Autism: Then and Now

Anne Larkin, Professor Emerita Lesley University June 16, 2015

Session Outline

- Overview of John's Early Life
- Transition Planning
- Strategies for the Classroom



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If we had a Hippocratic oath in education, it should be to presume competence and then go about the business of finding it.

Doug Biklen, 1996

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Then

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John's History

- Age(s)
- Diagnoses
- Placements
- Rationale
- Development



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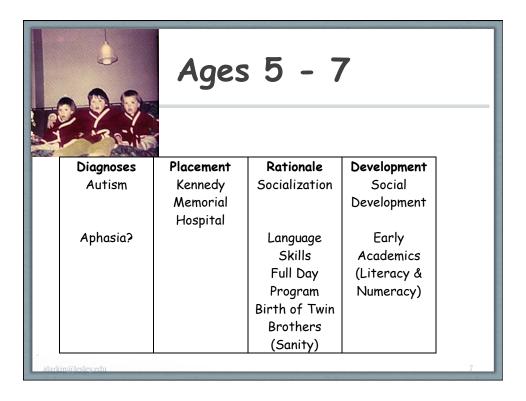
Ages Birth - 5

No federal protections at this time, Services negotiated through the district - one child at a time.



Diagnoses	Placement	Rationale	Development
Autism	Walden	Socialization	Role Models
	Nursery		Literacy
	Clinic		Skills
Language	Lesley	Normalcy	
Delay	College		
	Nursery		
	School		
Hyperactivity		Early	
		Intervention	

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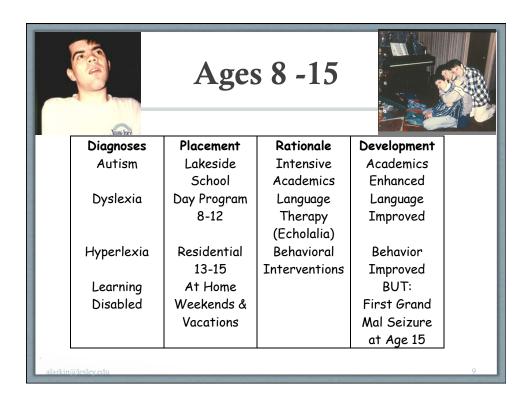


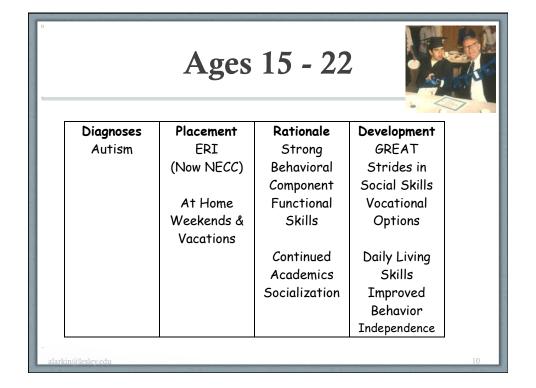
Options were becoming increasingly limited due to the lack of legal protections, as well as lack of institutional and pedagogical knowledge.



Diagnoses	Placement	Rationale	Development
Autism	Bedford	Home Town	
	Public	Integration	None
	Schools	_	
Mental	Class for MR		He Did Not
Retardation			Fit In

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Transition Planning

Started at Age 18 – Turning 22 Legislation

People Involved in the Planning Process

- Family
- Home Town
- Private School
- DMR



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Transition Planning

Activities includes:

- 1. Researched all Providers in the State
- 2. Checked out day programs/residential settings
- 3. Emphasis on family involvement
- 4. Social Security Benefits
- 5. Programmatic Issues:
 - Physical Activities
 - Socialization
 - Medical
 - Staffing

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ALL in place at age 22 when John transitioned to the over 22 program.

After 22

- Upon leaving the preK 12 system, even after the authorization of IDEA, mandates erode and the availability of resources shift dramatically
- High levels of advocacy and vision were required then and now to secure resources to support this population.
- Even with high levels of advocacy, there are no guarantees of resources as our children are growing up into unfunded mandates.
- The lack of funding is further highlighted by the long waiting lists for programs and services that do currently exist.

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Self-Determination ~ Working Together Massachusetts Department of Mental Retardation Alarkin@lestev.edu

"Fairness is not giving every child the same thing, but giving every child what he or she needs."

~Doug Biklen

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Now

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Looking at Autism Across Multiple Domains

- Social
- Communication
- Sensory
- Behavioral
- Movement

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Social Characteristics

Impaired Reciprocal Social Interactions

- Impairments in social recognition, communication, and understanding (or imaging)
- Absence of differences in eye contact
- Appear to lack desire to communicate, or use communication strategies which are simple and not complex.
- Little or no pretend play
- Inability to understand other' thoughts or feelings, particularly from facial cues.

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Interventions – Social Skills

Teach them as needed and in context, one piece at a time, teach:

What to do?

How to do it?

How to listen? Respond?

What to say?

Encourage social activities that don't require a lot of talking, i.e., parallel work. Conversations are very hard for them – need to coach other kids about technique – tell them to:

- 1. Get child's attention.
- 2. Wait for a response.
- 3. Interpret what they are saying.
- 4. Respond to their efforts.
- 5. Provide reminders.

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Interventions – Social Skills

Adaptations

- 1. Provide organizers
- 2. Augment communication options
- 3. Imitate peers can only understand when they experience it themselves (egocentric)

They are confronted with a world of social confusion, language misunderstanding, communication difficulties and sensory sensitivities.

What to do . . .

Organize every aspect of the child's world, i.e., space, time transitions, changes, sensory comfort, possessions, expectation, choices, learned information, sense of self, 1-to-1 and group interactions.

Practice all experiences.

Communication needs to be meaningful as an active responder and initiator.

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Interventions – Social Skills

Organizers (only when needed)

- 1. Where to go? Schedules, boundaries
- 2. What to do? Label materials, color code everything, who to watch
- 3. For how long? Time boards, first steps of activities, number of materials to complete Say it once!

Say it twice!

Show it!

Dry Erase Boards - hyperlexics, decoders, not necessarily readers

Cue Cards - reminders: I don't know. Help me.

Conversation Books – ideas of things to talk about with friends

Video Instruction _ target single communications (Hi/Bye), put familiar adult/kids in social contexts, i.e., "Please stop staring." "Not too lose."

Modify Style of Interactions

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Interventions – Social Skills

Social Stories: Types of Sentences

Descriptive: describe what people do in particular social situations

Directive: direct the person to a particular desired response

Perspective: presents others' reactions to a situation

Control: identifies strategies the person can use to facilitate memory and comprehension (Goldberg Edelson, 1995)

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Social Stories by Carol Gray

A Social StoryTM describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social StoryTM is to share accurate social information in a patient and reassuring manner that is easily understood by it audience.

http://www.thegraycenter.org/

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Absence of evidence is not evidence of absence.

~Anne Donnellan

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Communication Characteristics

- Language: both receptive and expressive is severely delayed
- Speech may develop late or not at all
- Any spoken language is often idiosyncratic and echolalic
- Echolalia may be immediate or delayed
- Find it difficult to respond to verbal-only speech and directions
- Eye contact, body posture, gestures and other nonverbal aspects of communication are severely impaired

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Communication Characteristics

Why Can't They Talk?

- Auditory processing problems
- Comprehension
- "Will" to communicate (social awareness)
- Theory of the mind
- Problems with expressive language
- Difficulty with motor planning (apraxia)
- Attention deficits

Purkinje cells are missing!

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My mind always gets there at the end.

It just takes the scenic route.

Student Quote from Panel Discussion, The Syracuse University Inclusion Conference

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Sensory Characteristics

May have difficulty with:

- Tactile issues: clothing, food textures, bathing, toothbrushing
- Responses to auditory stimuli: fear of alarms, bells
- Focusing in the presence of varied stimuli: producing work in a room with florescent lighting

Sensory Diet

- Provide a routine throughout the ay which is reasonably consistent, predictable and structured.
- Don't wait for it to be necessary (if you can help it!)

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Brief Summary of Strategies for Sensory Sensitivity

Auditory Sensitivity

- · Avoid some sounds, listening to music can camouflage the sound
- Auditory integration training may be helpful
- Minimize the background noise, especially several people talking at the same time
- Consider using ear plugs

Tactile Sensitivity

- Buy several duplicates of tolerated garments
- Sensory Integration Therapy may be helpful
- Areas can be desensitised using massage and vibration

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Brief Summary of Strategies for Sensory Sensitivity (continued)

Sensitivity to Taste and Texture of Food

- Avoid force feeding or starvation programs
- Only lick and taste new food rather than chew and swallow
- · Try new food when distracted or relaxed

Visual Sensitivity

- Avoid intense levels of light
- Use a sun visor or sunglasses

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Behavior Characteristics

Behavioral Abnormalities

- Desire sameness and resist change
- Restricted, perseverative, or stereotyped patterns of behaviors, interests, and activities
- Lack of representational or pretend play
- Ritual and adherence to routine are common
- Occasional intense attachments to unusual objects, such as a piece of string, rather that a teddy bear
- May have tantrums or other behavioral problems when schedules are changed, or any change is perceived in the routine

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Causes of Disruptive or Inattentive Behavior

- 1. Poor general management: attention, momentum, space, time, routines, personal relationship building
- 2. Inappropriate work that is too hard, too easy or a glaring mismatch to students' learning styles: objectives, learning, experiences
- 3. Boring Instruction: learning experiences
- 4. Confusing Instruction: clarity
- 5. Internal physical Causes: hearing, thyroid, fetal alcohol syndrome, drug dependency, attention deficit disorder
- 6. External physical causes: heat, light, hunger, over-stimulating environment

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Causes of Disruptive or Inattentive Behavior (continued)

- 7. Values and culture clashes
- 8. Student ignorance of how to do the expected behaviors
- 9. Extaordinary emotional baggage students bring with them: some <u>long</u> <u>term</u>, such as being convinced one is a failure, great insecurity or fear over one's safety; some <u>temporary</u>, such as a fight at home, feud with a friend, anxiety over a test
- 10.Student sense of powerlessness
- 11. Unclear or conflicting standards, expectations and consequences
- *12.A need for fun and stimulation*: goofing off its more fun that work (Mendler/Curwin)

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Purpose of Problem Behavior

- Attention seeking
- Escape/Avoidance
- Self-regulation
- Play or entertainment
- Learned

All are trying to communicate something to us.

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People tell me to self control, but I have so much self to control!

Student Quote from Panel Discussion, The Syracuse University Inclusion Conference

Interventions - Behavior

- 1. Stay neutral
- 2. Catch then being good (even if it's for a very short time).
- 3. When you find a child misbehaving, redirect, redirect, redirect.
- 4. Reinforce child as soon as s/he returns to the task, even if s/ he has been on task only two or three seconds.
- 5. Ignore the behavior, but not the child. Nonverbally redirect, remember what I demonstrated.
- 6. Avoid power struggles; give kids a way to return to task and save face.
- 7. Reinforce, reinforce, reinforce. Let them know appreciate their (sometimes minimal) cooperation.
 Gurry: Basic Reminders, p. 1, March 1996

Interventions — Behavior (continued)

- 8. Their behavior is not directed at you; chances are they are more frightened than you are!
- 9. If you are not a significant person in the child's life (e.g., you are another teacher in the hall), give a clear expectation, redirect, and state the school rule or policy . . .then summon someone who knows the child.
- 10. Don't give commands you can't enforce.
- 11. In certain situations, give attention to the 'victim' or other children who are complying; emphasize what it takes to do 'well'. For example, 'I like the way all the second graders have their hands to themselves.' Use your proximity to the child who needs help and redirect him/her nonverbally.

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Gurry: Basic Reminders, p. 2, March 1996

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Interventions — Behavior (continued)

- 12. State expectations positively, such as, 'When everyone is seated, we will begin . . . Good! You all sat down quickly.' 'When you have cleaned up your projects, you may go out to recess.'
- 13. Remember that some behaviors are: *allowed*, *permitted*, *tolerated*, *redirected*, *ignored*, *and consequated*.
- 14. These are children who have to be taught, step by step, by painstaking step, to do the right thing. They have to unlearn negativism and to learn positive behaviors.
- 15. Keep data. None of these changes takes place overnight.
- 16. Be alert for and reinforce each and every small attempt at 'being good'.

Gurry: Basic Reminders, p. 3, March 1996

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Make the environment predictable, understandable, and meaningful to the child.

Make it a visual environment.

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Interventions — Behavior (continued)

Agitation can be calmed effectively by:

- Soft, fleeting strokes on the bare skin (forearm is the best)
- Soft, calm voice with caring statements
- Soft music
- Limited time out in an empty, quiet, dimly lit space
- · Protein snacks

- Physical Exercise
- Behaviors such as pacing or walking
- Vestibular stimulation such as swinging or rocking
- Full body control (to protect the person, the caregiver and/or the environment

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Interventions – Behavior (continued)

Positive Behavioral Support is:

- Respectful
- Normalized
- Preventative
- Educational
- Individualized

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Not only is he the worst behaved pupil in my class, but he has perfect attendance!

~Harassed Teacher

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Summary of Best Practices

Focus on what kids can do rather than what they cannot.

What is spared? Impaired? By Helen Tager-Flusberg

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Assumptions that are not (necessarily) true!

- Children who do not LOOK, do not attend, do not notice, and do not care.
- Children who do not TALK, do not understand, do not have anything to say.
- Children who do not or cannot REACT, do not feel.
- Children who need extra help to learn some things, can only learn with our assistance.

"The child is not less developed, but developed differently." Vygotsky (60 years ago)

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To Create an Environment to Support Student's Understanding . . .

- 1. Teach children to understand the naturally occurring visual supports in the classroom
- 2. Create tools to give information
- 3. Create tools to give directions
- 4. Create tools to communicate rules¹

¹ Quill p. 269, 1995

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Classroom Best Practices

- 1. Literacy rich classrooms "word walls"
- 2. Structured environments
- 3. Clear expectations
- 4. Transitions "Social Stories" (Gray)
- 5. Technology
- 6. Cognitive picture rehearsal (Grodin & LeVasseur) 12. Behavioral techniques (predictive proactive)
- 7. Use of predictable materials

- 8. Communication strategies
- 9. Physical exercise (Boston Higashi)
- 10. Art and Music (Boston Higashi)
- 11. Stress and anxiety reducing strategies
- 12. Behavioral techniques (predictive, proactive, preventative not regulation, control

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