



# Family Life and Special Needs: Behind Closed Doors

By Amy Kelly

Director of Family & Community Services,  
Devereux PA

*Mother to Danny, Annie and Ryan*





# MY GOALS FOR TODAY

- Give you the sense of what families deal with everyday
- Allow you a safe and open forum to ask ANY question
- Leave you with a different perspective of one family's life



# ABOUT YOU...

- Who are you???
  - Parents?
  - Parents of a child with special needs?
  - Siblings of a person with special needs?
  - Provider or teacher to a person with special needs?
  - Self-Advocate?



# What IS Autism?

- Neurodevelopmental disorder
  - Social impairments
  - Communication difficulties
  - Restricted interests/ repetitive behaviors
- Spectrum disorder
  - Mild to Severe
  - Think of a rope



# What ISN'T Autism?

- A disease ..... NO!
- A virus ..... NO!
- Contagious ..... NO!
- Caused by vaccines .... NO!
- Curable ☹️ (unfortunately)



# Statistics

- 1 in every 68 children in the US are diagnosed with autism
- 1 in 42 boys
- 1 in 189 girls
- Four boys to every one girl has autism or another type of developmental delay



# Common Signs of Autism

- Social:
  - Lack of eye contact
  - Withdrawn/extremely shy
  - Lack of empathy or understanding others points of view
  - May not read social cues
  - May not understand social situations or humor



# Common Signs of Autism

- Communication:
  - Difficulty speaking
  - Limited vocabulary or speech
  - May act or seem deaf
  - May use an alternative means of communication like sign language or an iPad or pictures
  - May be very literal
  - May repeat things or ‘script’





# Common Signs of Autism

- Behaviors:
  - Rock, twirl or spin themselves or objects
  - Tantrum or self-abuse (biting, head banging) for no apparent reason
  - May be affected by lights, sounds or smells (sensory)
  - May run off away from caregiver (elope)
  - May do other unusual movements with eyes or hands



# Autism and Families

[https://youtu.be/PK5wFjd\\_kZ8](https://youtu.be/PK5wFjd_kZ8)




*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



*Four words changed my  
Whole life....*

*“Your daughter has Autism”*

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# THE BEGINNING: The Diagnosis

- Rollercoaster of emotions...
- Dealing with many dynamics – next steps? how to tell family and friends? what about their siblings? fears of the future...
- Feeling of extreme isolation
- Every family's experience is unique



*This is my Annie. The day before her 2nd birthday, she was diagnosed with autism.*



**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# WHAT TYPES OF THINGS HAPPEN THAT WE DON'T SEE IF WE DON'T LIVE IT?

- Information overload
- The land of acronyms
- Struggle sharing diagnosis with other people, even family
- Personal grieving process
- Dealing with a new reality & lifestyle

*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



*First, Annie  
learned to  
talk with  
PECS*



*Then Annie  
learned to talk  
to me with her  
iPad*


**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™





# HOW DO FAMILIES DECIDE ON TREATMENT AND CARE?

- Early evidenced-based interventions are proven to work over time
- Research all interventions, therapy and care options and talk with your team
- “Slow and Steady” really does win the race...progress takes TIME



*Every moment is a “teaching”  
moment – there is NO break  
from the special needs world*



*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™

*For my family, every moment is  
a teaching moment...even  
popping bubbles.*



**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



*Every night, I still have to ‘teach’  
Annie how to brush her teeth....*

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# DAILY LIFE

- There is no “normal”
- Very often, just simple day to day activities are a challenge
- Schedule, routines and preparation are KEY – many ‘visitors’ each day; doctors appointments, follow ups, etc.



*First, Annie  
learned to  
talk with  
PECS*



*Then Annie  
learned to talk  
to me with her  
iPad*

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



*This was our family about 5 years ago....*



# A Grandmother's Perspective:

- The only thing I knew about Autism: The 1988 movie Rain Man; I could make NO connection with that to my 2 year old granddaughter.
- Acronyms were too many and they keep coming. Leave that to Amy
- Personal Grieving...Shoved aside for immediate action — Action was easier.

*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™

- © All information is the intellectual property of Amy Kelly and should not be pirated or stolen for any reason
- Dealing with a new reality and





# A Grandmother's Perspective - 2:

- Struggle sharing diagnosis with others: Who knew some family members would have such high fenced boundaries?
- Packed suitcase, hit the road, do necessary daily tasks to free-up Amy's time to seek out, research and create a plan for Annie.

# A Grandmother's Perspective - 3:

- Keep ALL my grandchildren happy.
- Dealing with a new reality and lifestyle as a grandparent: God Bless My Husband.



*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# COPING – IT IS ESSENTIAL FOR FAMILIES TO ...

- Reach out and develop a support system – friends, doctors, families, support groups, church, neighbors
- Learn to ask for *HELP*
- Get involved to the level you can... therapy, child's day to day progress, fundraising, advocacy, school, siblings' activities
- Recognize the silver linings! In the midst of chaos, there are **MANY** gifts...

*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



*Our “normal” day at the beach*

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# FAMILY PRIVACY

## NO LONGER EXISTS

- The home becomes a revolving door
- Boundaries of “home life” and “therapy life” may become blurred
- Families may want to be more involved but might be drained/ burned out or just don’t know what to do
- Families are vulnerable – They trust YOU to make the right decisions for them and their child

**Devireux**  
ADVANCED BEHAVIORAL HEALTH

UNLOCKING  
HUMAN POTENTIAL™

# Some of our 'silver-lining moments'



**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



*We have all  
learned to  
embrace the  
“little things” ...  
as it turns out,  
they are the  
BIG successes*


**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# UNDERSTANDING & ACCEPTANCE OF A DISABILITY

- Affects each family differently
- Affects ALL ASPECTS of family's life: marriage, siblings, extended family, friends, teachers, neighbors, strangers, community
- NEVER ASSUME YOU KNOW FULLY WHAT IS GOING ON





# KEY TAKE-AWAYS:

- Having a family member with a disability can affect ALL ASPECTS of family's life: marriage, siblings, extended family, friends, teachers, neighbors, strangers, community
- Never assume you know fully what is going on
- Try not to make judgments or take things personally



*Rehoboth Beach, July 2015*

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# WHAT RESOURCES WOULD HAVE MADE MY LIFE EASIER?

- A “How To” Guide from the start (How to get MA; Wraparound 101; What is Autism? What is ABA?)
- Guidance to navigate the systems of care:  
Educational~Medical~Behavioral  
(Public school vs. approved private; outpatient services vs. residential; wraparound services)
- Connections with other families



# WHAT RESOURCES WOULD HAVE MADE MY LIFE EASIER?

- Transition planning at all ages (preschool, elementary, middle, high school, college, employment)
- Help to plan for the future ~ (special needs trusts, SSI, housing, waiver funding, .... what happens when I die???) ☹️)
- ME! 😊 (or at least a GREAT case manager!)
- ***DEVEREUX PROVIDES ALL OF THESE SERVICES!!!***

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™



# THE FUTURE???

- Unknown – even more than for the average family
- Teen years and puberty?
- College?
- Over 21 years old?
- Job? Where will they live?
- Marriage? Grandchildren?
- Financial Supports
- I can never die...



# Important Points to Remember

- Autism affects each family different
- If you know one individual with autism, you only know one individual with autism
- Even though they may show it differently, most people with autism hear and understand everything like you do



# HOW ANNIE'S SCHOOL DEVEREUX CARES CHANGED MY FAMILY'S LIFE

- Gave us our first taste of our “normal”
- Gave us a community of acceptance
- Gave us the ability to breathe
- Gave us HOPE

# Annie's First Job! Jan 2016



*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™





*Behind my closed door,  
with Annie....*

<https://youtu.be/H6iXZYKG7Fs>

<https://www.autismspeaks.org/news/news-item/very-special-mother039s-day-duet>

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™

*Thank You...*



*Devereux* | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™

© All information is the intellectual property of Amy Kelly and should not be pirated or stolen for any reason



**Questions? Contact Amy Kelly**  
[akelly2@devereux.org](mailto:akelly2@devereux.org)

**610-585-9250 610-710-4041**

**Devereux** | UNLOCKING  
ADVANCED BEHAVIORAL HEALTH | HUMAN POTENTIAL™

© All information is the intellectual property of Amy Kelly and should not be pirated or stolen for any reason