

Navigating Educational and Behavioral Services: What Parents of Autistic Children Need to Know

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Where children with special needs blossom.

"Being a parent of an autistic child is like having a full-time job"

Types of Services

- Early diagnosis and services
 - School services
 - Mental health services
 - Teen and adult transition services
-
- Medical Necessity/LRE versus Entitlement

Diagnosis

- 1940's: Leo Kanner, Hans Asperger
- DSM-IV-TR: Pervasive Developmental Disorders
 - Autistic Disorder
 - Communication, Socialization, Behaviors
 - Asperger's Disorder
 - Socialization, Behaviors
 - PDD-NOS
 - Rett's Disorder
 - Childhood Disintegrative Disorder

- DSM-V: No Asperger's, PDD-NOS, Rett's, or CDD... only ASD:

Must meet criteria A, B, C, and D:

- A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:
 1. Deficits in social-emotional reciprocity
 2. Deficits in nonverbal communicative behaviors used for social interaction
 3. Deficits in developing and maintaining relationships
- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
 1. Stereotyped or repetitive speech, motor movements, or use of objects
 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
 3. Highly restricted, fixated interests that are abnormal in intensity or focus
 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment
- C. Symptoms must be present in early childhood
- D. Symptoms together limit and impair everyday functioning.



Horse Boy with train:

Early Diagnosis

- Universal ASD screening on all children at 18 and 24 months regardless of whether there are any concerns... red flags:
 - ◆ no babbling, pointing, gesture by 12 months
 - ◆ no single words by 16 months
 - ◆ no two-word spontaneous phrases by 24 months
 - ◆ loss of language or social skills at any age

Very Early Detection Signs

(Zuckerman, 2010)

Hand Shaping & Reaching

- 6 mos: undifferentiated lunge
- 7-8 mos: hand shaped in at point of grasp
- 9 mos: hand shaped midway through reach
- 12 mos: hand shaped prior to reach

Cognitive Play with Object

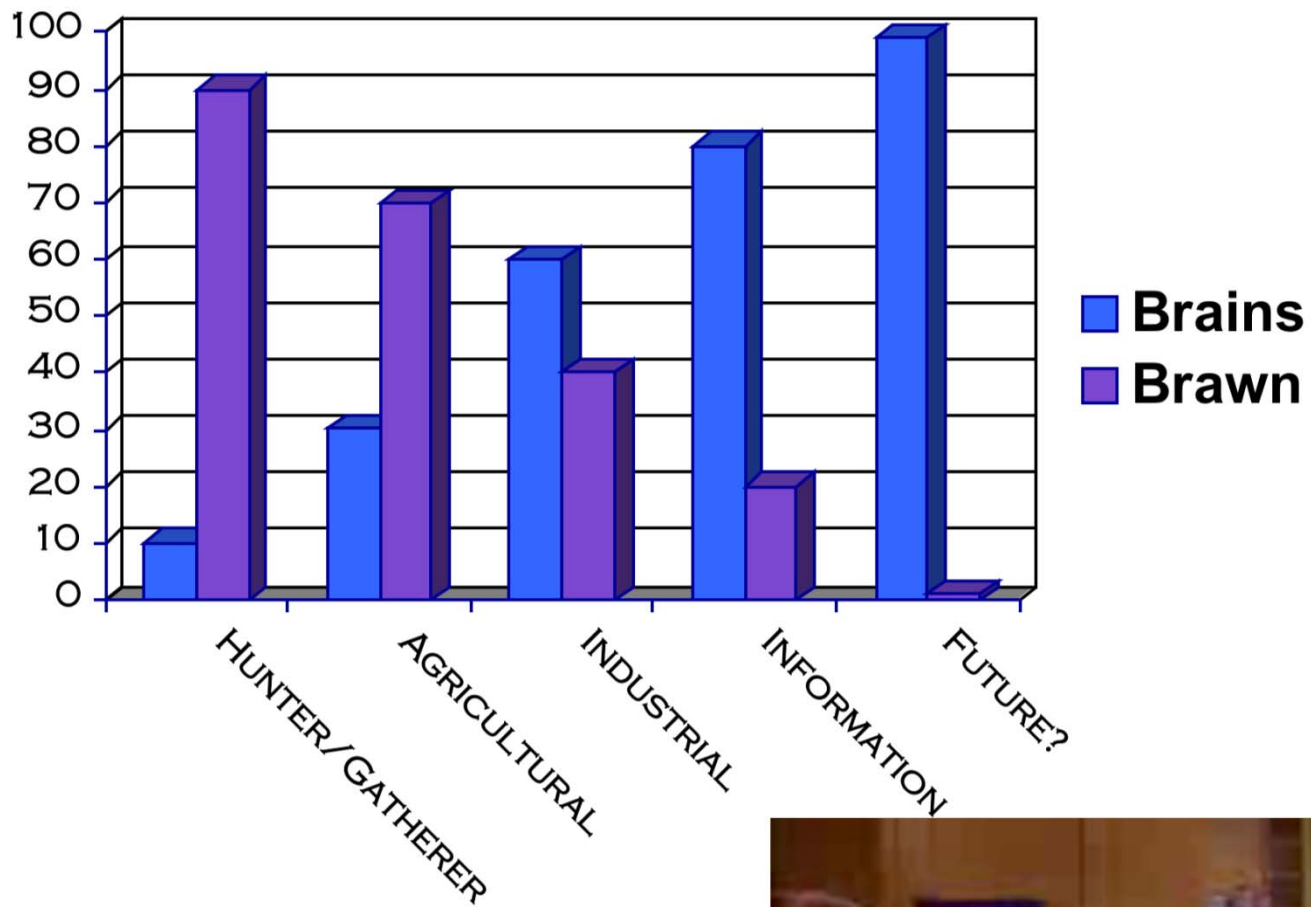
- 6 mos: undifferentiated grasp
- 7-8 mos: banging/shaking
- 9 mos: coordinated visual motor exploration
- 12 mos: socially discriminating use

Grasp

- ♦ 6 mos: uncoordinated rake
- ♦ 8 mos: rake with thumb and forefinger
- ♦ 9 mos: pincer grasp; thumb and forefinger perpendicular to surface

Social/Emotional

- ♦ 3 mos: most responsive to primary caregiver
- ♦ 6 mos: social referencing
- ♦ 9-12 mos: separation protest
- ♦ 12-24 mos: checking in when exploring



EVOLUTION?



NTs and Aspies/Auties

What Is NT?

Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs find it difficult to be alone. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviorally rigid, and frequently insist upon the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum. NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical is typically smaller than that of an autistic individual and may have overdeveloped areas related to social behavior.

* The Diagnostic and Statistical Manual of Normal Disorders: 666.00 Neurotypic Disorder

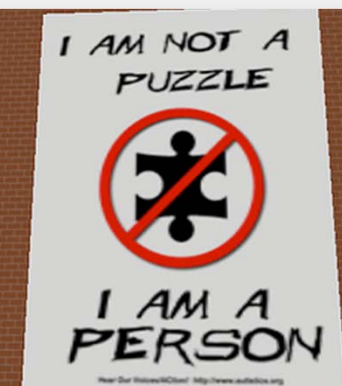
How Common Is It?

Tragically, as many as 9625 out of every 10,000 individuals may be neurotypical.

Are There Any Treatments For NT?

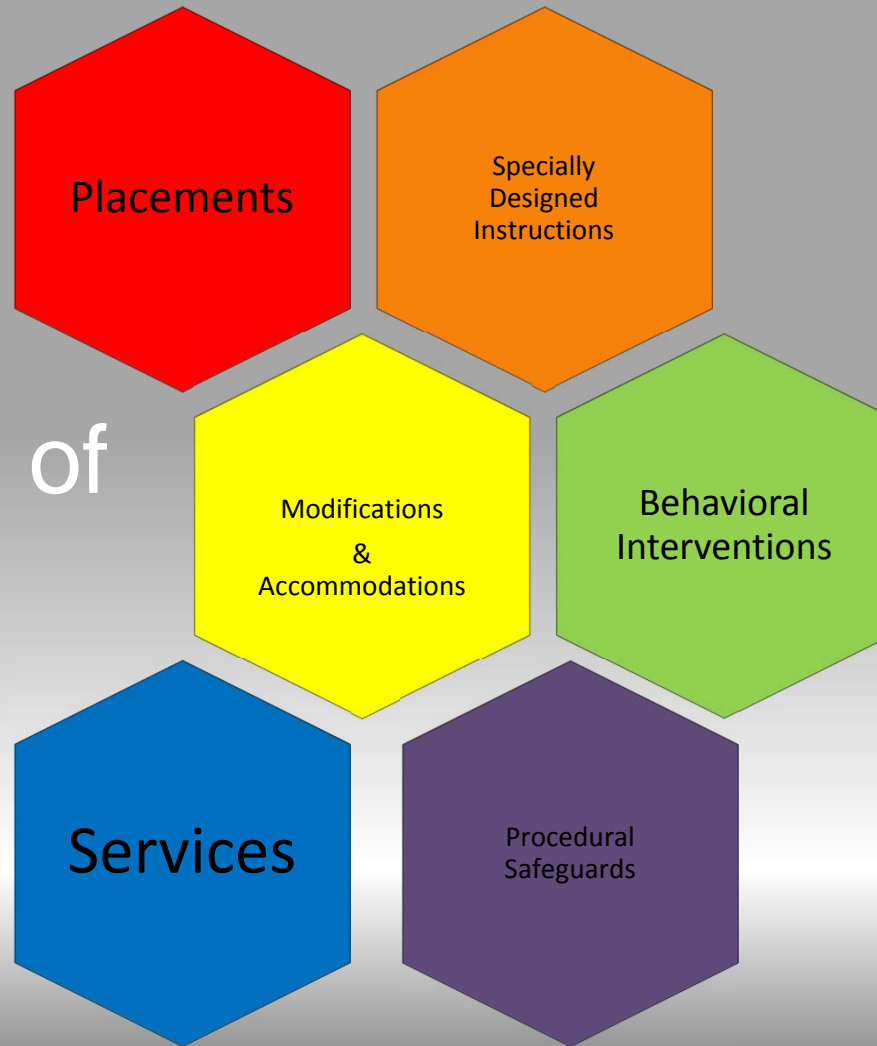
There is no known cure for Neurotypical Syndrome.

<http://isnt.autistics.org/>



■ Questions about early diagnoses?

Benefits of IEPS



LRE and Educational Placements

General Education/
Mainstreaming

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graph TD; A[General Education/  
Mainstreaming] --> B[Specialized Classrooms  
• Autistic support  
• Lifeskills  
• Emotional/Behavioral]; B --> C[Approved Private Schools]; C --> D[Non-Approved Private Schools  
Home-based instruction  
(w/cyber options)];
```

Specialized Classrooms

- Autistic support
- Lifeskills
- Emotional/Behavioral

Approved Private Schools

Non-Approved Private Schools
Home-based instruction
(w/cyber options)

Individual Education Plans (IEPs)

- Legal document of goals, services, and accommodations
 - Compensatory education funds
- Living document- can be modified as necessary
- Must be revised at least every year
- Specially Designed Instruction
- Modifications and Accommodations
- Manifestation Determinations

School Behavioral Supports

- Functional Behavioral Assessments (FBA)
 - Investigates behaviors of students
 - What the behavior looks like
 - Frequency, intensity, and duration
 - When it occurs
 - Why it occurs
 - Gain
 - » Attention, sensory stimulations, access to activities or toys
 - Avoid-
 - » social situations, work, sensory stimuli, transitions

School Behavioral Supports

- Behavioral Intervention Plan
 - Specific plan detailing how to address the negative behavior
 - Includes
 - Ways to strengthen the behavior (reinforcements)
 - Ways to decrease the negative behavior (consequences)
 - Specifically designed instruction (if needed)

IEP Services

- Occupational therapy- sensory diets, hygiene, life-skills, handwriting
- Speech/language therapy- PECs, assistive communication devices, emotional expression, pragmatic (social) skills
- Counseling- coping skills, social skills, emotional expression,
- Transitional Planning/Vocational Training
- Physical therapy-

Procedural Safeguards

- Notice of Recommended Educational Placement (NOREP)
 - Schools can not change the type of educational setting without parents' written consent
 - Child remains at current placement until decision is made

Timelines

- Parents must receive a permission to evaluate within 10 calendar days of oral request
- ER is completed within 60 calendar days of parental permission.
- Parents must have 10 days to review report
- Within 30 days of ER, school must write and IEP
- 10 days to fully implement IEP once it is developed
- IEPs must be revised every year
 - IEPs can be amended at any time with agreement from all parties

IEP vs. 504

	IEP	504
Under	IDEA	ADA
Purpose	Special education services	Equal rights to people with disabilities
Provides	General or spec. ed curriculum; possibly special classrooms; services (OT, Speech PT) interventions, accommodations	General education curriculum/ classroom with resource room assistance if needed, accommodations, simple interventions
Funding	Federal funding	none

504 Accommodations

- Wheelchair accessibility
- Medication administration
- Structured learning environment
- Repetition of directions
- Behavioral management/ intervention strategies
- Modified homework
- Second set of text books
- Modified testing procedures
- Tape recorders, computers, spell checkers word processor
- Reduced number of problems required.
- etc

Advocating

- Parents Involved Network
- Educational Law Center
- HUNE
- Advocates
- Lawyers
- Make the school your partner!!
- Attend meetings
- Express concerns in writing



Kershenbaum:

Autistic not graduating:



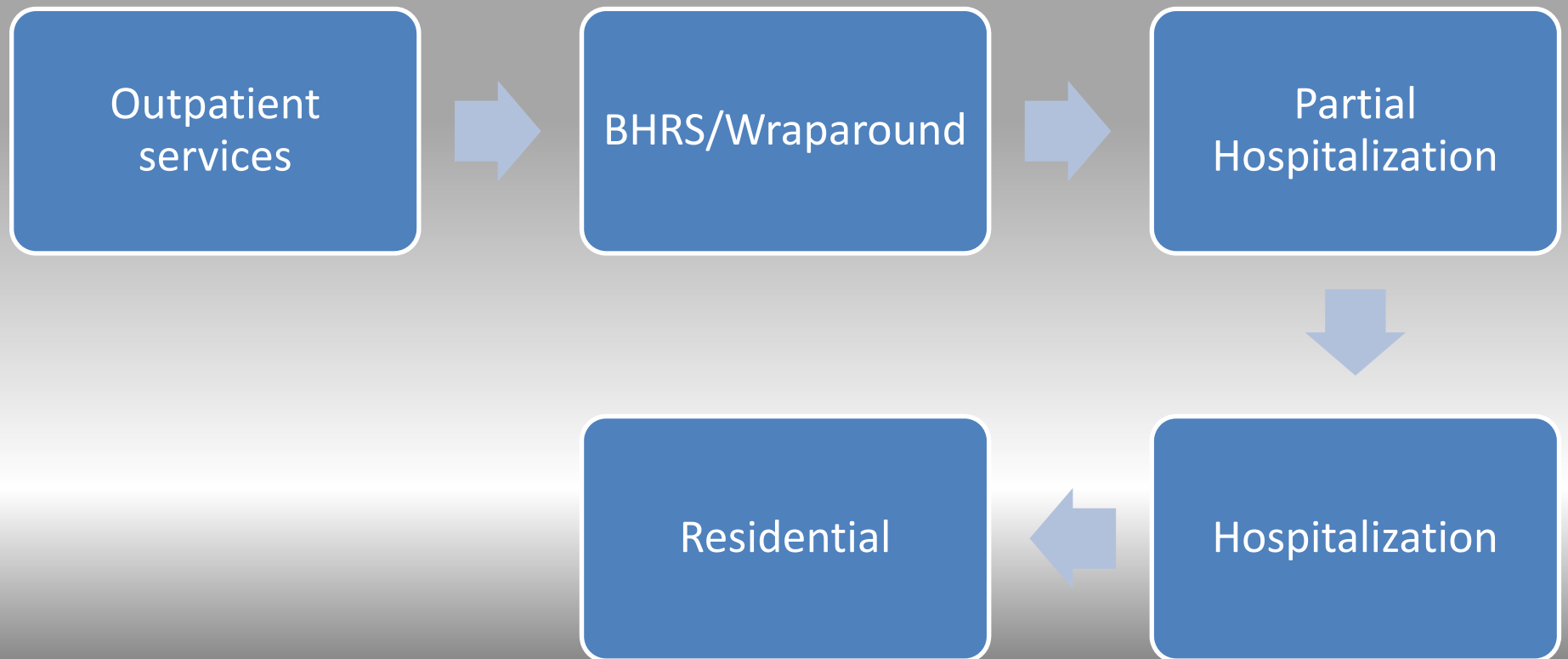
Sports and Disabilities



- January, 2013: US Department of Education indicates that similarly with Title IX (gender equality), all students with disabilities must be provided with opportunities for extracurricular athletics, and that additional athletic programs must be created if existing programs don't meet the needs of students with disabilities, including clubs.
- According to a 2010 report from the Government Accountability Office, disabled students do not have equal opportunities to sports, a right that is protected by the Disabilities Act of 1973
- Education Secretary Arne Duncan: Sports provide: “invaluable lessons in discipline, selflessness, passion and courage, and this guidance will help schools ensure that students with disabilities have an equal opportunity to benefit from the life lessons they can learn on the playing field or on the court”

■ Questions about school services?

Levels of Service



Medical Assistance

- Helps pay for services such as STS, BHRS, outpatient, etc.
- Must have proof that you submitted information to SSI (can be rejected)
- Need medical evidence of child's condition
- Need to reapply once a year
- ACT 62: Autism Insurance Act

ASD and Therapy



- Outpatient Therapy
 - Too cerebral and abstract at times
 - Cognitive behavioral
 - Motivation
 - Family involvement
 - Play
 - Video
 - Behavior planning
 - Self-esteem
 - Identity
 - Advocacy and resources

Drug Push



- Medications help with symptoms, but cannot cure ASD
- Risperdal, Geodon, anti-anxiety, anti-depressants
 - Low-dose Risperdal more effective (Grandin and others)
 - Possibly due to clients railing against effects of sedatives when unaware of impact
 - Weight gain side effect with recurrence of aggression... crisis
 - Geodon as alternative
 - Parent training with meds more effective (Aman et al, 2009)
- Contraindication of stimulant meds unless dually diagnosed
- Depakote usage and toxicity
- Lupron (typically used for chemical castration)
 - Dr. Mark Geier: "Lupron is the miracle drug"
 - 2011: Geier stripped of medical license
- Medical Marijuana controversial
 - Appetite increase
 - Behavior regulation

BHRS/Wraparound Services:

- **Psychological Evaluation**: This is the initial evaluation and reevaluation of the client at least once a year.
- **Behavior Specialist Consultant (BSC)**: Designs and implements a treatment plan. The BSC identifies the short and long term goals, and outlines intervention methods.
- **Mobile Therapy**: The (MT) provides intensive therapeutic services to a student and their family unit in settings other than a provider office or agency.
- **Therapeutic Staff Support: (TSS)**: The role of TSS is to provide support to the student in specify areas of social, behavioral, and emotional concerns that are identified as barriers to their success in the school, home and community environments.

When does my child needs BHRS?

- When behavioral needs can not be met by outpatient services and are not escalated enough to require emergency care
 - the child is unable to function independently in school
 - Aggression
 - Tantrumming
 - Social delays
 - Attention deficits
 - behavioral issues in the home
- BHRS Providers specializing with ASD:
 - Green Tree, Center for Autism, CGRC, SPIN/NET, Elwyn, PA Mentor

Partial Hospitalization

Day Treatment

- Individualized treatment planning to address specific behavioral, emotional and educational needs
- Individual and group psychotherapy
- Behavior management
- Recreational therapy
- Medication management
- Family therapy
- Nursing interventions

Things to Consider

- Many partial hospitalization programs use group therapy. Make sure the one you select for your child meets your child's needs such as providing movement therapy if your child is non-verbal
- You can remove your child at any point. The process is voluntary
- No regional partial programs specialize in autism in the Philadelphia area

Crisis Response Center (CRC)

- Purpose: Emergency behavioral health triage area for children exhibiting aggressive and/or destructive behaviors
- What it looks like: Brief, intensive assessment of immediate behavioral health needs
- Where it fits: Anywhere on the continuum of services as emergency can occur at any time during a child's life

When do I take my child to the CRC?

- Severe and prolonged aggression
 - Causing severe injury to themselves, others, or property
- Homicidal or suicidal ideation or behavior
- Profound behavioral reaction to medication change

Stories from Hospitalization

Examples of actual cases from just one psychologist in Philadelphia in recent years who could have been helped by specialized hospitalization at a crisis response center (CRC) include:

- MC: 11-year-old boy with autism who constantly bangs his head against the wall, so that the family has installed padding on the walls to cover the holes in the drywall. After taking him to the CRC and waiting for hours on multiple occasions for a bed could be identified, they took him home multiple times to remain at home, despite recommendations for hospitalization.
- JD: 15-year-old girl with autism with highly unpredictable violent outbursts who was pre-authorized for a hospital bed for 8 months following an episode of rendering her TSS worker unconscious by hitting him over the head with a large African drum from behind. Every hospitalization unit in the area reported daily that they either did not have space for her, or that she would be too violent and unresponsive to group therapy for their unit. She remained in the school and community until she was finally hospitalized under extreme pressure after she caused severe brain swelling to her BSC after throwing a glass bottle at her temple.
- DC: 10-year-old boy with autism who was brought to the CRC by his family after severe outbursts, and was chemically restrained, and under 5-point restraints for the majority of the time at the CRC, waiting 2 weeks for a hospitalization bed until his heart developed palpitations from the medication, and was transferred to a medical unit before eventually being placed in a residential setting.
- LB: 13-year-old boy with autism who waiting days at the CRC before being taken home by his father, who could no longer bear to watch his son in such agonizing tantrums in a setting foreign and devoid of sensory stimulation he required for self-regulation. He was eventually was placed directly in residential placement.
- KP: 15-year-old boy with autism who was in and out of CRC multiple times, sometimes initiated by the school and other times by his family, while his mother was told by CRC staff that due to his diagnosis of autism and lower functioning, that he would only be “traumatized” by a hospitalization stay. Most recently, the mobile crisis unit arrived at the school for the boy who was so out of control, they chose to wait for the police to come assist. However, the police did not arrive until 5:30pm, well after school hours, and once again, the CRC indicated that there was not an appropriate hospital bed that would not traumatize the client. The mother chose to take him home time and time again, feeling she was protecting her son, while putting herself in danger.

Inpatient Hospitalization

- Purpose: Intensive, inpatient hospital treatment facility to stabilize the aggressive and destructive child
- What it looks like: Intensive individual therapy, group therapy, psychiatric services, medication management, and scheduled family visits during an extended hospital stay which typically does not go beyond 21 days
- Where it fits: one step below residential, one step above partial hospital
- Regional Providers Specializing with ASD: Devereux, Foundations

Residential Treatment (RTF)

- Purpose: Long term placement for consumers who have been deemed unsafe in the home, school, and community environment
- What it looks like: Child lives on a campus and receives educational and mental health treatment for a period typically no longer than 1 full year, however, extended stays can be arranged depending on severity of need and insurance coverage
- Where it fits: Most intense treatment setting and is used when all over types of services have been exhausted, although must be stabilized for setting

When does my child need residential placement? *

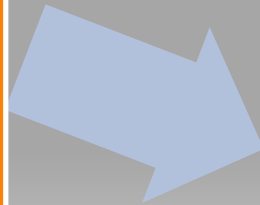
- Daily concern for safety in both home and school environments even with behavioral supports (BHRS).
- Two failed hospitalization periods or the hospital is unable to stabilize the child adequately to return to a home environment

Residential Treatment Facilities

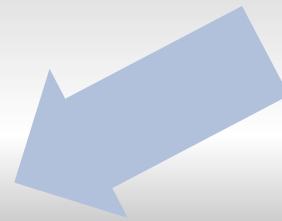
- Devereux
- Woods Services
- Bancroft (New Jersey)
- Melmark
- Kennedy Krieger (Maryland)

Stepping Down Levels

Hospitalization/Partial/RTF



BHRS



Outpatient

■ Questions about clinical services?

Supporting Families

- Support groups: ASA, Autism Sharing & Parenting, CFA, ASCEND, ASPEN, etc.
- Social groups: Holy Terror Stars, informal gatherings
- Online and social networking
- Hanen; More than Words
- Family Therapy
- Respite: therapeutic vs. recreational
- Extended family support
- Community and religious institutions

Parenthood: Support Group



Respite Care

- Purpose: A safe haven for parents to send their child when they need a break
- What it looks like: Can take the form of an afterschool program, Saturday day program, or overnight stay
- Where it fits: Anywhere on the continuum of services as this service is subsidized through DBHIDS

The Need for Respite

- David Mandell, CHOP Center for Autism Research
 - For every \$1,000 spent on respite, odds of hospitalization drop 8%
 - Level of services (speech, occupational, behavioral, etc) had no effect on odds of hospitalization
 - Based on 28,000 kids with autism ages 5 to 21, 675 of whom spent time in psychiatric hospitalization
 - “Raising a child with ASD is fraught with challenges and can place considerable stress on families. In many cases, hospitalization may result as much from the stress the child’s behavior places on the family as from the behavior.”
 - Children with ASD are far more likely to be hospitalized than peers with other conditions

Transition Planning

- ◆ IEP Team
- ◆ Mental Health Services
- ◆ Mental Retardation System
- ◆ Vocational Rehabilitation
- ◆ Occupational Therapy
- ◆ Social Skills Training
- ◆ Consistent routines
- ◆ Structured environments
- ◆ Attention to sensory integration

Steve Edelson &
Simon Baron-
Cohen:



Placements & Resources



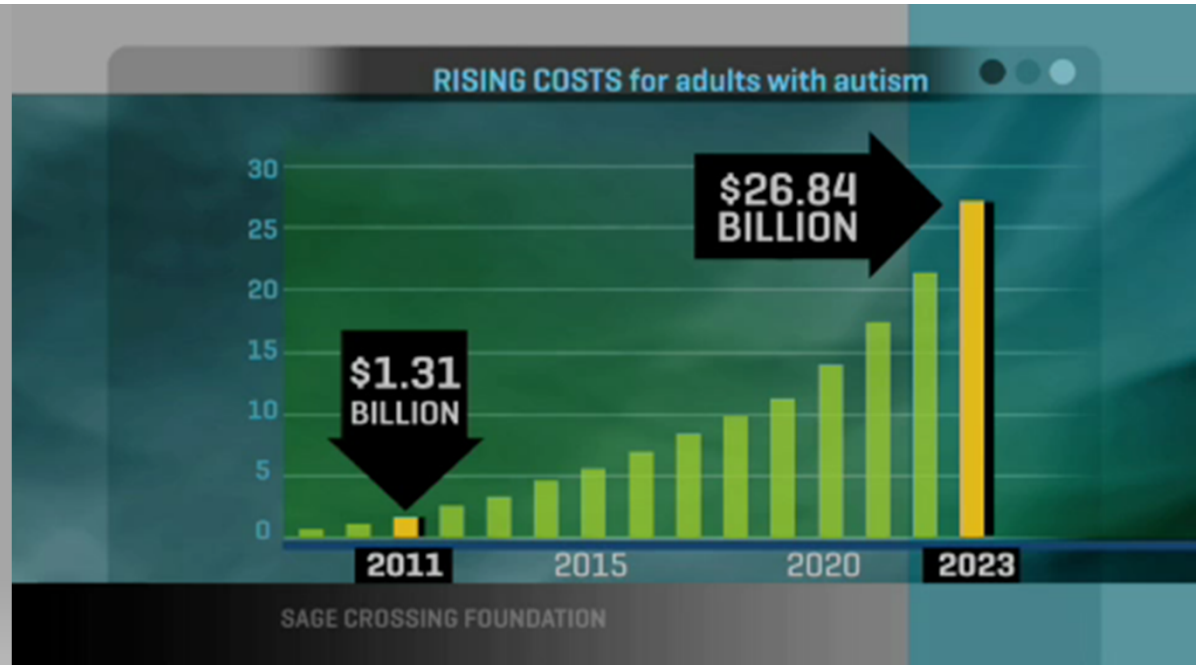
Susan Epstein and daughter

- ◆ Traditional:
 - ◆ Community Residential Rehabilitation (CRR)
 - ◆ Community Living Arrangement (CLA)
 - ◆ Outpatient services
 - ◆ Residential settings
 - ◆ Individual aide

- ◆ Next Steps:
 - ◆ Build-your-own Silicon Valley
 - ◆ Maximize strengths
 - ◆ Finding functional fixations
 - ◆ What CAN the individual do?
 - ◆ What CAN the group do?

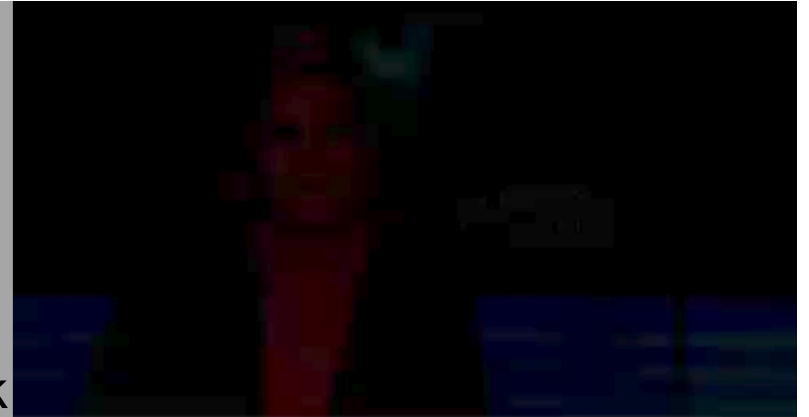


Transition to Adulthood



- Two families struggle to care for their autistic adult sons, with Peter Gerhardt: <http://video.pbs.org/video/2074757213/>
- Influx of ASD adolescents into adult system, with half a million individuals with ASD coming of age from 2011 to 2023
- Graduation often means no services
- Organizations often won't take applications, and don't realize that developmentally disabled adults can be the best employees
- Unemployment for ASD adults estimated between 70-90%
- Over 123,000 people are on waiting lists nationwide for residential services for disabilities in 2011
- Parents defer to siblings for disabled adults when they pass... not sustainable

The Specialists



ABC News: Specialisterne

- Specialisterne: Software Testing in Denmark
- 60 consultants are considered best-in-class
- paid industry-competitive wages
- customers include LEGO, Microsoft, and Oracle
- 75 percent have Asperger syndrome or some form of ASD
- consultants enjoy their work and are great at it
- Testing process—checking and rechecking outcomes, documenting test plans, and maintaining follow-through
- making use of high intelligence, precision-oriented skills, deep concentration, and patience that can be positive features sometimes accompanying ASD
- "This is not cheap labor, and it's not occupational therapy... We simply do a better job."
- Model is taking off with public and private funding

Job Coaching vs. Job Carving

- ◆ Fitting a square peg into a round hole
- ◆ Underestimating abilities of those with developmental disabilities
- ◆ Splinter skills
- ◆ Strengths-based assessment and placement
- ◆ Filling a hole vs. finding a need
- ◆ Finding partner employers... often limited to corporations with executives who have family members with developmental disabilities
- ◆ Issues of possible exploitation

Post-secondary options

- ◆ Day programs
- ◆ Work
- ◆ Trade-school
- ◆ College
- ◆ Online
- ◆ Paradigm Shift!!!

School & College Selection Criteria Checklist for Students with Aspergers Syndrome (AS)

Name of School: _____ Date of Contact: _____

	☺ Necessities	☺☺ Niceties	☹ No-Nos
Campus	<input type="checkbox"/> Small campus <input type="checkbox"/> Easy to navigate <input type="checkbox"/> Low crime/violence/bullying <input type="checkbox"/> Calm atmosphere	<input type="checkbox"/> Clearly posted maps <input type="checkbox"/> Easy transitions <input type="checkbox"/> Anti-bullying/violence programs	<input type="checkbox"/> Large, confusing campus lay-out <input type="checkbox"/> Great distance from residence to classes, library, counseling services
Faculty & Staff	<input type="checkbox"/> Low faculty & staff to student ratio <input type="checkbox"/> Admissions personnel who can describe AS when asked	<input type="checkbox"/> All faculty and staff received training in AS (including support staff)	<input type="checkbox"/> No staff training in AS <input type="checkbox"/> Admissions personnel does not adequately describe AS <input type="checkbox"/> No other known AS students
Academic Program	<input type="checkbox"/> Program in area of special interest (niche utilization is critical) <input type="checkbox"/> Assigned advisor that meets on a regular basis who understands AS <input type="checkbox"/> Predictable daily routine, schedule <input type="checkbox"/> Clear, campus-wide policies and procedures	<input type="checkbox"/> Specific program for AS students <input type="checkbox"/> Demonstrated record of success with other AS students <input type="checkbox"/> Flexible programming with opportunities to individualize majors based on interest <input type="checkbox"/> Advisor with specific training in how to work with AS <input type="checkbox"/> Regular, systematic communication with parents <input type="checkbox"/> Courses on social skills & pragmatic language <input type="checkbox"/> Internship opportunities	<input type="checkbox"/> Inflexible requirements in areas of weakness <input type="checkbox"/> No or weak advisee system <input type="checkbox"/> Faculty who rely on teaching via group activities <input type="checkbox"/> Disorganized teaching <input type="checkbox"/> Limited focus on area of special interest
Counseling & Support Services	<input type="checkbox"/> Counseling available at no cost <input type="checkbox"/> Counselors who know how to work with students with AS <input type="checkbox"/> 504 accommodation procedures for students with AS <input type="checkbox"/> College or career counseling services <input type="checkbox"/> Tutoring available	<input type="checkbox"/> Strong disabilities services department - experience with AS <input type="checkbox"/> Counselors available 24 hours <input type="checkbox"/> Clinical psychologist on staff <input type="checkbox"/> Speech-language pathologist and occupational therapist available <input type="checkbox"/> Counselors work with residential staff to help support in dorms and with living skills <input type="checkbox"/> Coaching services	<input type="checkbox"/> Inexperienced disability services department <input type="checkbox"/> No 504 accommodations for students with AS <input type="checkbox"/> Counselors rarely available and inexperienced with AS
Technology	<input type="checkbox"/> Up-to-date, accessible technology	<input type="checkbox"/> Assistive technology, especially for writing	<input type="checkbox"/> Poor technology and no assistive technology
Recreation	<input type="checkbox"/> Structured, planned recreational activities (clubs, sports, trips)	<input type="checkbox"/> Assistance with creating social groups based on special interests <input type="checkbox"/> Non-competitive, non-team-based physical recreation	<input type="checkbox"/> No physical recreation except team-based, competitive sports
Student Population	<input type="checkbox"/> Low total student population – not crowded	<input type="checkbox"/> Diversity education programs <input type="checkbox"/> Other students with disabilities <input type="checkbox"/> Education on AS for peers	<input type="checkbox"/> Lack of diversity and tolerance <input type="checkbox"/> Too many students – feels crowded
Residence Life	<input type="checkbox"/> Freshman orientation that begins before classes start and runs throughout the year. <input type="checkbox"/> Some form of structure and support in dorms	<input type="checkbox"/> Assignment of high-status, sympathetic peer to assist in non-structured times <input type="checkbox"/> Assistance with hygiene and daily living skills	<input type="checkbox"/> Students seem on their own – no support in dorms for daily living <input type="checkbox"/> Dorms are loud, dirty, chaotic <input type="checkbox"/> Proximity to laundry and food services is too far

Independent Educational Consultants Association 2005 Conference
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 For the most up-to-date version of this form, visit www.caseydixon.com and click on "Tools for My Clients".

Training the Community

- Airport and Museum Accessibility initiatives w/ Dr. Wendy Ross
- <http://www.autismir.com>



People | HEROES AMONG US

Seeing "another family that can now fly—it's amazing," says Ross (with Julian and mom Sheila, United pilot Rich Parella and crew).

FOR KIDS WITH AUTISM, WINGS TO FLY

WENDY ROSS, 42
Philadelphia

Pediatrician Wendy Ross was in the office in '09 when the mom of a patient, a girl with autism, called frantically from a Florida airport. Rattled by the boarding process, the child had such a terrible meltdown the family decided to get off the plane. "These

families feel so trapped, it's heartbreaking," Ross says. "I thought, 'What can I do to make this right?'"

So Ross, a married mom of two boys, worked with clinicians and airlines to develop an air-travel program at Philadelphia International Airport that lets kids with autism practice everything from check-in and security screening to boarding a mock flight. This month United Airlines starts rolling it out

nationally through Ross's Autism Inclusion Resources (autismir.com). Among those grateful for Ross's help Sheila Mitchell-Green and husband Derek. Their 11-year-old son Julian struggles with lines but traveled smoothly when they visited Disney World last year. "This made," Sheila says, "all the difference in the world."

By Moira Bailey

KNOW A HERO? SEND SUGGESTIONS TO HEROESAMONGUS@PEOPLEMAG.COM

December 3, 2012 PEOPLE

Photograph by MIKE MCGREGOR

Putting it all together

- Navigating services:
 - Save everything!
 - Old reports, IEPs, OT evals, Speech evals, medical records
 - Create a contact log
 - Make meetings!
 - Be aware that services may expire
 - Reschedule when necessary- avoid no-shows
 - Advocate
 - Educate yourself
 - Ask questions
 - File grievances
 - Get a professional advocate or educational lawyers if necessary

– Collaborate

- Talk to people on your team regularly
 - (phone conversations, meetings, notes to and from the teacher)
- Make suggestions for goals and treatment plans
 - Johnny really likes
 - Can we use his love of sports to help with
 - Can we try to address X behavior?
- Listen to the advice- everyone has room to learn
 - you don't always have to take it!
- Be positive and thank people when possible
- Be careful not to overstep professional boundaries
- Connect with other families

Always Remember:

You are a vital part of the treatment
team and should be your child's #1
advocate

■ Questions about transition services?

■ Any other questions?

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