

*Autism Family Wellness:
Educating and Training Parents to Support their
Child with Autism from Diagnosis to Adulthood*

SCERT Conference

Breakout Session

Montreal, Quebec, Canada

November 1, 2019

BRYNA SIEGEL, PHD

EXECUTIVE DIRECTOR, AUTISM CENTER OF NORTHERN CALIFORNIA

PROFESSOR, CHILD & ADOLESCENT PSYCHIATRY, UCSF (RET.)



Autism Center of Northern California

Three Junctures In the Educator-Parent Relationship

▶ **The Early Post-Diagnosis Period:**

Educators need to establish themselves as mentors for parents trying to reach and teach their toddlers and preschoolers at home.

▶ **The Transition to Middle School/ Age 12-13 Years:**

Educators need to have a 'dusty crystal ball' talk so parents can effectively select secondary education curriculum geared to a vision for post-high school capabilities.

▶ **High School Entry:**

Educators need to continue foundational discussions from middle school years to select curriculum with focus on needed adaptive skills, functional academics, prevocational, and vocational training, as well as post-secondary education *if* appropriate.

School-Entry/ Preschool Special Education

-teacher partnerships

- ▶ Teachers need to understand the impact of autism on the family.
- ▶ Teachers can taking on a mentoring role with parents vis a vis evidence based treatment versus and unproven ones/ 'magical thinking.'
- ▶ Teachers need to be able to discuss how children with autism grow up.

End of Elementary/ Transition to Middle School



Discuss/ Plan Secondary Ed Geared to Post-High School Realities:

- ▶ **Nonverbal/ minimal verbal pupils will remain so.** What will define good quality of adult life? What will they be able to do? Where can they live?
- ▶ **Pupils reading/ writing or doing math at the early elementary level.** What will define their quality of adult life? Parents need to learn about moving into 'functional academics'
- ▶ **Pupils at or near academic grade level.** Will they be 'indistinguishable from normal' soon? Addressing focal social and adaptive problems so they don't limit future. Discuss 'aiming low and going slow.'

High School Entry

Plan adaptive skill training, functional academics & prevocational training

Adaptive Skill Issues:

Life is not 1:1/ If you are going to college, you should be able to ride the bus/ After-school tutoring vs an afterschool job

Functional Academics:

Math embedded in prevocational training, consumer math, following written directions and community signs

Prevocational and Vocational Training:

School jobs, job sampling, counselling of youth about likely outcomes is essential

School-Entry/ Preschool Special Education

THE NEED TO DEVELOPMENT A MENTORING
ALLIANCE WITH PARENTS

Being the Parent of a Very Young Child with ASD Means:

- ▶ 24 hours day x 7 days= 168 hours
- ▶ Sleep: 60-70 hours per week
- ▶ School & Therapies: 24-40 Hour/Weeks at Best
- ▶ That leaves 100+ hours per week to parents....

A Child with a Autism is a 'Life Event'

- ▶ Nobody asked or planned for it.
- ▶ An autism diagnosis is a major life event major stressor—like cancer, divorce, or losing your home.
- ▶ Stress tends to bring out pre-existing strategies for maladaptive coping: Anxiety, depression, withdrawal, anger.
- ▶ Two years of 'reactive' depression may be the 'norm'. (Take note you preschool teachers who struggle with 'tiger moms' & 'disengaged' moms!)

The Need for JumpStart: Autism Education for Parents

- ▶ Comparing a diagnosis of an ASD to a diagnosis of diabetes in a 2 year old.
- ▶ What would you need to learn?
- ▶ When would you feel you'd need to learn and master it?
- ▶ How could you develop confidence you were getting it right?

"Give a man a fish and he'll eat for a day;"



"GIVE A MAN A FISHING POLE AND HE
WILL EAT FOR A LIFE TIME..."

LAO TZU (600BC CHINESE PROVERB)



Autism Center of Northern California

JumpStart Learning-to-Learn



- ▶ Provide initiation to intervention for ASD children by their parents
- ▶ Help child benefit from a range of approaches as applied to daily living
- ▶ ‘Extended diagnostic period’ to develop on-going treatment plans based on individual learning strengths and weaknesses, and motivational profile

How Can Teachers Support Parents to Make Home a Natural Environment for Teaching?

How Teachers Can Apply JumpStart Principles in Work with Parents

- ▶ Teach about consistent expectations
- ▶ Developmentally-calibrated expectations: Just like with typically-developing kids-- development is step-by-step—just smaller steps taken slowly.
- ▶ Continual practice and ‘upping the ante’ once a new skill begins to emerge
- ▶ Don’t just tell parents– Show them how you do it and get them to practice with you.



More on Supporting Parents in Making the Home a Natural Environment for Teaching:

- ▶ Identify functional/ natural opportunities
 - ▶ Meal times
 - ▶ Bath (or other preferred activity) times
 - ▶ Times with the child's preferred activities
- ▶ Describe how to take as small steps as possible
- ▶ Don't sweat the small stuff
- ▶ Coach parents to remember: It's half-full; not half-empty

When Teachers Have Taught Parents Something About Their Child:

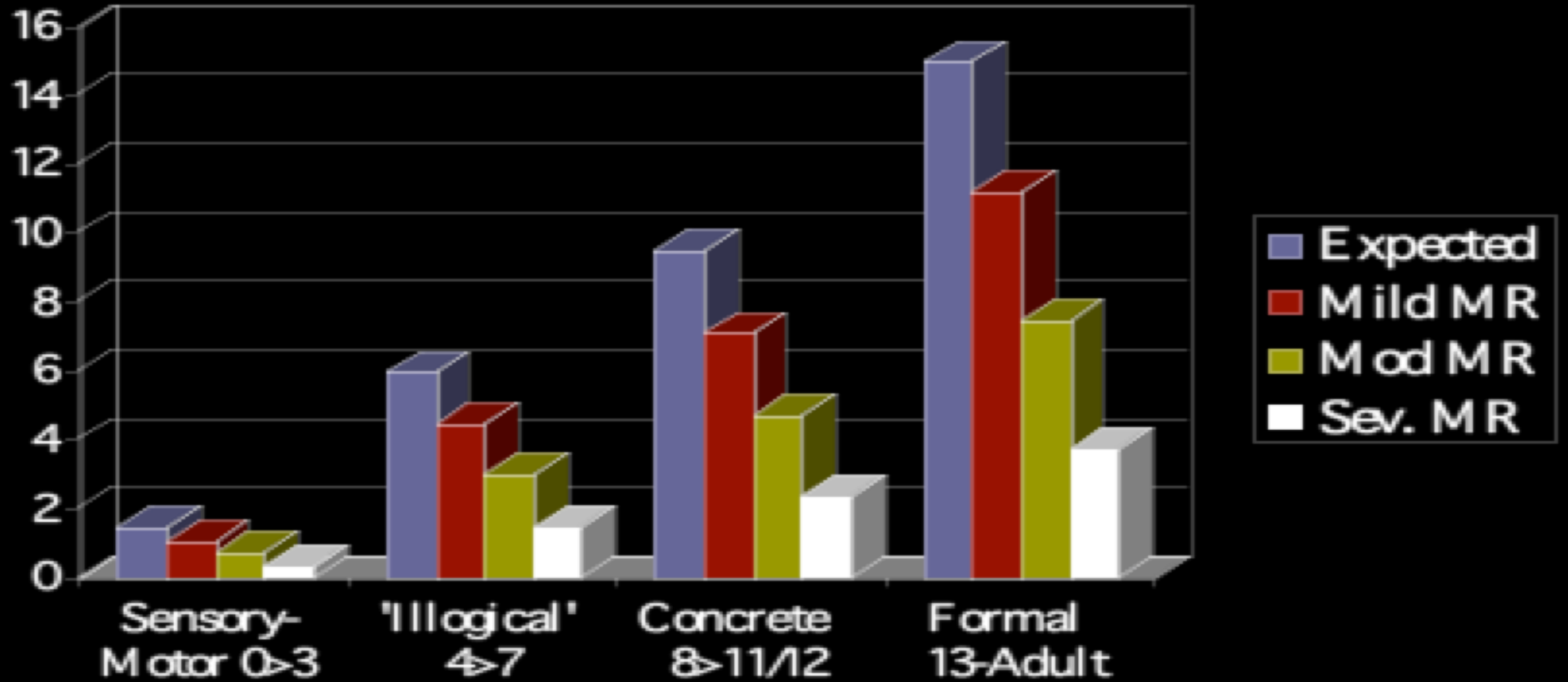
- ▶ The teacher garners more well-earned respect.
- ▶ If the child know that what his parent and teacher expect are the same, expectations are more likely to be met than 'gamed.'
- ▶ Failures at home can be posed to the teacher as a call for help, not a question if classroom experience is to blame.
- ▶ If a teacher can guide a child to master 'what comes next,' she'll then be ask, "And now, what should we teach? Not-- 'I want ___ in his IEP, because my advocate told he must have it..'"

End of Elementary/ Transition to Middle School

10 YEAR PLANS:

DISCUSSING AND PLANNING FOR POST-SECONDARY
EDUCATION

Planning for Developmental Expectations: Mental and Chronological Ages



ASD in Teens: The WYSIWYG Stage of Development

- ▶ Mental development finishes at puberty- more will be learned, but not more complex operations; meaning we can learn more, not more abstractly.
- ▶ But, people with ASDs often are many developmental 'ages' at the same time
- ▶ As educators & parents, be mindful that the chain may only be as strong as the weakest link.
- ▶ Parents need to be mindful of not confusing optimism with setting their child up for failure.
- ▶ Life becomes the child's, not the parent's—what are his/her interests and goals that can realistically be achieved?

The 10 Year Plan: Extending Developmental Trajectories

Where will a 10 year-old be at 20?

Where will a 12 year -be at 22?

Where will a 14 year-old be at 24?

- ▶ Incidental learning can be low due to lack of social motivation to be like and do like peers.
- ▶ What does he need to learn for best *adaptive* outcome?
- ▶ What des he need to learn for best *employment-related* outcome?

Who will teach it? When? Where?

The Goals: Independence, Adjustment, Achievement

Independence:

Teaching Adaptive Behavior

Adjustment:

Respecting Developmental Competencies

Achievement:

What Can this Individual Succeed at?

High School Entry

IDENTIFYING WHEN TO TEACH ADAPTIVE SKILLS,
FUNCTIONAL ACADEMICS AND/OR FOCUS ON
PREVOCATIONAL TRAINING

HFA: Strategies for Facilitating Academic Success

- ▶ Organizational Accommodations:
Resource room first and last, check schedule/homework
Extra books in Resource room/ subject class/ home
- ▶ Academic inclusion within 'reach' of grade level
- ▶ HFA Learning Center Model:
CAI, distance learning, recorded lectures
- ▶ Fifth year student/ extra electives/ GED v certificate of completion
- ▶ Para-professional aides only stigmatize

HFA: Facilitating Social Integration at School

- ▶ HFA Club Room Model
- ▶ Library/ Computer room as a recess lunch retreat
- ▶ Elective activities with social contact
Clubs, theatre, band, chess, computers
- ▶ Non-'theory of mind' sports, sport team equipment support

HFA: Facilitating Social Integration Outside School

- ▶ Support extra-curricular socialization with 'scaffolding' peers (sibs, relatives, neighbors)
- ▶ College-age friends-for-hire
- ▶ 'Parallel' group activities outside school (sports, community orgs, church)
- ▶ Work with much younger kids (camp/ day care counselor, library reader)

Post-Secondary Education: Individuals with HFA (18-22 years)

- ▶ Anticipating social difficulties
 - ▶ Flexibility/ Listening to a boss
 - ▶ Inappropriate overtures to co-workers
- ▶ On-the-Job Training:
 - ▶ Vocational aptitude examination for ASDs
 - ▶ Job coaching
- ▶ Higher Education:
 - ▶ Does the individual want it? Why?
 - ▶ What's the goal? Is it a fit for abilities?

High School for the Pupil with ASD and Moderate to Severe ID: Academics 25

- ▶ Self-contained classes with other comparably DD pupils promote friendships and socialization
- ▶ Shift from academic instruction to functional academics (if not done earlier)
- ▶ Functional reading (safety/ directions w/ visual supports)
- ▶ Functional math (money/ debit card handling)
- ▶ Meaningful community-based instruction (CBI) aimed to increase ADLs

High School for the Pupil with ASD and Moderate to Severe ID: Social

- ▶ Focus on increasing spontaneity of task completion & independence
- ▶ **Self-care:** Hygiene and dressing routines especially must be independent
- ▶ **Adaptive Skills:** Classroom as studio apartment:
Meal prep, shopping, cooking & kitchen care, laundry & housecleaning
- ▶ **Leisure Skills:** Identify leisure skills that can be pursued independently:
 - ▶ Exercise, music, books, puzzles, art

Transition to Adult Living for Individuals with ASD/ ID (18-22 years): Workplace

- ▶ Determining vocational aptitudes (ALSs?)
 - ▶ Can desire for sameness be a strength?
 - ▶ Can preference for aloneness be a strength?
 - ▶ Can follow complex routines be a strength?
 - ▶ Can high visual-spatial-motor skills be a strength?
- ▶ Accommodations to learning style
 - ▶ Visual supports (picture/ visual schedules)
 - ▶ Choice/ breaks (adult recess)

Transition to Adult Living for Individuals with ASD/ ID

(18-22 years): Leisure

- ▶ Identifying and expanding 'healthy' leisure activities (e.g., gym, swim, bike).
- ▶ Friends for hire/ 'guy' trainers.

- ▶ Independence at leisure skills
 - ▶ Pre-choice of a reinforcing 'break' activity
 - ▶ Organizing a break (start to finish)

- ▶ Respecting the 'space' of others (e.g., headphone, sitting to watch TV)

- ▶ DRO for maladaptive behaviors that limit functional independence (e.g., talking to self in public, motor stereotypies)

Conclusions:

- ▶ We don't know everything about what the future will hold for a child with autism—like any child.
- ▶ But, we don't know nothing....
- ▶ Current studies of adult adjustment in autism suggest a future that parents are not aiming to.
- ▶ Let's go for a sea change—maybe it will help!

Dr. Siegel's Books Related to Today's Talks

On THE POLITICS OF AUTISM

Siegel, B (2018). *The Politics of Autism*, New York: Oxford University Press.

On COLLABORATION BETWEEN PARENTS AND SCHOOLS

Siegel, B (2008). *Getting the Best for Your Child with Autism*, New York: Guilford Press.

On th DEVELOPMENTAL-BEHAVIORAL-APPROACH

Siegel, B (2003). *Helping Children with Autism Learn: Treatment Approaches for Parents and Professionals*, New York: Oxford University Press.

On HELPING PARENTS UNDERSTAND WHAT AUTISM IS

Siegel, B (1996). *The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorders*, New York: Oxford University Press.

On WORKING WITH FAMILIES

Siegel, B. and Silverstein, S. (1994). *'What About Me? Siblings of Developmentally Disabled Children'* New York: Perseus Press