CLDDV 173: Autism: Overview and Treatment

Chapter 4: Working With Families of Children with Autism


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Getting the Diagnosis

- Stages of grief: Kubler-Ross
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance
- The stages are not necessarily linear but circle back over and over depending on events

- [http://dsnetworkaz.org/holland/](http://dsnetworkaz.org/holland/)
- [https://www.youtube.com/watch?v=KvCJZw8Ymxk](https://www.youtube.com/watch?v=KvCJZw8Ymxk)
- [https://www.youtube.com/watch?v=YlQlOG6sxkg](https://www.youtube.com/watch?v=YlQlOG6sxkg)

- Important to recognize and respect parents’ experience
- Some parents may feel relief
- Some parents may feel obliged to become an advocate or piranha
Parental Priorities for Their Children With Autism

- Play with classmates
- Have friends
- Receive an invitation to a birthday party
- Improve language skills
- Have adequate vocational and leisure skills
- Be happy
- Receive acceptance in the community
- Live independently
If I Could Wave a Magic Wand, Here Are My Wishes - By Liz Bullington

- Accept and *include* him as a part of your class, just like everyone else
- Try to understand and respect his differences
  - He did not choose to have autism and learning to live with it is harder for him than it is for us
If I Could Wave a Magic Wand, Here Are My Wishes - By Liz Bullington (cont)

- Be patient with his limited communication skills
- Encourage him to try new things, but go slow
  - New experiences can be scary for him
If I Could Wave a Magic Wand, Here Are My Wishes - By Liz Bullington (cont)

- Give lots of praise for his accomplishments, no matter how small
- Understand that he learns differently but believe he can learn
- Help him feel comfortable in the classroom
  - Give him the space he needs but don’t isolate him
If I Could Wave a Magic Wand, Here Are My Wishes - By Liz Bullington (cont)

- Embrace the fact that he is a visual learner
  - Pictures and examples are better than just words
- Encourage him to interact with his classmates when appropriate
  - But realize that social situations are difficult for him
- Focus on the positive and be careful not to reinforce the negative
If I Could Wave a Magic Wand, Here Are My Wishes - By Liz Bullington (cont)

- Have realistic expectations but don’t underestimate his potential
  - Even though some things are harder for him, you’ll be amazed at what he can achieve
  - His successes may not be the same as the rest of the class but they are something to be proud of
Impact of Autism on Parents

- Learn a new language
- Learn about therapies
- Learn about services
- Learn about IFSP/IEP
- Is dependent on culture
- Is dependent on SES
- Is dependent on race
Impact of Autism on Parents (cont)

- STRESS!!!
- Mothers of children with autism are one of the most stressed parental groups
- Child’s level of functioning will affect degree of stress felt
- Fear of public scrutiny
- Limited social supports as a result of child’s behaviors
  - Others may not want to help or don’t know how so they don’t
Impact of Autism on Parents (cont)

- Depression
  - Most common associated negative impact of autism on families
  - Mothers more affected than fathers
    - Mothers are more positive toward their child with autism
  - The more depressed the mother, the greater the stress on father
  - Fathers’ perceptions - negative and positive - based on maternal depression
  - Mothers’ stress dependent on partner’s depression
  - Interdependency
Impact of Autism on Parents (cont)

- Positive impact:
  - Expand the mind
  - Thankful for child
  - Importance of human relationship
  - Unconditional love
  - Learned to give love when strong and accept love when weak
  - There is beauty in giving and receiving
  - Caring for child is not a burden but a privilege

Real love begins where nothing is expected in return.
Impact of Autism on Parents (cont)

- Impact over time (longitudinal)
  - Impact changes over time
- Depression and anger still present 10 years later
  - But much lower level
- Parents develop coping skills
- Parents of children with severe aggressive or obsessive behaviors have highest levels of stress
Impact of Autism on Parents (cont)

Family Needs
- Financial support
- Emotional support
- Respite care (child care)
- Resources to aid in understanding the child’s disorder
  - And how that changes over time
- Resources for dealing with the child’s disorder

What Can Teachers Do?
**What Can Teachers Do?**

- **EMPOWER** families to meet their own needs
- Be aware of community and state resources
- Provide community and state resources to families
- Create “Family Information Center”
  - Bulletin Board
- Create monthly newsletter
  - Highlight new community resource each month
- Make classroom computer available to parents who don’t have access to computer
Impact of Autism on Parents (cont)

Family Involvement

- Widely acknowledged to be a critical “best practice”
- Parent support and training
- Collaboration across home and school
- Ensuring necessary skills are being addressed through the education plan
- Parents are well informed
  - This is a positive
Welcoming All Families
Standard 1

Communicating Effectively
Standard 2

Supporting Student Success
Standard 3

Speaking Up for Every Child
Standard 4

Sharing Power
Standard 5

Collaborating with Community
Standard 6
Legal Mandates

Early Intervention - Part C

- IDEIA 2004 - Part C
  - IFSP - Family Friendly
  - Birth - 3 years
  - Completed by team, including parents
  - Parents must be a part of all decisions
    - How much and what type of involvement not specified

- [http://www.parentcenterhub.org/repository/partc-module1/#section2](http://www.parentcenterhub.org/repository/partc-module1/#section2)
Legal Mandates (cont)

Special Education

- IDEIA 2004 - Part B
  - Transition from Part C
  - 3 - 21 years
- IEP
  - Services focus on education of child only
- New vocabulary
  - FAE, LRE, Due Process, Mediation
- New staff
- New agency cultures
- New set of assumptions
Lack of collaboration may stem from lack of cooperation from parents as result of:

- Struggle for diagnosis
- Fighting for services
- Communication
  - Critical to the family-educator relationship
- Trusting relationship
  - Teacher disposition can either enhance or reduce trust
Getting to Know the Child and Family

- Family Needs Assessment
- “Who Am I” book about child
  - Open-ended questions
  - Make your own, don’t use templates
    - Avoid “my favorite color is” questions that tell you nothing about the child and the child may not have a favorite color
  - Have pages for different family members to fill out
    - Siblings
    - Grandparents
    - Extended family
  - Have book be loose-leaf so parents can toss pages that are not relevant
The Impact of Autism on Siblings

- Important to understand the needs of the family unit
- The functioning of the family will affect all children within the family and their development
- Family’s attention, time and energy focus on the child with the greatest needs
- Less intimacy
- Fewer interactions
- Less nurturance
- Negative relationships with parents
- The greater the stress level of parents, more negative sibling relationships
- Some studies found poor adjustment, higher rates of depression, poor social competence (inconsistent research)
The Impact of Autism on Siblings (cont)

Adjustment: May be an issue

- **Risk factors**
  - Number of children in the family
    - 2 children high risk
    - The more children in the family, more shared responsibility and someone else to talk to
  - SES
  - Gender (boys higher risk)
  - Birth order (if younger than child with ASD, higher risk)
  - Age of siblings
    - Older siblings have greater difficulty and internalize and have external behavior problems
The Impact of Autism on Siblings (cont)

Adjustment (cont)
- Siblings with good coping strategies does not seem to be helpful
- Siblings with good understanding of ASD did not adjust better
- Siblings of children with ASD had more positive self-concept that siblings of children without disabilities (Macks and Reeve)
  - More positive view of their own behavior
  - More positive view of their own intelligence
  - More positive view of their own scholastic performance
  - More positive view of their own anxiety
The Impact of Autism on Siblings (cont)

Adjustment (cont)

- Positive responses in siblings’ self-concept may be attributed to:
  - Comparing themselves with their sibling with ASD
  - More mature
- Parents may report their other children with more internalizing and externalizing behaviors
  - May be because they don’t observe as carefully
- When multiple risk factors exist, great challenge to siblings
Family Issues Across the Lifespan

Infancy and Early Childhood

- Feeling of loss
- Be aware of the range of grief symptoms
- More children come into the family, changing the family dynamics
- Therapies, some claiming to “cure” the child
- Time of hope and disappointment
- Waiting for the child to “outgrow” autism
- Transition
Family Issues Across the Lifespan (cont)

Elementary School Years

- Challenge to have spontaneous family outings
- Have to decide on treatments
- Decisions about medications
- Gaps in language and cognitive development become more apparent
- Sibling concerns
- Transition to adolescence, high school
Family Issues Across the Lifespan (cont)

Adolescence

- Puberty
  - Masturbation
- Hygiene
  - Training to use menstruation products
- Concern about sexual predators
- Independence
  - Driving
- Planning transition into adulthood
- Parents examine their goals as they have a clearer picture of their child’s abilities
Family Issues Across the Lifespan (cont)

Adulthood

- Children with autism grow up to be adults with autism
- Parents may pass away
- Siblings may have increased responsibility
  - Financial challenge
  - Emotional challenge
  - Psychological challenge
FOR A FAIR SELECTION EVERYBODY HAS TO TAKE THE SAME EXAM: PLEASE CLIMB THAT TREE.