  • http://www.autism-society.org/

• Autism Speaks
  • https://www.autismspeaks.org/

• National Autism Center
  • http://www.nationalautismcenter.org/

• National Professional Development Center on Autism
  • http://autismpdc.fpg.unc.edu/

• Community Report on Autism 2016
  • https://www.cdc.gov/ncbddd/autism
The Right Way is Many Ways

- Find what is right for your family
- Family-centered care
- Balance