NYTimes Article

467 COMMENTS

The Kids Who Beat Autism

By RUTH PADAWER   JULY 31, 2014

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CALVARY
NOW PLAYING
GET TICKETS

At first, everything about L.'s baby boy seemed normal. He met every developmental milestone and delighted in every discovery. But at around 12 months, B. seemed to regress, and by age 2, he had fully retreated into his own world. He no longer made eye contact, no longer seemed to hear, no longer seemed to understand the random words he sometimes spoke. His easygoing manner gave way to tantrums and head-banging. "He had been this happy, happy little guy," L. said. "All of a sudden, he was just fading away, falling apart. I can't even describe my sadness. It was unbearable." More than anything in the world, L. wanted her warm and exuberant boy back.

A few months later, B. received a diagnosis of autism. His parents were

Mark Macluskie, 16, who is no longer autistic. Mark Peckmezian for The New York Times

Fein's study found that formerly autistic people often have residual symptoms, at least initially; these include social awkwardness, attention deficit hyperactivity disorder, repetitive movement, mild perseverative interests and subtle difficulties in explaining cause and effect. For Mark, the main remnant is his continued disgust at food that he considers slimy, like omelets, and his dislike for the texture of paper, which he avoids. His mother says that whenever she mentions that Mark once had autism, people look at her as if she's delusional. "Even doctors say, 'Well, he must have been misdiagnosed, because a person can't stop having autism,' " she said.

L. was ecstatic, but she was also plagued by guilt. Though Jackie's son received the same treatments as B., he had made no such progress. Matthew still could not talk. He remained uninterested in other children and most toys. And despite efforts to teach him, Matthew's communication remained extremely limited: When he squealed loudly, he was happy. When he threw up — which for a year he did daily — his parents concluded that he was distressed.

"Jackie did everything for him," L. told me, her voice filled with angst. "Everything. She tried just as hard as I did. She hired the same people, did the same work. . . . " Her voice trailed off. She was sure that the behavioral therapy had allowed her to reclaim her son, but she could not understand why it had not done the same for Matthew.

Article Summary

- Some people diagnosed with ASD "beat autism", typically after intensive ABA (but not always)
- Even after recovery, there are residual symptoms
- There is no way to predict how well children will respond to intervention
- The biology of ASD is not well understood
- "Optimal outcomes" may also be associated with fewer psychiatric comorbidities than others with ASD
- The "neurodiversity" movement

ASD Diagnostic Criteria (DSM-5)

A. Persistent deficits in social communication and social interaction across multiple contexts:

- Social-emotional reciprocity
- Deficits in nonverbal communicative behaviors used in social interactions
- Deficits in developing, maintaining, and understand relationships

ASD Diagnostic Criteria (DSM-5)

B. Restricted, repetitive patterns of behavior, interests, or activities (≥2):

- Stereotyped or repetitive motor movements, use of objects, or speech
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment

ASD Diagnostic Criteria (DSM-5)

C. Symptoms must be present in the early developmental period.

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability or global developmental delay. If co-occurs with intellectual disability, level of functioning below that expected with ID.

Can Children Outgrow Their Diagnosis of Autism?

- Optimal Outcome:
  - No longer meet criteria for ASD
  - Normal cognitive function
    - "A small number of the OO children continued to show some difficulty on components of executive function."

"Thus, the aim of the present study was to retrospectively examine the intervention history of the OO and HFA individuals to determine if intervention differences may have contributed to their outcomes. The unique aspect of this study is having a group of OO children and adolescents who have clearly lost their autism diagnosis and are functioning essentially identically to their typically developing peers."

Limitations of Retrospective Studies

- Unmeasured confounders may skew data and, by definition, cannot be controlled for.
- Selection bias
- Information bias (error in classifying level of exposure or disease)
- Are groups really comparable?
        - Initial severity higher in HFA than OO group

A Pinch of Statistics...

- x^2: comparing actual incidence of an event between two or more groups versus expected incidence (ANOVA and t-test for continuous variables)

    - Fisher's exact test for small n (< 10 in cell)

- Cramer's V is the effect size in x^2: for 2 rows and columns, small (0.1), medium (0.3), large (0.5)

- Cohen's D is effect size in ANOVA, t-test: small (0.02), medium (0.15), large (0.3)

Methods

- Retrospective study to examine intervention history of
  - optimal outcome (OO) and high-functioning autism (HFA) individuals
  - to determine if there were differences in intervention that explain difference in their outcomes.
- Participants included:
  - 34 patients with OO
  - 44 patients with HFA
  - No statistical difference between groups in terms of
    - Age (range 8-21 yo, gender, nonverbal IQ)
  - Mean verbal IQ in HFA 104.4 vs OO 114.4 (p=0.008)

Methods Continued……

- Demographics:
  - Patients were from Massachusetts and Connecticut (10 participants were from other states e.g. AZ, CL, DC, ME
  - Ethnicity : mostly white
    - 3 OO and 4 HFA other race or ethnicity.
  - Income: generally of middle and high class (13/34 HFA <$100,000, 10/24 OO <$100,000),
- Recruitment: through media outlets, private practices, word of mouth between families and clinical referrals, PI's private practice, other studies at University of Connecticut

Methods Continued....

- Inclusion Criteria for OO participants;
  - Verbal, nonverbal, and full-scale IQ >77
    - within 1.5 SD of average of 100
  - ASD diagnosis <5 years of age, documented language delay
  - Participants had typicall developing friends.
  - Participants did not meet criteria for ASD on ADOS by research interviewer
  - Vineland adaptive Behavior Scales Score >77 (within ⅕ SD of mean =100).
  - Fully included in regular education classes
    - no special education to address autism deficits
    - no one-on-one assistance

Methods & Procedures Continued

- HFA inclusion Criteria:
  - verbal, nonverbal, and full-scale IQ>77
  - Meet criteria for ASD on ADOS
- Exclusion Criteria:
  - major psychopathology (e.g. active psychotic disorder).
  - severe visual or hearing impairment
  - head trauma, seizure disorder, fragile X syndrome
- Procedures:
  - after initial telephone screening, participants were scheduled for assessments.

Measures

- Wechsler Abbreviated scale of Intelligence
  - assess verbal and nonverbal cognitive abilities
- Vineland Adaptive behavior scales
  - assess communication and socialization skills
- ADOS to assess symptoms of autism
- Autism Diagnostic Interview & Social Communication Questionnare:
  - symptom severity and age of first concerns
- Parents reported specific type of intervention and hours/week (ABA, speech-language, development therapy, OT, before 1.5 yo
  - 1.5-2 yo
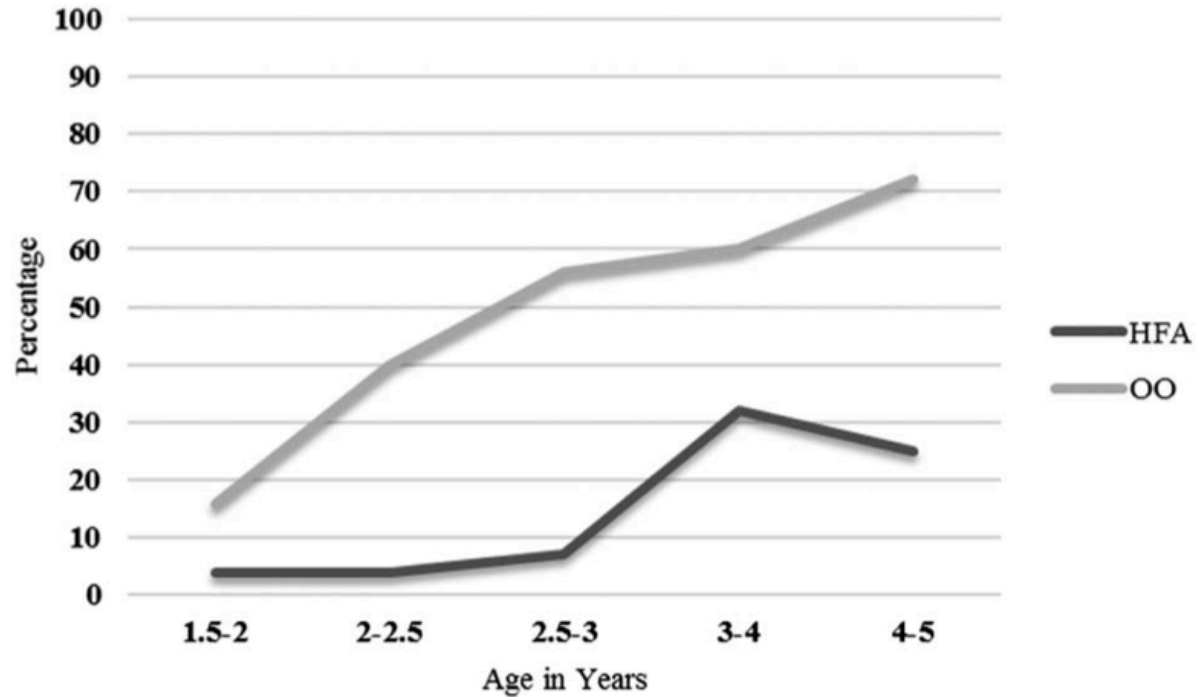 - 2-2.5 yo
  - 2.5-3 yo
  - 3-4 yo
  - 4-5 yo

Results

Figure 1. Percent of participants receiving ABA therapy, by age.

Results

Table 1. Percent of Participants Who Received Any Type of Intervention and Mean Number of Weekly Intervention Hours, By Age

Frequency of Participants Receiving Intervention

Age, yr	HFA; N = 28, n (%)	OO; N = 25, n (%)	Chi-Square p	Effect Size *Cramer's V*
Before 1.5	1 (4)	3 (12)	.25	.16
1.5–2	11 (39)	9 (36)	.81	.034
2–2.5	12 (43)	17 (68)	.066	.25
2.5–3	17 (61)	22 (88)	**.025**	**.31**
First year of preschool (3–4)	24 (86)	22 (88)	.81	.034
Second year of preschool (4–5)	19 (68)	23 (92)	**.031**	**.30**

Mean Number of Weekly Intervention Hours

Age, yr	HFA Group				OO Group				p	Cohen's d
	Mean	SD	Range[a]	n	Mean	SD	Range[a]	n		
Before 1.5	4.0	No SD	No range	1	5.3	4.2	2–10	3	.81	−0.44
Between 1.5 and 2	9.4	15.3	0.5–49	9	7.1	6.4	1–17	9	.69	0.20
Between 2 and 2.5	4.1	4.0	0.5–13	8	14.8	12.8	1–42	16	**.006**	**−1.13**
Between 2.5 and 3	7.3	9.5	0.25–28	14	21.1	16.9	1–52	20	**.005**	**−1.01**
First year of preschool (3–4)	15.4	15.1	1–40.5	19	24.2	15.5	1–51	21	.076	−0.58
Second year of preschool (4–5)	18.9	17.0	0.5–47	17	25.8	14.3	1.5–60	22	.17	−0.44

[a]Means, SDs, and ranges only include participants who received some intervention. HFA, high-functioning autism; OO, optimal outcome. Significant values are indicated in boldface.

Results

Table 2. Types of Therapy by Age

	HFA (Total = 28), %	OO (Total = 25), %	p (χ^2)	Effect Size Cramer's V
1.5–2 yr				
ABA	4	16	.12	.21
Speech	29	28	.96	.006
Occupational therapy	14	12	.81	.034
Physical therapy	4	8	.49	.096
Developmental therapy	0	16	**.028**	**.30**
Sensory integration therapy	4	8	.49	.096
2–2.5 yr				
ABA	4	40	**.001**	**.45**
Speech	32	52	.14	.20
Occupational therapy	18	32	.23	.16
Physical therapy	7	8	.91	.016
Developmental therapy	0	20	**.013**	**.34**
Special school	0	8	.13	.21
Sensory integration therapy	4	12	.25	.16
2.5–3 yr				
ABA	7	56	**<.001**	**.53**
Speech	50	64	.31	.14
Occupational therapy	29	48	.15	.20
Physical therapy	14	8	.47	.099
Developmental therapy	4	12	.25	.16
Special school	4	12	.25	.16
Sensory integration therapy	7	12	.55	.083
First year of preschool (3–4 yr)				
ABA	32	60	**.042**	**.28**
Speech	71	56	.24	.16
Occupational therapy	46	60	.32	.14
Physical therapy	21	24	.82	.031
Developmental therapy	4	4	.94	.011
Special school	18	40	.07	.25
Sensory integration therapy	7	4	.62	.068
Second year of preschool (4–5 yr)				
ABA	25	72	**.001**	**.47**
Speech	50	68	.18	.18
Occupational therapy	36	72	**.008**	**.36**
Physical therapy	21	24	.82	.031
Developmental therapy	4	20	.06	.26
Special school	14	36	.07	.25
Sensory integration therapy	0	4	.29	.15

HFA, high-functioning autism; OO, optimal outcome; ABA, applied behavior analysis. Significant values are indicated in boldface.

Results

Table 3. Pharmacologic and Complementary-Alternative Medicine Treatments

	OO (n = 25), %	HFA (n = 32), %	p (χ^2)	Effect Size Cramer's V
Any medication—current	20	50	**.020**	**.31**
Any medication—ever	24	69	**.001**	**.44**
CNS stimulant—current	16	19	.79	.036
CNS stimulant—ever	24	38	.28	.14
Antidepressant—current	4	25	**.031**	**.29**
Antidepressant—ever	4	50	**<.001**	**.50**
Atypical Antipsychotic—current	0	13	.067	.24
Atypical Antipsychotic—ever	0	25	**.007**	**.36**
Anticonvulsant—current	0	6	.20	.17
Anticonvulsant—ever	0	6	.20	.17
Norepinephrine reuptake inhibitor—current	0	9	.12	.21
Norepinephrine reuptake inhibitor—ever	0	13	.067	.24
Alpha-2 adrenergic agonist—current	4	9	.43	.10
Alpha-2 adrenergic agonist—ever	4	9	.43	.10
Benzodiazepine—current	0	6	.20	.17
Benzodiazepine—ever	0	6	.20	.17
Casein-free, gluten-free diet	23	30	.56	.081
Dietary supplements	40	41	.96	.006

HFA, high-functioning autism; OO, optimal outcome; CNS, central nervous system. Significant values are indicated in boldface.

Summary of Results:

- Specific Therapies:
  - More OO children received ABA than HFA children
    - Birth -3 yo: 83% vs 43%
    - Preschool years (3-5 yo): 60% VS 25%
  - more OO children received development therapy
    - At age 1.5-2 year of age (16% vs 0%)
    - At age 2-2.5 years of age (20% vs 0%)
- Intensity of Intervention: OO children received on average more hours of therapy per week than HFA children
  - 2-2.5 years of age (14.8 vs 4.1 hours)
  - 2.5-3 years of age (21 vs 7.3 hours)
- For both groups receiving ABA, number of hours per week were similar between groups

Summary of Results

- Age of concerns/ Early symptoms:
  - age of onset of symptoms did not differ
  - Children with OO came to early attention by average 5 months of earlier than HFA children
  - Referrals to specialist were made sooner in OO children than in HFA children (average 26 months vs 44 months)
- Higher percentage of OO children received any intervention than the HFA children(83% vs 48%).
- HFA participants were more likely to have received medication

Discussion

- Children with ASD who then achieve OO are more likely to get early intervention very early in life.
  - majority of children with OO (83%) received intervention 3 years of age, vs 45% of HFA children.
- Children on the OO group did not receive more hours of ABA than HFA who received ABA.
- Unable to predict outcome based on particular type of intervention or # of hours of early intervention
  - some children in HFA group received intensive early intervention
  - Some children in OO group had limited early intervention
- No difference between groups in terms of use of special diets or supplements.

Limitations of study

- Retrospective parent report
  - large range of age of participants → parents had to recall details from several years ago
- Unable to assess severity at time of initial diagnosis objectively
- Unable to assess quality of interventions
- Homogenous sample
  - ethnicity
  - geographic location of participants
  - socio-economic status
- No genetic workup of participants

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