

# Parenting, Education and the Long View...

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National Autism Conference



Pennsylvania Training and Technical Assistance Network

# Every Parents Dream for their Child...

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Maximum Independence

Reaching their Fullest  
Potential

Best Health Possible

Happy and Fulfilling Life

# No Easy Task

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- This session will review considerations and effective interventions to help make informed decisions and support your child with ASD along the way
- But don't lose sight of the big picture. “Keep your eyes on the prize!” (W. Heward, NAC 2011)

# Confounds:

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- Myths that are used as explanations for failed interventions
  - Individuals with autism don't make eye contact; they do not look at you
  - Individuals with autism don't speak.
  - Autism can be outgrown.
  - Underneath all the difficult behaviors is a normal person.
  - Individuals with autism cannot show affection and do not respond to physical affection.
- Promising treatments with no evidence are popular and appealing
- Effective interventions do not stop at school
- Coexisting medical conditions
- Life goes on and the clock does not stop ticking!





# Impact of Autism on Families:

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- Each family is as unique as each child.
- In many cases the child is developing “typically” and then begins to lose skills
- Some families have more than one child diagnosed with ASD

# Stages of Grief and Loss

(Elizabeth Kubler Ross)

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- Grieving what? Typical child, normal life, uncomplicated existence.
- These help frame what many parents facing this diagnosis also feel: denial, anger, bargaining, depression and acceptance.
- The grieving process is unique and not linear. Not always in order, not all completed, no predictable response. Each individual family member's response unique.
- A death or serious illness, as tragic and jarring as it might be, carries with it the opportunity for some finality and closure. Autism is a chronic, lifelong disability.
- Every family member will experience the loss differently

# The Stress of Dealing with “THE SYSTEM”

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- The experience is often overwhelming due to the fragmentation of systems and the difficulty accessing supports in a system which in many cases was not designed to meet the complex needs children with ASD present
- Navigating the system is often a full time job

# Invasion of Privacy

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- The services the children require are often very intrusive to family life.
- Many systems want very private information.
- Getting services means giving up some control of your family's privacy.

# Other Challenges

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- Lack of sleep
- Financial hardship-can both parents work?
- Keeping a job
- Parenting siblings
- Keeping marital relationships intact
- Childcare and respite

# Other Challenges

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- Pervasive, intense, and chronic deficits for individuals with ASD may trigger the following behavioral challenges:
- Elopement
- Aggression
- Tantrums/screaming
- Self-injurious behavior
- Severe restriction of food intake
- Extreme isolation /Limited social interactions
- Limited play or age appropriate leisure skills

# Further Impact on Families:

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- Chronic economic strain
- Higher divorce rates
- Impact on siblings particularly older females
- Problems with younger siblings-noise
- Co-morbid medical issues-seizure disorders, M/H, accidents and injuries, dental problems, nutritional problems due to self-limited diets.
- Families often become isolated due to their inability to cope with the stress of bringing the child into the community.



# Impact on Education

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- Problem Behavior
- Need for intense and repeated trials to learn
- Lack of generalization of skills
- Deficits with language, academic or other relevant basic learning skills
- Need for staff with specific skill sets in procedures and interventions that are evidence-based

# The Good News!

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- Evidence on effective interventions continues to accumulate
- We can make a difference!
- No matter what the cause of the disorder, it is imperative we use evidence-based interventions to make that difference
- If behaviors have an environmental basis, then we can manipulate the environment to change the behaviors!

# Pathway to Making the Right Decisions

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- Become informed!
  - *“Parents can act as very effective advocates if they know what they are advocating for” (DiPuglia, A. 2018)*
  - Attend trainings- learn about what works :
    - Effective/evidence-based interventions
    - What to teach- based on assessment AND skill sequences)
    - How to teach- protocols and procedures
    - Under what conditions will skill be taught/will skill occur
    - How to monitor progress
  - Ask questions- the answer should not be “this is the way we do it here”

# Guidelines to Assist in Decision-Making Process:

- Whenever possible elect interventions from established evidence
  - If clearly established evidence not available, select intervention from a model consistent with evidence (basic principles, data system)
- Interventions should be selected that are in line with current evidence (Maine report, 2009):
  - Early Intensive Behavioral Intervention | *ESTABLISHED EVIDENCE*
  - Applied Behavior Analysis for Adaptive Living Skills| *PROMISING EVIDENCE*
  - Applied Behavior Analysis for Communication| *ESTABLISHED EVIDENCE*
  - Applied Behavior Analysis for Social Skills| *ESTABLISHED EVIDENCE*
  - Applied Behavior Analysis for Vocational Skills| *PRELIMINARY EVIDENCE*
  - Applied Behavior Analysis for Academics| *PRELIMINARY EVIDENCE*:

# Guidelines to Assist in Decision-Making Process:

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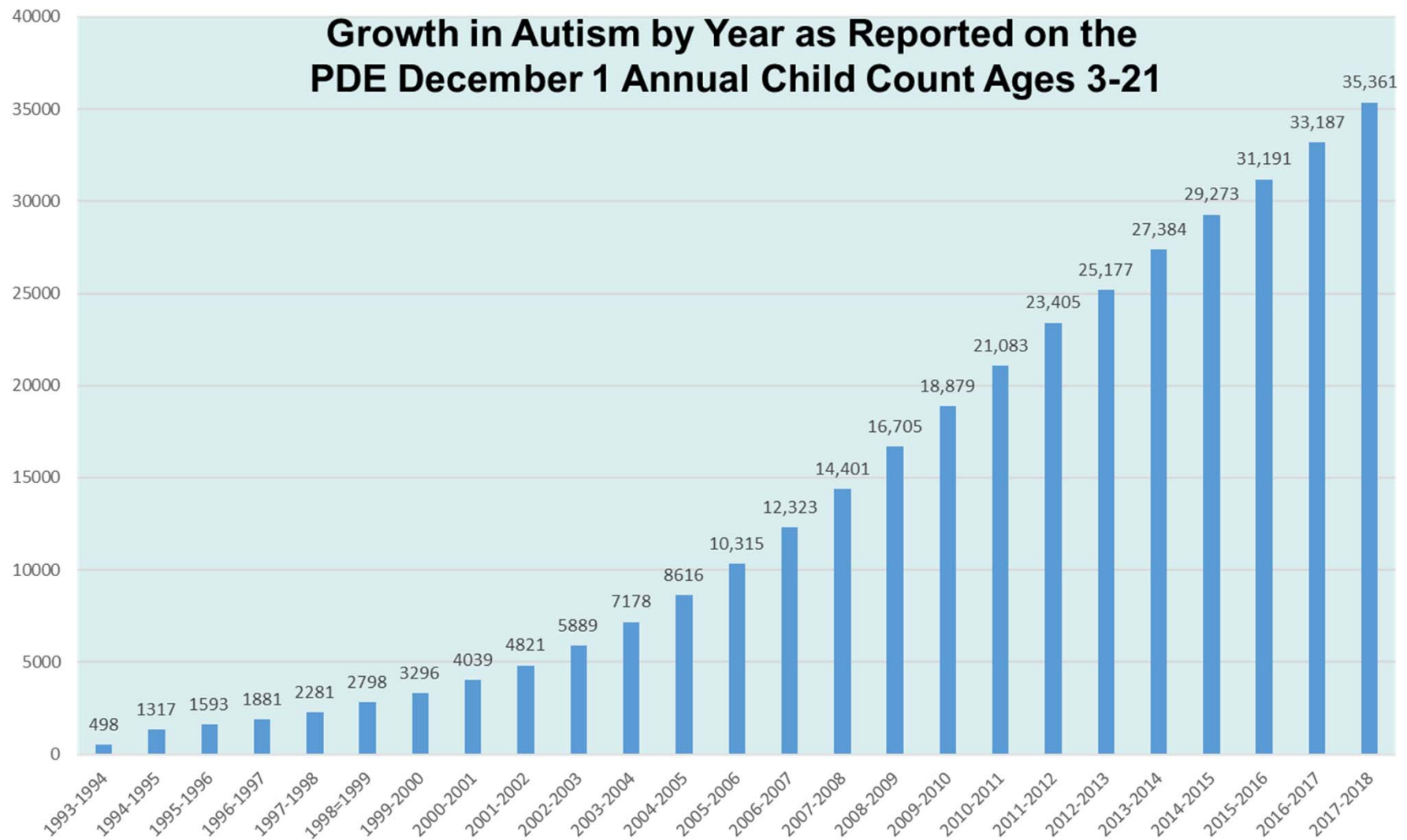
- Assessments and program design need to be practical, relevant, and build toward meaningful skill sets
  - Focus should be on skills that will be applied in every day life and address individual skill deficits:
    - Social communication- priority
    - Skills which lead to independent life skills, employability, or access to post-secondary education
    - Academic skill building- caution! (“Can identify Saturn, but I can’t brush my teeth”, Ayres et al, 2011)

# Choosing Interventions

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- Approximately one in every 59 children has an ASD [CDC, 2018]
- As the number of children diagnosed with ASD continues to skyrocket, so do the number of treatment options.
- Families, educators, and service providers must sift through a massive amount of confusing and often
- Conflicting information about the myriad treatments available
- *National Autism Center Standards Report*

# In Pennsylvania Alone...



# Importance of Effective Treatments

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- Societal costs for each individual with ASD across the lifespan is estimated at 3.2 million dollars (Ganz, 2007)
- With EFFECTIVE treatment the life-time costs can be reduced by 65% (Jarbrink & Knapp, 2001)
- Individuals with autism DESERVE effective treatments



# Treatments Based on ABA

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- Approximately two-thirds of the Established Treatments were developed exclusively from the behavioral literature (e.g., applied behavior analysis).
- Of the remaining one-third of the Established treatments for which research support comes predominantly from the behavioral literature.
- This pattern of findings suggests that treatments from the behavioral literature have the strongest research support at this time

# Applied Behavior Analysis

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- A scientific approach to behavior
- Focuses on environmental events that are crucial to the understanding of behavior
- Its principles are used to change and improve behaviors
- Many experimental studies confirm the effectiveness of these principles
- These principles can be applied in a variety of settings with different types of people—infants to adults.

# Some Interventions With Insufficient Evidence (Maine Report, 2009)

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- DIR/Floortime| *INSUFFICIENT EVIDENCE*
- Relationship Development Intervention (RDI)| *INSUFFICIENT EVIDENCE*
- Auditory Integration Training| *INSUFFICIENT EVIDENCE*
- Sensory Integration Therapy| *INSUFFICIENT EVIDENCE*

# Some other Interventions with Insufficient Empirical Support

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- Social stories (note the requirement of rule-governed behavior); insufficient evidence (Maine Report)
- Advanced warnings and activity schedules to reduce problems with transition (Lalli, et al. 1994; Wilder, et al., 2006; Wilder et al. 2010)
- TEACCH; insufficient evidence (Maine Report)
- Weighted vests (Reichow, et al. 2010; Cox, et al. 2009)
- Ambient prism lenses (Chok, et al., 2010)

# Careful with the Infomercials!

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- Researchers pitch findings to the media
- Does not allow for replication
- If it sounds too good to be true, it's probably not
- Testimonial/anecdotal evidence
- Personal benefit/conflict of interest

Adapted from: “When should I be skeptical?”, Ryan Butler, Autism Speaks,  
[www.autismspeaks.org/blog/2012/09/07/when-should-i-be-skeptical](http://www.autismspeaks.org/blog/2012/09/07/when-should-i-be-skeptical)

# Beware of the Media and Internet!

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- “There is a need to differentiate effective treatments that are scientifically validated from the plethora of “therapies” and “cures” lacking scientific support”

Celiberti, PhD, BCBA (2011)

- Research vs. the “next big thing” sensationalized by the media

# “Googling” Autism Treatments:

The screenshot shows a Google search interface. The search bar contains the text "autism treatments". Below the search bar, it says "About 10,200,000 results (0.14 seconds)". To the right of the search bar is a blue button with a magnifying glass icon and the text "Advanced se".

On the left side of the page, there is a sidebar with the following options:

- Everything
- Images
- Videos
- News
- Shopping
- More

Below the sidebar, there is a section for location and time filters:

Scranton, PA  
Change location

Any time  
Past hour  
Past 24 hours  
Past week  
Past month  
Past 2 months  
Past year  
Custom range...

The search results are displayed in a list format. The first result is titled "Treatment For Autism - Find Out About Hyperbaric Therapy" and includes the URL "www.hbtusa.com" and the text "Contact Us Today for Consultation".

The second result is titled "Autistic Disorder Symptom" and includes the URL "www.autisticdisorderinfo.com" and the text "Treat Irritability Associated With Autistic Disorder In Patients 6-17."

The third result is titled "Treatments for Autism | KylesTreeHouse.org" and includes the URL "www.kylestreehouse.org" and the text "Educate yourself about choices with our online resources and more!"

The fourth result is titled "Treatment - Autism Speaks" and includes the URL "www.autismspeaks.org/what-autism/treatment" and the text "Treatment for autism is a very intensive, comprehensive undertaking that involves the child's entire family and a team of professionals. ..."

The fifth result is titled "Autism Treatments -- Therapies, Medications, and Alternatives" and includes the URL "www.webmd.com/brain/autism/autism-treatment-overview" and the text "Apr 12, 2010 – WebMD provides in-depth autism treatment information including behavioral therapy, speech therapy, medications, physical therapy, ..."

# Checklist of Things to Look for When Reviewing the Research :

- Needs to be empirical – based on experiments
- Needs to have been scrutinized by scientists in the field
- Results need to be measurable and objective
- Research should be able to be reproduced



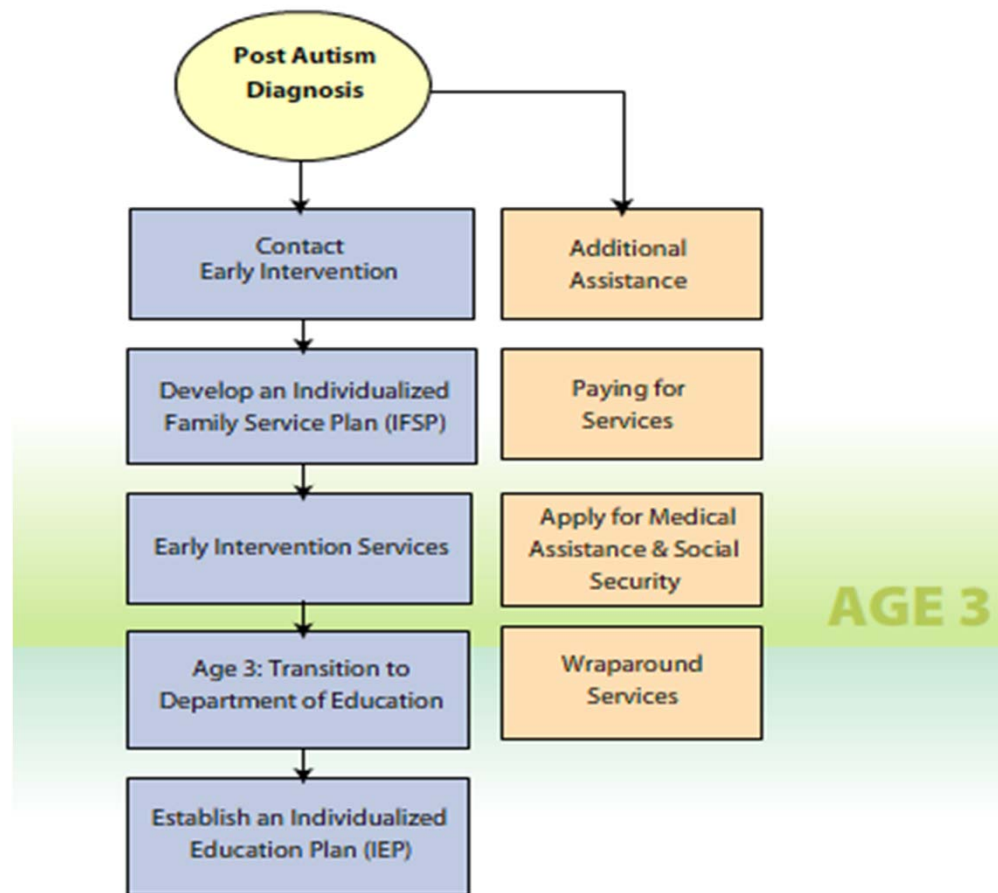
# Diagnosis, Research, then what?

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- INTERVENTION ASAP!

# Diagnosis, Research, then what?

- For birth to 3 years old:



# Individuals with Disabilities Education Act

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- IDEA
- Nation's special education law
- Defines processes of:
  - evaluating eligibility
  - creating an IEP
  - providing services
  - measuring progress
  - Re-evaluating

# Eligibility determined

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- According to IDEA, there is NO requirement to get a medical diagnosis of any autism spectrum disorder for your child to be considered “educationally autistic”
- For school purposes, your child has to meet only the following definition:

# Educational Definition of Autism (IDEA)

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- Autism means a developmental disability significantly affecting verbal and nonverbal communication evident before age 3, that adversely affects a child's educational performance.
  - Once individual found eligible for services there must be a meeting within 30 calendar days to write the IEP

# Creating the IEP

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- The IEP is:
  - A team approach
  - An assessment of the individual
- An IEP identifies:
  - Strengths, challenges and needs
  - Potential goals
  - New Information from parent(s)

# Heward's metaphor for the IEP:

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- “ The IEP is a system for spelling out...where the child [is]with current skills, where she should be going, how she will get there, how long it will take, and how to tell if and when she has arrived. Thus, a good IEP serves as both a road map and a guidebook for meeting the challenges posed by a student's disability. The annual goals and benchmarks developed by the team identify the destinations for the journey and provide signposts along the way.”  
(Heward, 2006)

# IEPs should include:

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- Current performance
- Annual goals
- Special Education and related services required
- Participation with nondisabled peers
  - Must explain the extent(if any) to which a child will not participate with non-disabled peers in regular classes or other activities



# IEPs should include (continued):

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- Participation in state and district-wide tests
- Dates and places
- Transition services planning (begin at 14 years)
- Transition services needs (begin at 16 years)
- How progress will be measured

# FAPE and LRE

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- In Pennsylvania, IEP teams are required to adhere to the following guidelines when making educational placement decisions:
  - A free and appropriate public education (FAPE) must be provided to every student with an IEP
  - FAPE must be delivered in the least restrictive environment (LRE) as decided by the IEP team.

# Remember:

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- The general education environment is always the first option for individuals with ASD
- Individuals with ASD have the right to access typically developing peers

# IEP needs to be:

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- Framed around how to help the child:
  - Advance towards annual goals
  - Be involved in the general curriculum
  - Participate in extracurricular activities and non-academic activities
  - Build/lead to lifelong skills

# Reviewing the IEP

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- At least 1 time a year
- Parent or school can ask for a review at any point
- Parents attend IEP meetings, make suggestions, agree or disagree with goals or placement

# Re-Evaluation

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- At least every 3 years
- Or before if:
  - Conditions warrant
  - Parent/Teacher asks
- Assesses whether the individual is still “a child with a disability” (IDEA) and reviews level of their current needs

# Remember:

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- Throughout this process it is important that everyone understands both the child and the world in which he or she lives.
- Changing the environment is the only tool we have to make life better for our children

# Reminder

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- “PARENTS ARE THE BEST ADVOCATES FOR THEIR CHILDREN”



# Be an Active Member of the TEAM

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- Parent knows best- “if” they know best
- Ongoing Communication:
  - What is being taught?
  - How can we support at home?
- Focus on skills
- Focus on protocols
- Have a plan to respond to data
- Discuss details of instruction such as:
  - Where, when, who, how long?

# Helping Parents Understand Data

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- Be aware of skill sequences
- Learn what has been mastered
- Look at a graph! (teachers should be able to provide these)
- Don't settle for "he's doing great"

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# What Works?

## Evidence-Based Principles for Effective Education

# PATTAN: Research-Based Effective Teaching Principles

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- Students learn more when they are actively engaged in instructional tasks.
- High success rates correlate positively with student learning outcomes.
- The more content covered, the greater the potential for student learning.
- Students achieve more in classes where they spend most of their time being directly taught by a teacher.
- Students become independent, self-regulated learners through instruction that is deliberately and carefully scaffolded.
- The critical forms of knowledge (declarative, procedural, and conditional) must be addressed in order for instruction to be effective.

# PATTAN: Research-Based Effective Teaching Principles

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- Learning is increased when teaching is presented in a manner that helps students to organize, store, and retrieve information.
- Strategic instruction helps students to become critical thinkers.
- Teachers can increase their students' achievement through instruction that is explicit.
- By teaching sameness both within and across subjects, teachers promote the ability of students to access knowledge in any problem-solving situation. (concept formation)
- Using formative assessment as a diagnostic tool can help teachers make the necessary adjustments to their practices to meet the individual needs of students.
- Teachers can gain more class time for academic instruction by directly teaching classroom behavioral expectations and routines to students.
- Students achieve greater success when supported by intentional and intensive family engagement.

# Data and Consumer Rights

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- Parents, teachers, other professionals, and funding agencies have the right to hold prospective providers accountable for delivering quality services (e.g., to ask them how they use objective data to plan, implement, and evaluate the effectiveness of the interventions they use).

» ABAI Autism SIG revised consumer guidelines

# Considerations in Evaluating Interventions

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- Is intervention being done correctly and consistently?
- Is instruction (concepts/stimuli) arranged flawlessly? clear examples/non-examples across irrelevant variables
- Is intervention being done often enough?
- Is data accurate?
- Is enough time allotted to do the intervention?
- Are interventions procedures clearly stated?
- Are staff able to adjust prompt level and reinforcement on a moment to moment basis?

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An example of educational programs  
guided by both Evidence-Based  
Practices and student level evidence:  
PATTAN's Autism Initiative ABA  
Supports



# Key Considerations in Effective Educational Practices for Students with Autism

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- Classroom Organization and Management
- Systematic Training and Consultative Support
- Inclusive Practices
- Effective Instruction
- Treatment integrity
- Social Skill Instruction
- Effective Positive Behavior Support Plans
- Family Involvement

# Site Review: ABA Supports

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- Main criteria for evaluating implementation of evidence based practice resulting from consultative efforts
- Tied to effective teaching/evidence based practice
- Implementation criteria is rigorous and reliable (IOA data over 93% over 10 year period)
- SLO relation: site review criteria to average performance of students

# Site Review: Overview

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- Classroom Organization
  - Schedules
  - Classroom environment
  - Materials
  - Data: student notebooks
- Consultation/Training
- Inclusive Practices
- Family Engagement

# Site Review: Overview (continued)

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- Instruction
  - Mand
  - Intensive teaching
  - Natural Environment Training
  - Vocal training
  - Direct Instruction and group instruction
  - Fluency
- Behavior Interventions to reduce problem behavior
  - FBA
  - Implementation (data, treatment integrity, implemented as written, staff training, etc)
  - Plan design (reduce motivation, teach competing response, extinction)

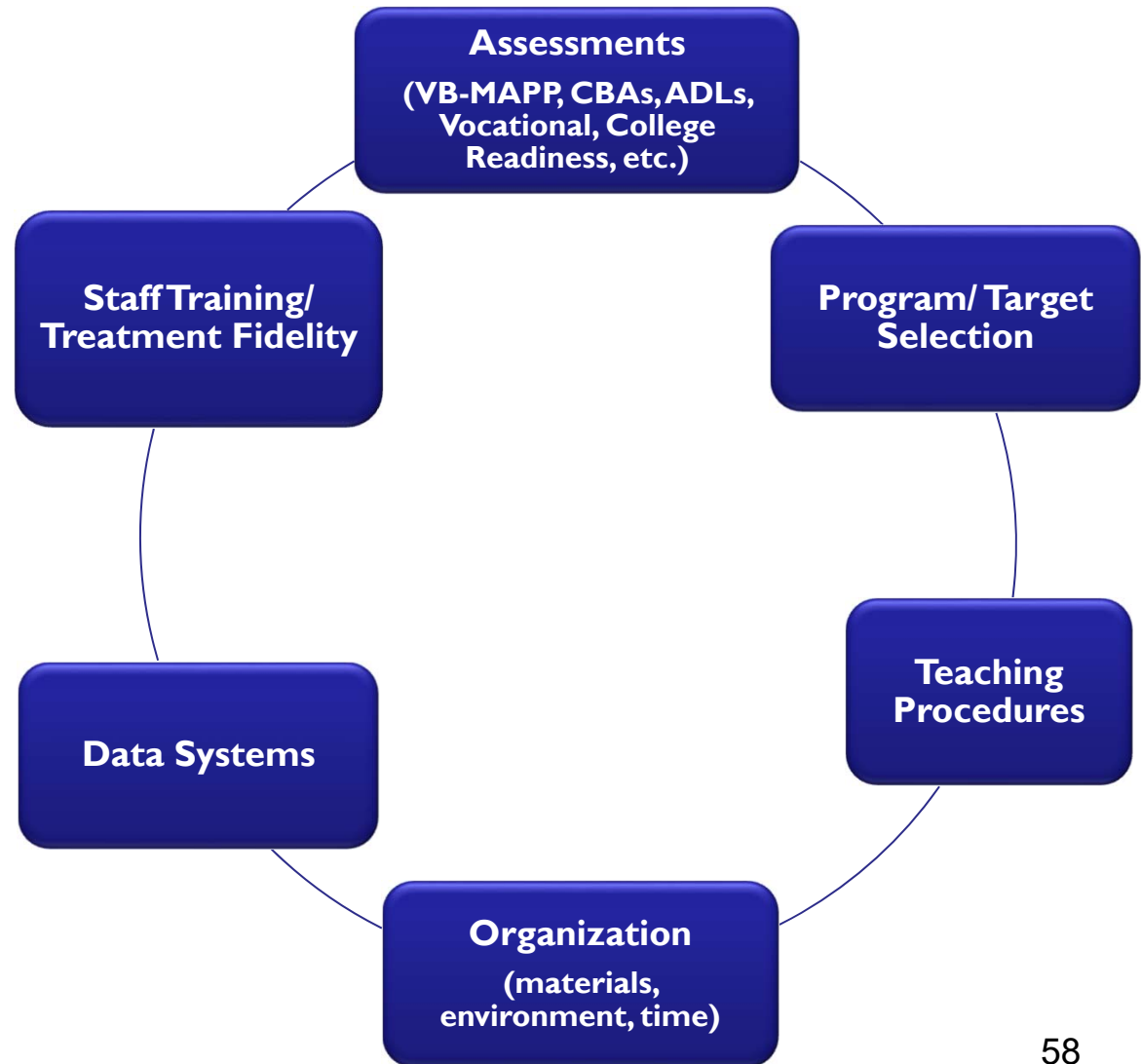
# Systematic Instruction

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- Identification of meaningful goals that are socially valid (what to teach).
  - Communication skills- Requesting wants and needs
  - Social Skills-Initiating and responding to social bids
  - Appropriate play/leisure skills
  - Self-help, completing independent activities

# An Integrated System of Instruction

- Assessment and instruction systems are probably most effective when they are integrated and form a feedback loop.



# Skills Needed by School Personnel to Implement Effective Practices in Autism Support Programs

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- Skilled management of social and physical environments to allow effective instruction
- Assessment skills
- Ability to monitor progress through data organization and analysis
- Consistent skill in delivering instructional protocols
- Dynamic responsiveness to student performance

# Teachers of Students with Autism Benefit from Effective Consultation

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- Consultation provides ongoing support and allows transparency
- Provides systematic feedback
- Effective consultation focuses on:
  - instructional behavior
  - teacher responsiveness to data systems
  - analysis of the many variables that can affect student outcomes
  - Motivating teachers and staff
- It helps teachers be aware of when to make changes



# Process

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- **Application** (late school year) including designation of internal coach
- **Initial Training:** 3 Day Boot Camp (intensive skill training: competency based)
- **Fall Site review**
- **On site consultation:** Guided practice model/behavioral skill training
  - Collaborators teachers/paras/support staff/internal coaches/administration
  - Manualization: resource file and video training resources
  - Instruction and Problem Behavior Reduction: two sides of same coin
- **Treatment integrity/Consult notes**
- **On site trainings** including review of boot camp
- **2 day trainings** Intermediate and Advanced protocols; Establishing Basic Skill Sets
- **Spring Site Review** and site designation (New, Return, Model, Model Independent)

# Instruction and Accommodations

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- This session has focused primarily on instruction
- Most accommodations become some aspect of an intervention and must be evaluated for effectiveness
  - Is accommodation needed?
  - How does the accommodation work?
  - Does it build toward independence?

# Common Accommodations:

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- Capture responses on an audio recorder
- Use a spelling dictionary or electronic spell-checker
- Use a word processor to type notes or give responses in class
- Use a calculator or table of “math facts
- Work or take a test in a different setting, such as a quiet room with few distractions
- Use special lighting or acoustics
- Take a test in small group setting
- Use sensory tools such as an exercise band that can be looped around a chair’s legs (so fidgety kids can kick it and quietly get their energy out

# Would such accommodations be necessary if....

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- Instruction is at the right level? Skills are well sequenced
- Pace of instruction is effective?
- Errors are reduced through errorless teaching?
- Error correction procedures are effective
- Motivation to complete tasks is considered including meaningful reinforcement system
- Sufficient practice is provided
- Skills are taught to fluency
- Skills are taught to a generative level (novel responses)

# Remember

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- Evidence should guide our selection of what will be taught and how it will be taught
- Currently, selecting interventions that include a behavior analysis is likely a prudent first step
- Selection of interventions is only step one: we also need to teach people to obtain direct evidence of effect (**evidence of practice**)
- To accomplish this, apply a systematic approach to instruction
- Effective collaboration between school and parents is essential!

# Become Informed About:

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- Your child's disability
- How the disability impacts the child's education
- Effective Interventions that are evidence-based
- Professionals who service children with the disability
- Controversies
- Special Education Law/Educational Rights
- Education Acronyms and Jargon

# Develop a Positive Parent-Teacher Relationship

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- Establish a partnership with your child's teacher
- Identify common goals
- Share decisions about your child's goals with the teacher
- Remember partnerships are bi-directional
- Give constructive criticism to help him/her become a better person
- Provide support to help achieve goals
- Be kind and supportive through the rough times
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# THINK POSITIVE, ACT POSITIVE!

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- Give recognition for efforts being made, accomplishments, good communication, etc. Don't forget to put them in writing and send copies to the district office and program supervisor.
- Communicate concerns in a respectful manner and don't hesitate to offer possible solutions and support to help solve existing issues
- Keep in mind that being assertive does not equate to being aggressive



# Communicate Effectively

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- Make sure you have specific and clear goals and/or desired outcomes.
- Clear, concise, and precise!
- Remain calm when speaking
- Communicate in writing whenever possible (even if you do this after the fact to summarize meeting discussions)
- It is perfectly fine to ask questions or disagree, but when doing so, remain respectful of the staff
- Set timelines for specific goals
- Follow up when due date is approaching

# Set Priorities Straight

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- Focus on the more critical issues that will make the most significant impact for your child
- You will be more likely to make things happen when you are willing to compromise on the "little things"
- Staff is more likely to listen and follow through
- In the long run you will achieve more in a shorter time...often times "less is more"

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Compromising and prioritizing does  
not equate to jeopardizing your  
child's education and progress

# Be a Record Keeper

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- Keep notes on all communications and meetings
- Keep copies of all reports, assessments, and/or recommendations
- Organize your notes and records

# Keep Your Cool

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- Set your emotions aside
- You will be better understood when you express yourself calmly
- Keep in mind everyone wants your child to succeed
- Avoid the turning point when it turns into a “battle of the wills”

# “I don’t want my child labeled”

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- Be clear with the health practitioners and/or evaluators about “preferring the truth” as much as it might hurt.
- What are the benefits of having a label:
  - Early planning and intervention, which research shows will yield better outcomes.
  - Leads to useful information, advocacy organizations, and support groups
  - Will help you formulate appropriate expectations
  - Protect your child from ridicule, maltreatment, or injustice

# Become Familiar with Educational Law

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- Three federal statutes that guarantee that every child with a disability have access to a Free and Appropriate Public Education (FAPE)
  - Individuals with Disabilities Education Act
  - Section 504 of the 1973 Rehabilitation Act
  - Title II of the American Disabilities Act

# Individuals with Disabilities Education Act (IDEA)

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- The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs.
- IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student.



# IDEA (continued):

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- IDEA also mandates that particular procedures be followed in the development of the IEP. Each student's IEP must be developed by a team of knowledgeable persons and must be at least reviewed annually. The team includes the child's teacher; the parents, subject to certain limited exceptions; the child, if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents' or agency's discretion.

# Understand the IEP

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- Within 30 days of being determined eligible for special education, a meeting to design your child's Individualized Education Program (IEP) must be held.
- You are an active member of the design team!
- Reasonable goals and services to be provided should be determined at this meeting
- IEP meetings are held once a year and a comprehensive re-evaluation must be done every 3 years.

# IF ALL ELSE FAILS:

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- IDEA provides parents and children other means of protection:
  - Give them the benefit of the doubt
  - Mediation
  - Due process hearing
  - Formal hearing

# In Summary.....

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- Diagnosis can assist in:
- Specifying interventions
- Understanding Autism
- Accessing helpful information
- But:
- Diagnosis is not enough, we will need more information to be able to program for our children and make a difference in their lives

# Some important things to remember:

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- The individuals we love and work with are not “autistic individuals” they are “individuals with autism”
  - People with ASD are individuals first
  - People with ASD respond to the world around them
  - There are no new principles of learning that apply only to individuals with ASD: the evidence shows that, like all students, students with autism respond to good instruction!

# Think BIG Picture

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- Where is everything being done today, headed tomorrow?
- Annual IEPs may inadvertently take away from a long term focus
  - What are the long term goals for your child?

# Alexander

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- 20 years old
- Diagnosed with PDD-NOS at age 2
- Formal diagnosis of Autism at age 4



# A dream come true!





# Just Like That.....

- Regression began at about 13 months
- First signs:
  - Social withdrawal
  - Appeared to “Stop” listening
  - Early terrible twos?
- Within a few short months, lost all language and responded to one thing....
- BARNEY (Yikes!)
- The journey began. My urgency: What do I need to do to help him?

- Answers from the supposed experts:
  - “Good news, it’s not autism, it’s just PDD-NOS”
  - Your child will probably never speak
  - We can teach him to communicate with pictures
  - Institutions are hard to get into so you probably want to start looking and planning as early as possible

# What I Quickly Learned:

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- Needed to start an ABA program as soon as possible
- It was the only thing with valid empirical research I could find
- People saying “we do ABA” is not enough.
- There were not enough behavior analysts who were getting good outcomes available
- Caring for kids is not enough...if you care enough, then you should be doing what is right and it should result in good outcomes for kids!
- Blaming the student for not learning is a major red flag.
- I urgently needed to learn this “ABA” thing

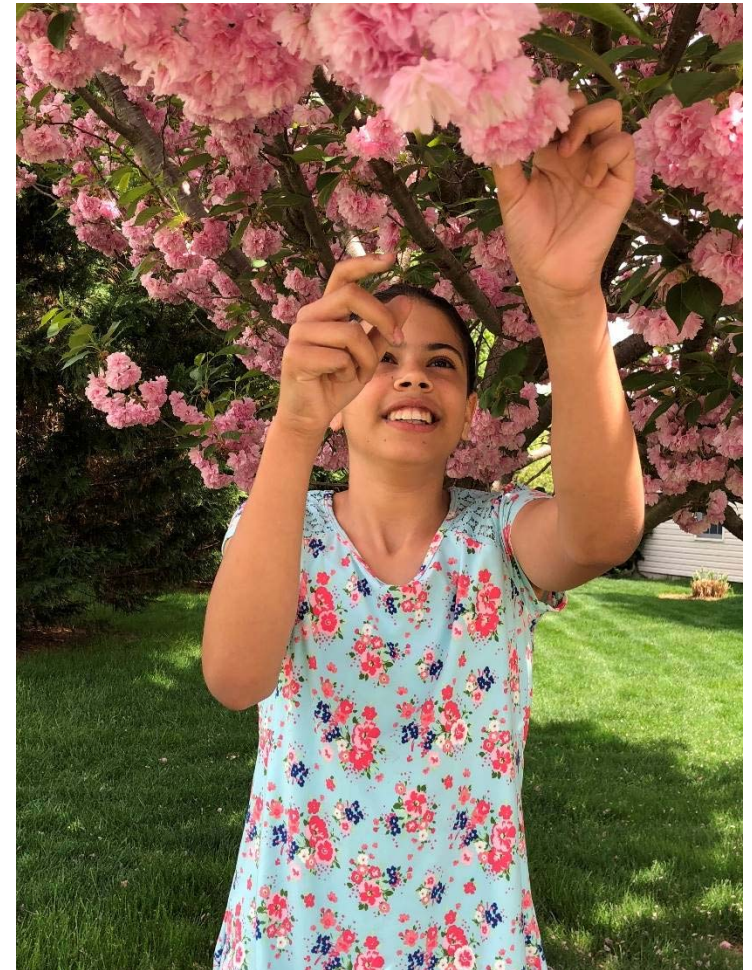
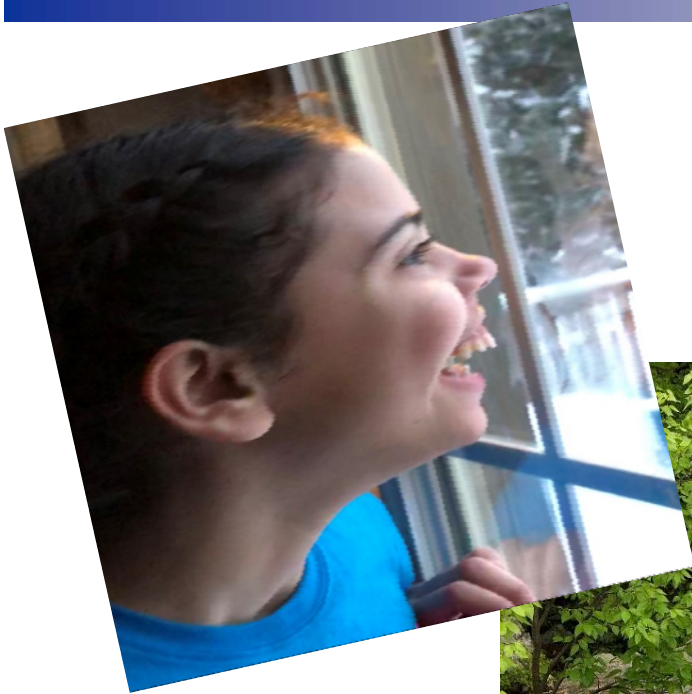
# Next Steps:

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- I researched local schools in New York that provided ABA services
- Set up a home program as well
- Started with a center-based program that provided 5 hours/day, 5 days a week of “ABA” with one: one ratio
- Began accessing as many trainings as I could
- But he is still not talking! There had to be more to this.

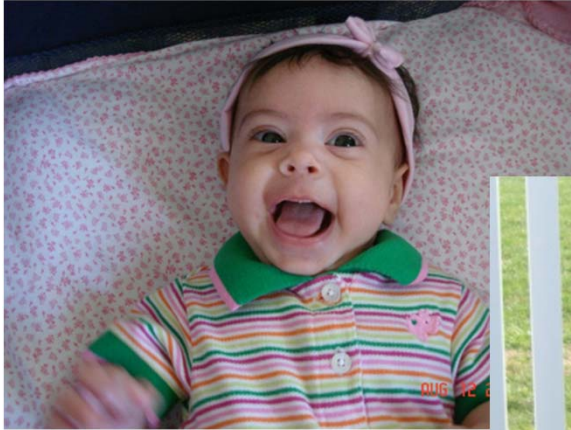
Sarah: 12 years old

Diagnosed with autism shortly after age 2





# Worry Free..."she's two, she's a girl, and she's doing great"... Not Quite



- Regression began at 25 months
  - First signs:
    - Social withdrawal
    - Stopped responding to name
    - I know it's not terrible twos!!!!
  - Here we go again
  - Could I do this again?
  - Well, at least I'm ready now.
- 89

# Two Great Kids Who Love Life





# Monkey Around





# Pro-Chefs





Child's name:		Alexander Dipuglia			
Date of birth:		8-19-97			
Age at testing:		1	2	3	4
1	2.5	2	4.11	3	4

Key:	Score	Date	Color	Tester
1st test:	15.0	1/30/00	Red	
2nd test:	31.5	7/2/02	Blue	
3rd test:				
4th test:				

### LEVEL 3

	Mand	Tact	Listener	VP/MTS	Play	Social	Reading	Writing	LRFFC	IV	Group	Ling.	Math
15													
14													
13													
12													
11													

0000 0000 0000 0000 0000 0000 0000 0000 0000 0000 0000 0000 0000

### LEVEL 2

	Mand	Tact	Listener	VP/MTS	Play	Social	Imitation	Echoic	LRFFC	IV	Group	Ling.
10												
9												
8												
7												
6												

0000 0000 0000 0000 0000 0000 0000 0000 0000 0000 0000 0000

### LEVEL 1

	Mand	Tact	Listener	VP/MTS	Play	Social	Imitation	Echoic	Vocal
5									
4									
3									
2									
1									

0000 0000 0000 0000 0000 0000 0000 0000 0000



After 2 ½ years of intensive ABA:

- Could ask for two items only if prompted
- Could not reliably label anything
- Could follow a few simple directions
- Could imitate a few motor movements
- Could echo a few sounds/words
- Could match identical items, complete puzzles and sort by color



# What was different?

## Why did Sarah do so much better?

### Alexander

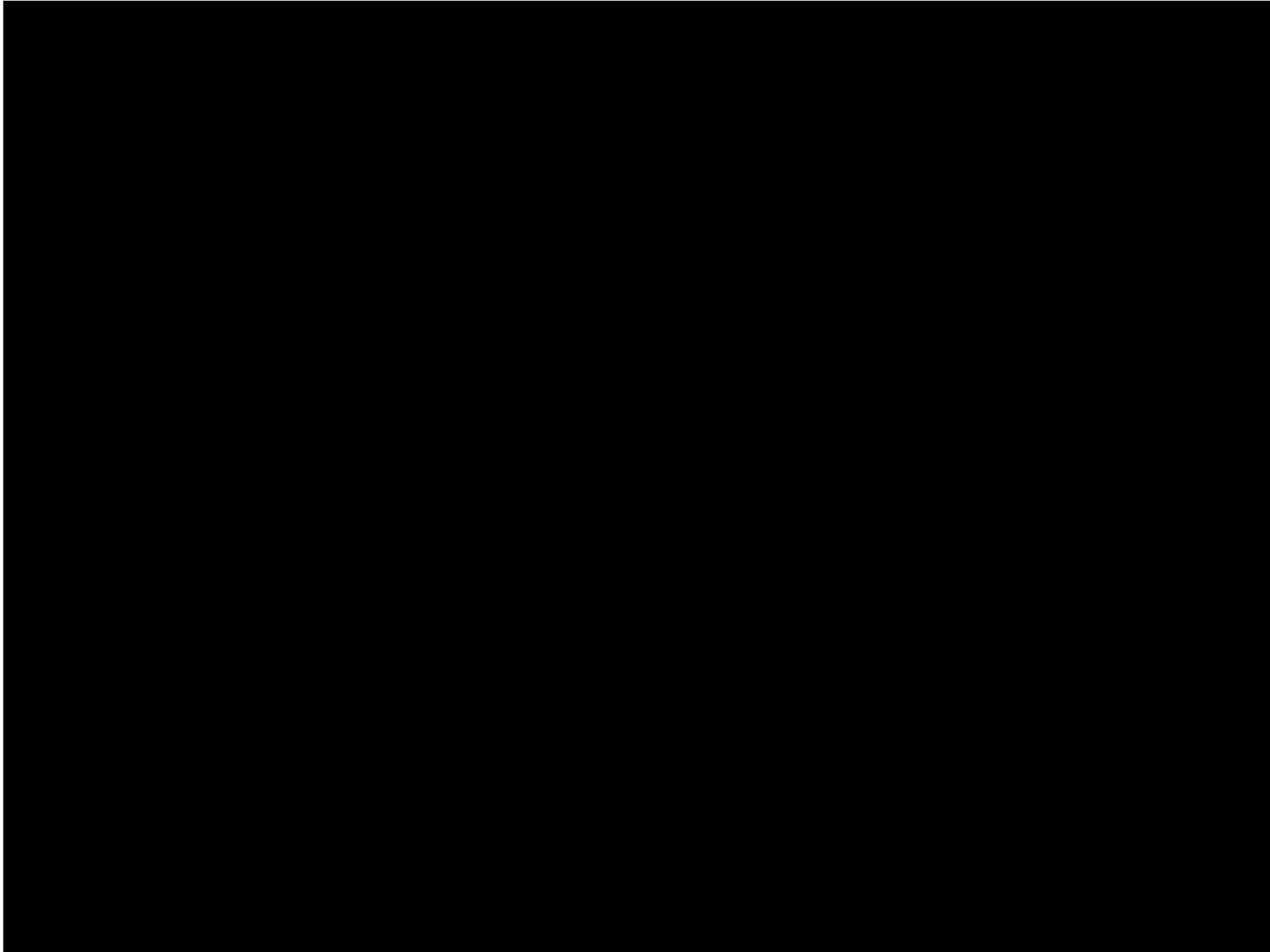
- 40 hours of intensive ABA therapy (25 in school, 15 in home)
- Program focused on imitation, receptive language, matching, tacts (labeling)
- No account for motivation, poor control of reinforcement
- No account for a behavior analysis of language
- Teaching procedures allowed for many errors and not enough teaching and practicing correct responses
- Bulk of sessions running target skills that were all difficult

### Sarah

- 12-15 hours a week of intensive ABA therapy
- Bulk of initial instruction focused on getting her motivated to respond, natural environment training (NET) and mand training (teaching to request wants and needs)...talking results in good things happening!
- Skinner's analysis of verbal behavior used for assessment, programming and teaching language.
- Clear teaching procedures as well as other procedures that motivate students to respond and are associated with high response rates and faster acquisition of skills
- Systematic and sequential teaching across all areas of instruction

# Early Video Sarah

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# Kindergarten





# 1<sup>st</sup> Grade



# 2<sup>nd</sup> Grade



# Procedures that changed Alexander's fate and made such a difference early on for Sarah:

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- Behavioral language assessment to guide programming...focus on mand training and systematic sequencing and building component skills
- Correlating instruction and everything about it with reinforcement...things get better during instruction!
- Fading in demands (number and effort)
- Interspersing easy and hard demands
- Mixed and varied format
- Fast paced instruction
- Reducing student errors (errorless and error correction procedures)
- Variable ratio schedule of reinforcement



# Don't forget relevant daily living skills

- Don't rush...build strong language and learning skills first.
- Think of critical skills that will allow student more independent and meaningful participation in the community



# Peer-Interactions:

## How did we make it happen?

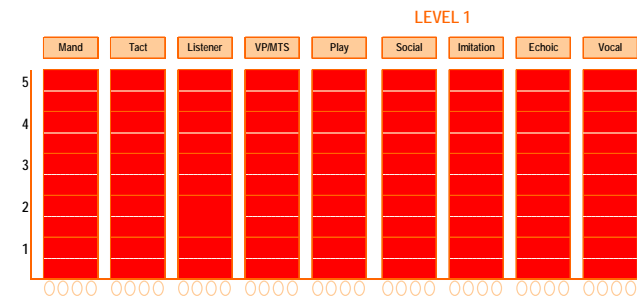
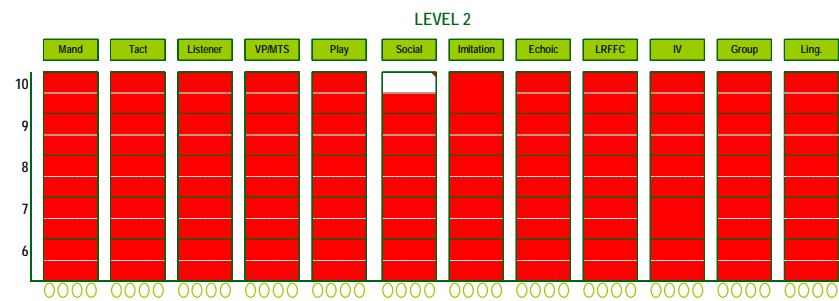
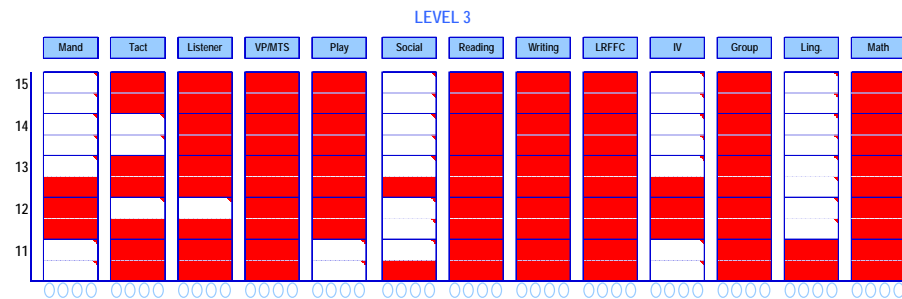
- Correlating peers with reinforcement...make them valuable!
- Teach explicit skills in a systematic sequence:
  - Accepting reinforcers from peers and approaching peers
  - Requesting from peers
  - Responding to peer requests



# Alexander Today

Child's name:	Alexander Dipuglia			
Date of birth:	8-19-97			
Age at testing:	1	2	3	4

Key:	Score	Date	Color	Tester
1st test:	146	9/1/17		
2nd test:				
3rd test:				
4th test:				



# Alexander Today

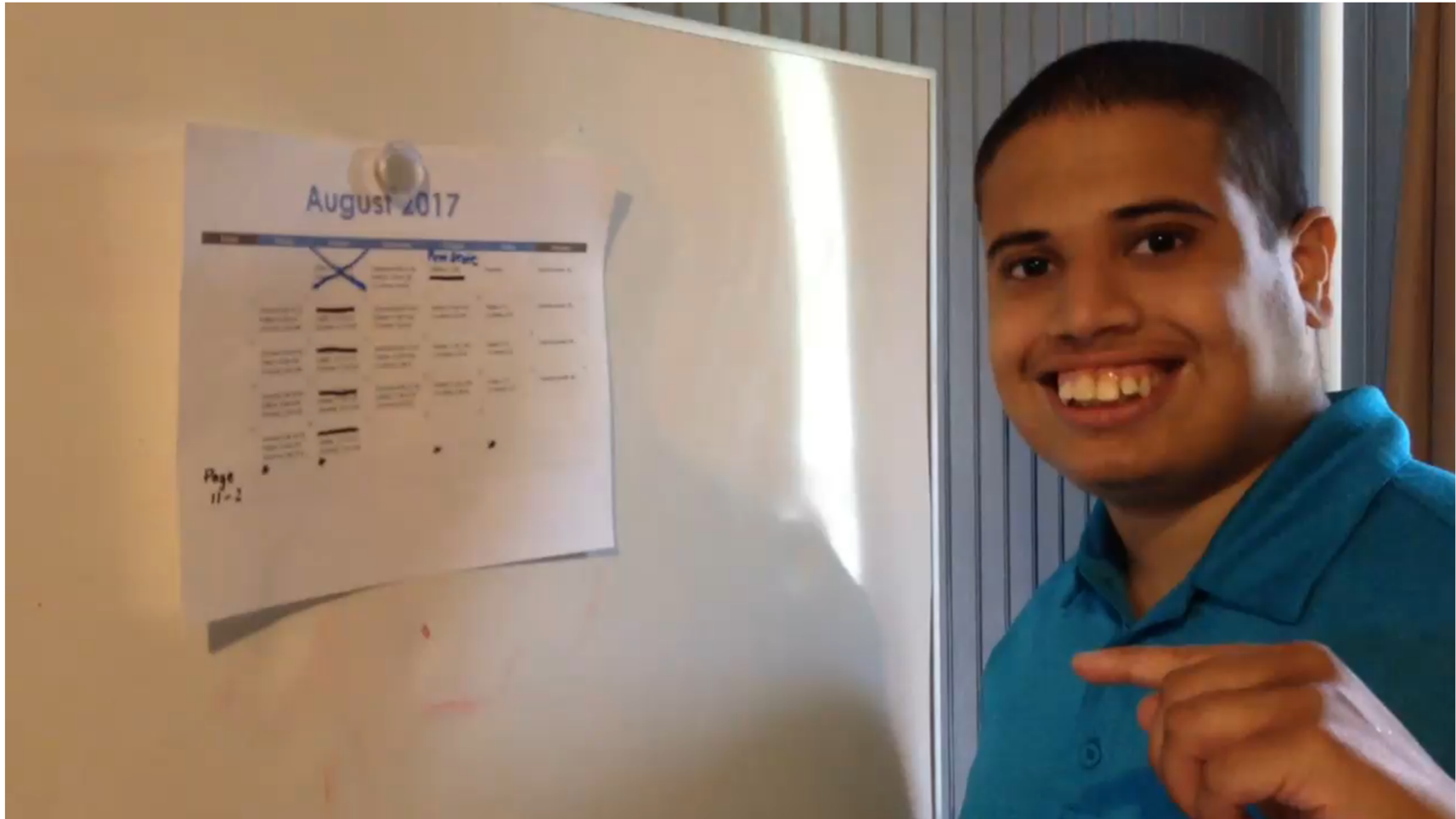
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# Alexander Today

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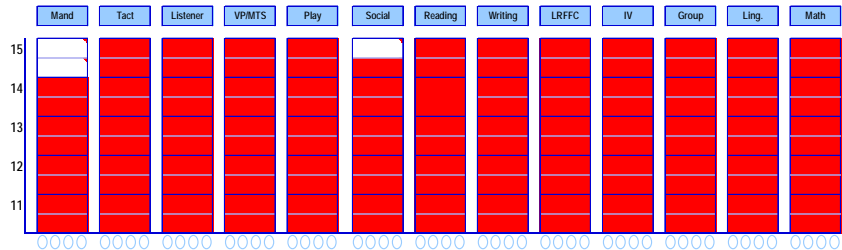


# Sarah Today

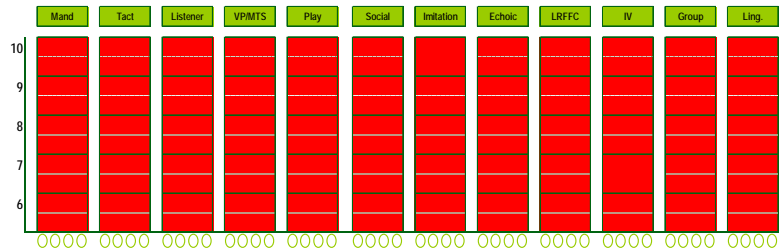
Child's name:	Sarah Dipuglia			
Date of birth:	5/5/06			
Age at testing:	1	11.3	2	3
	4			

Key:	Score	Date	Color	Tester
1st test:	165.0	Aug. 2017		Team
2nd test:				Team
3rd test:				
4th test:				

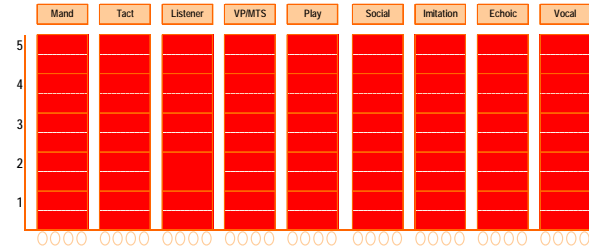
## LEVEL 3



## LEVEL 2

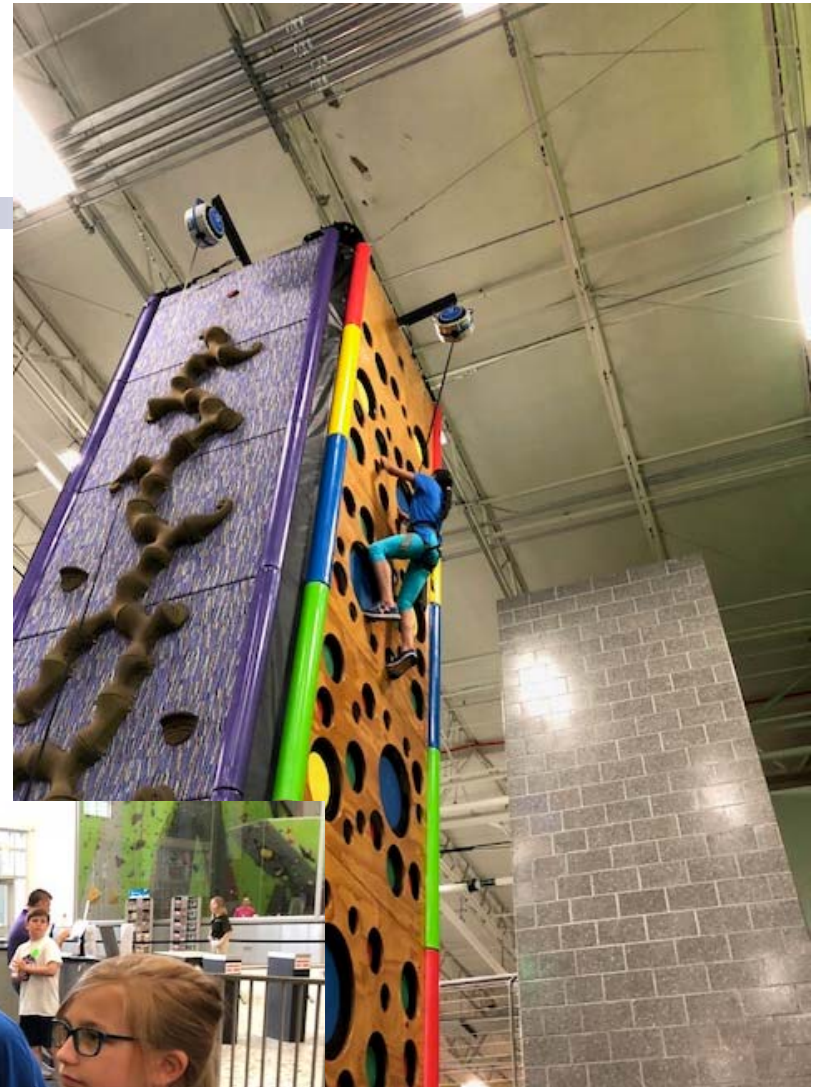


## LEVEL 1





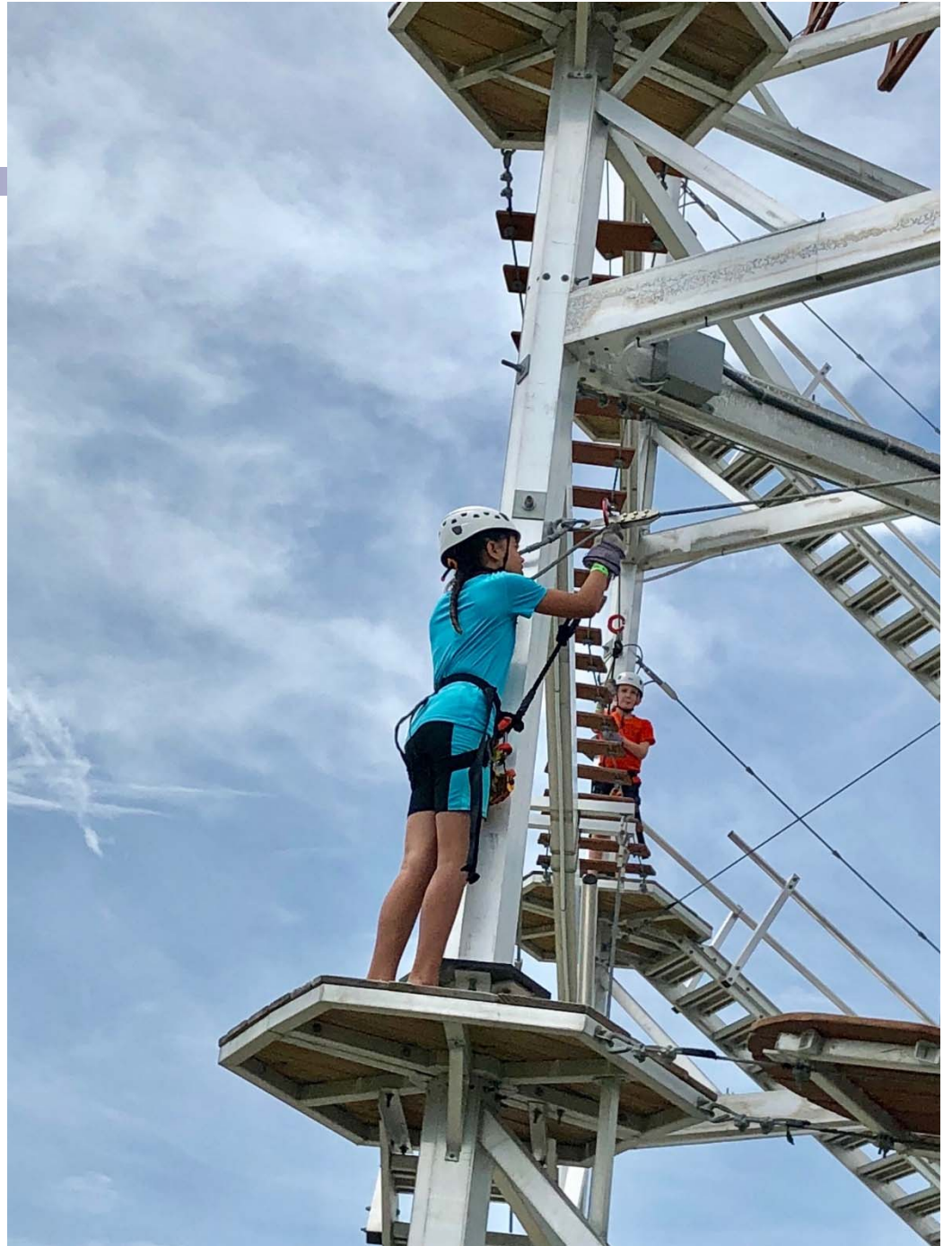
# Sarah Today



# Sarah Today

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- Life is better because of the skills she has developed!





# Tips for Success

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- Become as knowledgeable as possible
- Ask questions...careful with responses such as “we feel”, “we think”, “we like”...ask for the proof
- Some helpful questions:
  - What interventions do you use to teach?
  - What approach do you take to teach language?
  - What specific training have staff members received?

# Tips for success

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- Seems like a lot? It is!
- Tap into resources. Don't forget the good ol' wraparound services (BHRS). But remember, just because you don't pay a bill for it, doesn't mean it's free.

# Wraparound (BHRS)

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- Funded by DPW and intended to provide behavioral health rehabilitation services to keep children in their homes
- Based on medical necessity criteria
- Roles of BHRS and precautions:
  - Behavior Specialist Consultant (BSC)
  - Therapeutic Staff Support (TSS)
  - Mobile Therapist (MT)

# Challenges with Wraparound

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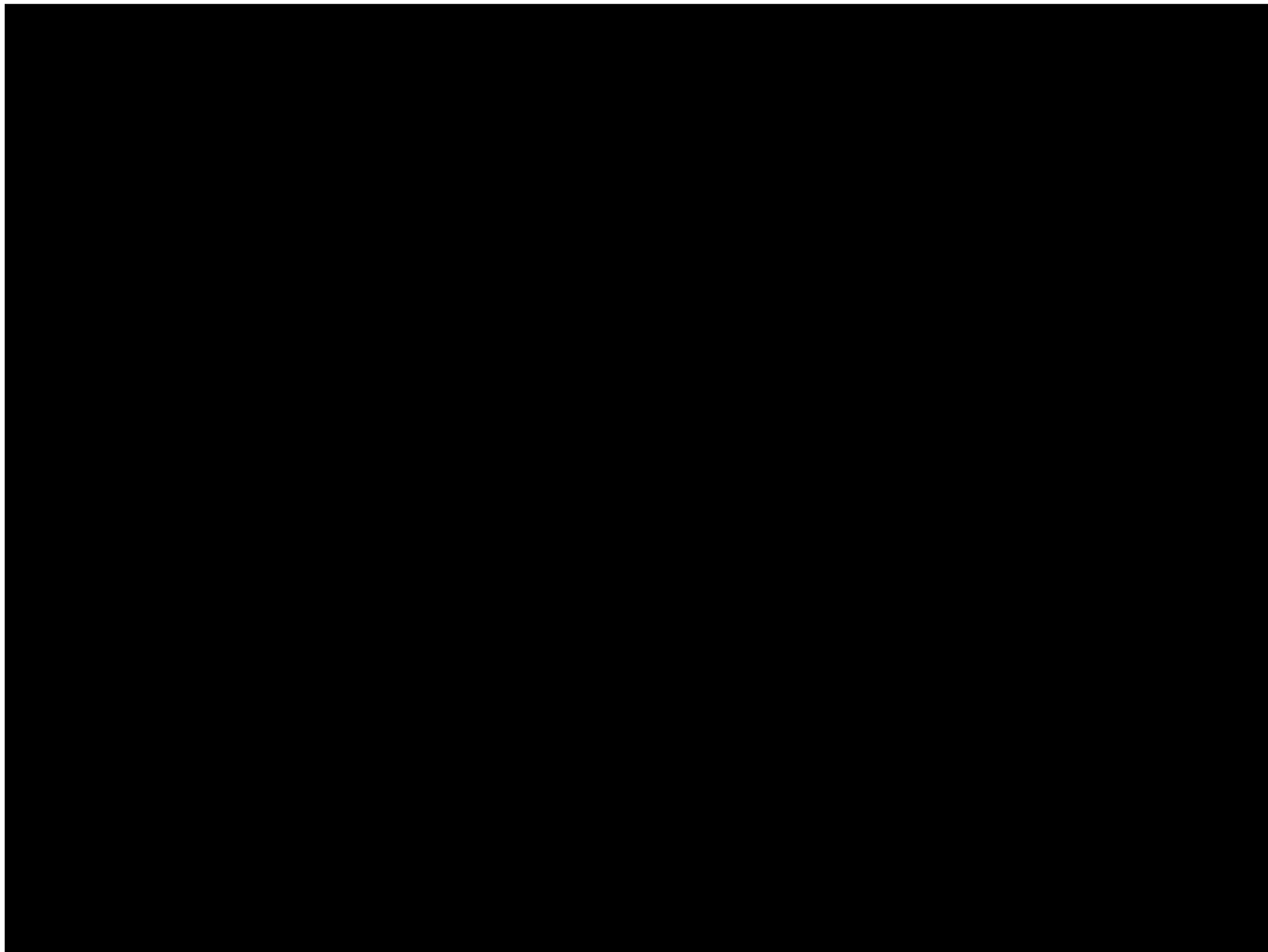
- Not originated with autism in mind
- Standards of practice not at par with current research or evidence of effective interventions
- Very limited, if any, training in behavior

# ABA Providers

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- BCBA's
- RBT's

Now accessible to PA families!



# We are Thankful for ABA!!!

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Thank You for Your  
Participation!

# Contact Information

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