FROM PROVIDER TO PARENT: A VIEW FROM BOTH SIDES OF THE SYSTEM

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Who Are You, Anyway?
Why is Your Story Interesting?
The Support Staff

- **1998: TSS**
  - Lack of support

- **1999: Grad School/Residential Substitute/TSS**
  - Trained in ABA
  - Working two jobs while pursuing Master’s
  - Found my passion
Direct Care is a Tough Job!

- Day 1 = Sweat
- Breaking a Toilet
- Bicycle Kicks at the Mall
- Diapers (and more diapers)
- Handprints
- “Oreos”
- 50 lbs.; 1 foot
Direct Care is an Amazing Job!

- No More Diapers!
- First Words/Phrases
- Passive No More
- Community Successes
- Paper Mache
- Do I Really Do That?
- The Bond
My Families and Kids Taught Me…

- Patience, Humor, Humility
- Parenting a child with special needs is a full-time job
  - Parent
  - Case Manager
  - Advocate
  - Behavior Support
- Not to judge the so-called “difficult” parent
  - Their reality as parents ≠ ours as staff
The Clinician/Executive

- 2000: Completed Master’s
  - Began developing and conducting trainings for staff
- 2002: Started ABA coursework
- 2003: Passed the Boards — official BCBA!
- 2004: Continued in clinical leadership roles
- 2009: moved into operations
The Parent

Motherhood
The Toughest
Job You’ll Ever
Love
Being a Parent is Hard!

- D. had digestive issues from birth (i.e. NO SLEEP!)
- Diagnosed with FPIES, a rare type of food allergy, at 11 months
- Elimination diet
- Diagnosed with Unspecified Immunodeficiency at 14 months after 4 day hospitalization for septicemia
- Began biting children at daycare
Being a Parent is Hard!

- Chose to pull from daycare for a few months due to continued infections (fevers of >104), accidental food exposures and behaviors
- Began Early Intervention
  - Didn’t qualify due to delays, only behavior and sensory
- Drove to Western PA to have evaluated
  - Borderline
- Diagnosed at age 2.5 (April 2015)
- Worry ensues…

Note to self: Worry will NEVER change the outcome ☺️ME
D. Growing Up

- Odd blinking/squinting as a baby (~9 months)
- Not consistently responding to name
- Did not respond as expected to loud noises
- Lack of response when someone was hurt
- Extremely high tolerance to pain
- “No” meant nothing
- NO FEAR
D. Growing Up

- Aggression (primarily biting) started and was intense
  - Latching on, breaking skin
  - Not responding to “typical” interventions

- No interest in peers
  - Seen as barriers; “things” that take/block access to toys

- No real play; wandering from item to item
D. Growing Up

- Early interest in academics; obsessed with colors, then numbers and letters
- Amazing memory
- Counted to 10 independently (~ 19 months)
  - “Oh my goodness…”
- Diagnosed as moderate to severe autism through ADOS at 2.5 years
- Language on level or above 6 months after diagnosis (tested low receptively initially)
- Prescribed ABA through BHRS; started September 2015
I AM the “Difficult” Parent

- Things I have done:
  - Cried in meetings
  - Called the state
  - Sent “pointed” emails (that friends needed to edit to “tone down” prior to sending)
  - “Fired” staff
  - Called people out for inaccurate information
  - Refused to agree with placements and interventions

- Squeaky Wheel Syndrome: a true representation of the power of ABA

- Job vs. your life

- If you don’t advocate, who will?
The System is Hard!

- Accessing services
  - Knowing what services to choose
  - Too “High”/Too “Low”
- Habilitative vs. Rehabilitative
  - “teaching”/social skills
- Staffing
  - Competent; right fit
- Cookie cutter approaches
- MEDICAL ASSISTANCE
I Know the System, Right?

We Can Do It!
The System is REALLY Hard!

- Took over 4 months to access services
- Knowing more than your team
- “We can’t do that.”
- The plight of the high-functioning: “Maybe it isn’t autism.”
- “He doesn’t need that level of support”/”He can’t be supported there.”
- Credentials over experience and the “it” factor
- No “good fit”; expelled from preschool
What Can We Do as Providers?
Training

- **Staff Training**
  - Diversity, customer service, working with families
  - Soft skills such as conflict resolution, communication, professionalism
  - Teaming
  - ALL LEVELS

- **Parent Resources and Trainings**
  - How to navigate the system
  - Hands-on behavioral training and support
Build Relationships

- Get to know your families
  - People are more likely to work with you when you have fostered rapport
  - Respect parents’ knowledge of their children
  - Explain decisions and include families in the decision-making process as much as possible
Build Relationships

- Get to know your clients
  - “Hard for me to take advice from someone who has never met my child”
  - Set up opportunities to meet
  - Different individuals require different types of staff
    - Sensory defensive vs. D.
    - High energy vs. Passive
    - Preschool vs. Teenager
Advocacy

- Work to change the system limitations
  - Become involved with provider groups like RCPA
  - Actively participate in meetings/workgroups
  - Give feedback on draft regulations and service descriptions
  - SPEAK OUT

DON'T BE SILENT
Advocacy (cont.)

- Most of the things that will benefit you as a provider will ultimately benefit children and families
  - Higher reimbursement rates = better pay for staff = bigger, stronger workforce
  - Ability to do, and bill for, all necessary components of a service = things getting done!
Advocacy (cont.)

- Propose and develop innovative, unique programming.
  - In a perfect world, what would exist?
    - Early Intervention alternatives
    - Alternative Case Management
    - Parent Peer Navigators
      - Offer support from someone who has been there
Advocacy (cont.)

- Educate families on the system and requirements
  - Many don’t know about service requirements; they just want to have their child’s needs met
- Involve families in advocacy efforts
What Can You Do for Your Employees?

- Understand that flexibility and time off are going to be needed
  - Meetings, appointments, crises
- Don’t need to treat in a special manner; just allow to use the resources that are already available (time off, employee protections, etc.)
- Find ways to support
  - Check-ins
  - FML
  - EAP
Employee Assistance Programs (EAP)

- Counseling

- Child Care Resources
  - Daycare
  - Preschools
  - Nanny/Babysitter

- Legal/Financial Resources
What My “Village” Adds

- Having good relationships with the families you serve benefits the agency as well
  - Best referrals and advocates are other families
- Providers/clinicians don’t have all the answers...remember the only one that has a PhD in that child is typically the parent
  - Staff get to leave; families are there 24/7
- Family struggles can become even more difficult as the child ages
  - Expect to have to provide a lot of care for a 2 year old, not when child is 20
- Parenting a child with special needs is often lonely
  - Friends, and even family, don’t understand
  - “Normal” family activities not so normal for the family of a child with special needs
  - “Having a child with autism makes a strong marriage just slightly weaker. I’m afraid to think what it would do to a weak marriage.”

- “Well-meaning” advice

- Parents will take a dedicated, caring staff who can be taught over one with the highest credentials who isn’t there for the right reasons
Welcome to My Home...
I Think
Welcome to Holland
Where Are We Today?

- Full-time support in typical pre-K
- Self-taught to read at 4
- Amazing imaginative play
- Inquisitive
- Incredible sense of humor
- Empathy emerging
- Making friends
- Behavior status
- Loves his mom!
THANK YOU!!