Revised: ASD Advisory Committee
July 26, 2017 Meeting Notes

Participants

Rene Bartos, MD, MPH, FAAP, Medical Director, Mercy Care Plan & Arizona Chapter American Academy of Pediatrics

Aaron Blocher-Rubin, PhD, BCBA/LBA, Chief Executive Officer, Arizona Autism United

Carey Burgess, MS, LBA, BCBA, Clinical Director, Behavioral Consultation Services, Arizona Autism United

Maureen Casey, Assistant Director, Division of Developmental Disabilities (DDD), Arizona Department of Economic Security (DES)

Ron Copeland, Senior Director of Program Development, Cenpatico Integrated Care (CIC), RBHA

Bryan Davey, PhD, BCBA-D, CEO, Touchstone Health Services

Diana Davis-Wilson, DBH, BCBA, LBA, Director of Clinical & Business Development, Hope Group

Diedra Freedman, JD, Board Secretary/Treasurer, Arizona Autism Coalition

Joe Fu, Senior Director for Children's Health, First Things First

Aaron Goldman, MD, Children's Medical Director, Health Choice Integrated Care (HCIC), RBHA

Ramiro Guillen, MD, Chief Medical Officer, Southwest Behavioral & Health

Tenasha Hildebrand, Mercy Maricopa Integrated Care (MMIC), RBHA

Joyce Millard Hoie, MPA, Executive Director, Raising Special Kids

George Jacobson, Project Manager Payment Modernization, Arizona Health Care Cost Containment System (AHCCCS)

Michelle Katona, Chief Program Officer, First Things First

Joanna Kowalik, MD, Chief Medical Officer, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)

Lisa Kunz, Autism and Low Incidence Specialist, Professional Learning and Sustainability, Arizona Department of Education

Kelly Lalan, Health Choice Integrated Care (HCIC), RBHA

Carol Lee, Division of Health Care Management, Arizona Health Care Cost Containment System (AHCCCS)

Terry Matteo, PhD, Clinical Child Psychologist, Private Practice & Southwest Human Development

Brian van Meerten, MEd, BCBA, LBA, Director of Behavioral Health Services, Behavioral Consultation Services of Northern, Arizona, LLC (BCSNA)

Janna Murrell, Director of Family Support and Education, Raising Special Kids

Daniel Openden, PhD, BCBA-D, President and CEO, Southwest Autism Research & Resource Center (SARRC)

Leslie Paulus, MD, PhD, FACP, Medical Director, UnitedHealthcare Community Plan

Sydney Rice, MD, MSd, Board-certified Developmental Pediatrician; Associate Professor, Pediatrics, The University of Arizona College of Medicine in Tucson

Sara Salek, MD, Chief Medical Officer, Arizona Health Care Cost Containment System (AHCCCS)

Katie Scherer, Crisis Response Specialist, Cenpatico Integrated Care (CIC), RBHA

Kim Skrentny, MSW, LCSW, Behavioral Health Services Administrator, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)

Karrie Steving, Children's System of Care Administrator, Mercy Maricopa Integrated Care (MMIC), RBHA

Christopher Tiffany M.A. Ed., Director of Family Support and Education, Raising Special Kids

Paulina Tiffany, Outreach Director, Arizona Autism United

Ginger Ward, MAEd, Chief Executive Officer, Southwest Human Development

Minnie Williams, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)

Megan Woods, MEd, BCBA, LBA, Behavior Analyst, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)

Facilitator: Sharon Flanagan-Hyde

Update on Targeted Investments (TI) Program

George Jacobson, Project Manager, Payment Modernization, AHCCCS

The Targeted Investments (TI) Program is the strategy of AHCCCS to provide financial incentives to eligible AHCCCS providers to develop systems for integrated care. Managed care plans will provide financial incentives to eligible Medicaid providers who meet certain benchmarks for integrating and coordinating physical and behavioral health care for Medicaid beneficiaries. AHCCCS will incorporate these payments into the actuarially-sound capitation rates. The TI Program aims to:

- Reduce fragmentation that occurs between acute care and behavioral health care.
- Increase efficiencies in service delivery for members with behavioral health needs.
- Improve health outcomes for the affected populations.

This is a five-year program. It will facilitate whole person care, an integrated care plan, bidirectional exchange of information, and care management.

AHCCCS is accepting applications from providers. The deadline is August 18, 2017. Provides must have the capability to share bidirectional electronic records. Information is available at https://www.azahcccs.gov/PlansProviders/TargetedInvestments.

Comprehensive ABA Benefit

Ron Copeland, Senior Director of Program Development, Cenpatico

Karrie Steving, Children's System of Care Administrator, Mercy Maricopa Integrated Care

Aaron Goldman, MD, Children's Medical Director, Health Choice Integrated Care

Updates on the comprehensive ABA Benefit for acute members through RHBAs prior to 10/1/18 system integration: available in-network treatment providers.

Cenpatico Integrated Care has a list of providers who can diagnose on the website: https://www.cenpaticointegratedcareaz.com/content/dam/centene/cenpaticoaz/Provider%20Forms%2C%20Attachments%2C%20and%20Deliverables/PMA_3-3-2.pdf.

Autism Spectrum Resources is at https://www.cenpaticointegratedcareaz.com/inthecommunity/community-resources/autism-spectrum-resources.html.

Cenpatico is working with Touchstone to bring services to southern Arizona, and is conducting trainings with staff to ensure high quality customer service.

Mercy Maricopa Integrated Care is focusing on the two ASD Centers of Excellence, and is incorporating feedback from the ASD Advisory Committee and other advisory groups. The providers are Southwest Behavioral & Health Services and Touchstone. Goals include improving access and availability of services through an increased number of providers and bringing BCBAs in house. Aurora Behavioral Health is open and slowly increasing the ages served, from 11-17 to 8-17. MMIC is also working closely with the Melmed Center (http://www.melmedcenter.com) and with Dr. Rene Bartos, Medical Director of Mercy Care Plan. MMIC is continuing to train member services staff so that calls about ASD services are handled appropriately. A focus is on helping staff understand the range of terminology callers might use and having clear protocols around communication.

Health Choice Integrated Care's goal is to provide a comprehensive work-up diagnosis within 45 days of initial concern for members within its GSA.

- On 6/30/2017 there were 1,227 enrolled members with an Autism Spectrum Disorder or Global Developmental Delay diagnosis.
- Of the 1,227 enrolled members, 902 (73%) were in an open episode of care (receiving services).
- Of the 902 members in an open episode of care, 474 (53%) were children, 313 (35%) were GMHSA, and 115 (13%) were SMI.
- Of the 474 children in an open episode of care, 467 (99%) encountered at least one claim with BCS/CPES for FBA/ABA since 2015.

HHIC provides ongoing training for providers at brown bag lunches. An advisory committee that includes network providers, other providers, and consumer advocates meets bimonthly.

DDD Habilitation Consultation Implementation Plans/Accessing DDD Policies and List of Policies Out for Public Comment

Kim Skrentny, MSW, LCSW, Behavioral Health Services Administrator, DES/Dept. of Developmental Disabilities

Joanna K. Kowalik, MD, MPH, FAPA, Chief Medical Officer, DES/Dept. of Developmental Disabilities

A work group reviewed all the public comments regarding contract amendments and policies and made minor changes. Rates were reworked as a result of research, using an independent model approach to rate setting. Separate rates were developed based on qualifications and licensure, and urban or rural location.

DDD policies, with manuals broken out by section (medical, operations, eligibility, provider, etc.), are available at:

https://des.az.gov/services/disabilities/developmental-child-and-adult/laws-rules-policy-forms-developmental

Scroll down on this link to see a list of policies currently posted for public comment.

Policies posted for public comment on July 28 are:

- Medical Policy 1240-E Habilitation Services Draft for Public Comment
- Provider Policy Chapter 35 Progress Reporting Requirement Draft for Public Comment
- Public Comment Announcement-Medical Policy 1240-E
- Public Comment Announcement-Provider Policy Chapter 35

Written comments and opinions on the proposed policy will be accepted until 11:59 PM (Arizona Time) on August 27, 2017. For clarity, when referencing your comment, identify the numerical line(s) associated with the section that you wish to comment on. Send Comments to DDDPolicy@azdes.gov.

If a group has similar comments, please send a single comment; this will save review time and speed up the process for finalizing the policy.

Improvements in Behavioral Health Crisis Intervention System

Ron Copeland, Senior Director of Program Development, and Katie Scherer, Crisis Response Specialist, Cenpatico Integrated Care

Karrie Steving, MMIC

Aaron Goldman, HCIC

Kim Skrentny, DDD

The DDD Behavior Health administration is setting up a central mailbox so that each RBHA can send data reports. DDD is still working through a few glitches. DDD is in conversations with MMIC about daily reports. HHIC did an outreach effort and is looking into this further. Cenpatico is holding an internal meeting to set up reports. CRS has set up a daily behavioral health inpatient report.

An ongoing challenge is the fact that the RBHAs can't identify DDD members with Medicaid coverage who aren't DD/ALTCS. The BH system, as well as DDD is aware of this issue and understands the importance of finding a solution.

Behavioral Intervention Benefit Management

Megan Woods, MEd, BCBA, LBA, Behavior Analyst DES/Dept. of Developmental Disabilities

Behavioral intervention benefit management after ECM completion (ALTCS DDD members who had been receiving early intensive behavioral intervention through the DDD-contracted provider): Children age out at age 7; when they start school, there is a shift to less intensive interventions. Hab C, when ready to go, will meet the gap between ECM and the rest of the individual's life. Until then, DDD relies on relationships with the RBHAs to be creative in putting in place programs and staffing to meet individuals' needs. The goal is the least amount of disruption for families.

Support to Prevent Parental Burnout

Diedra Freedman, JD, Board Secretary/Treasurer, Arizona Autism Coalition

Respite and other support services for parents with children with ASD: the importance of preventing parental burnout and avoiding out-of-home placement.

Diedra opened with this statement:

> I am pitch hitting for Cynthia Macluskie today so please bear with me. Cynthia and I have been alarmed by the increased number of families who have contacted Cynthia and/or posted in online Autism Family Support Groups about their dire circumstances. This weekend a Surprise mother of a child with ASD took her own life. This spring a Gilbert mother and her child with ASD died in a house fire she may have set. For me this brings back the tragedy of seven years ago when one of my son Andy's classmates was killed by his father who drove them both over the side of a mountain. For the local online Autism Family Support Network these recent tragedies were an opportunity to discuss caregiver needs including our own behavior health needs and caregiver burn out.
>
> In the past few months Cynthia was contacted by more families than in the past two years who decided to place their children who are younger than 18 in group homes . All of these children are DDD/ALTCS qualified and all have complex medical and behavior health needs. All parents expressed burn out and a lack of needed services provided by DDD. Unfortunately several parents also have decided that even if needed services were somehow miraculously provided now, they still want to place their child in a group home.
>
> Cynthia also recently was contacted by a family desperate for morning Attendant Care for their ten year old who wets the bed nightly. The parents both work and are at risk of losing their jobs because of their lateness to work caused by bathing their son and cleaning up after him each morning. This child, too, is DDD/ALTCS qualified.
>
> Cynthia already forwarded information about these individuals and their families to DDD and AHCCCS. We aren't here this afternoon to talk about specific individuals. We are here to talk about policies and procedures. Obviously we all understand that integrated care coordination is the key and currently a weak link.
>
> Do we currently have any procedures being used to identify and track these individuals who are at risk for needing out of home placement because of possible caregiver burnout? Do we have any available data? If so can it be shared with this committee. If not, how can we collect the data and use it to improve policies and procedures so that critical services are readily available for these individuals and their families before caregiver burn out occurs and families are ready to throw in the towel?

Meeting participants noted that parental burnout is a problem throughout the system, not just with DDD parents, and with parents of adults as well as children. There will be additional discussion about this at the October ASD Advisory Committee meeting.

Update on Evidence-Based Practice Tool

Terry Matteo, PhD, Clinical Child Psychologist

The ASD Evidence-Based Practice Tool that was included in the February 2016 ASD Advisory Committee Report is now available as a stand-alone PDF.

- You can search for the document easily by typing into your web browser “AHCCCS ASD EBP Tool” (comes up in your search as: EBP Tool 053117-ahcccs).

- Or you can go to the AHCCCS ASD Resource Page: AHCCCS.gov/shared/ASD (webpage) to find the document—https://www.azahcccs.gov/shared/asd.html

  The tool is located on our AHCCCS Shared Documents page under the link Autism Spectrum Disorder (ASD) Advisory Committee

  Just under the full report…"EBP TOOL"
- Direct link to the document:

  https://www.azahcccs.gov/shared/Downloads/ASD/EBPTool053117.pdf

Coordination of Benefit/Third Party Liability

Sara Salek, M.D., Chief Medical Officer, AHCCCS

A Technical Assistance document is being drafted to support the most appropriate utilization of Medicaid dollars. Medicaid is the payer of last resort. It is clear that providers need more education about who to bill and how to bill. The best way to coordinate services is through providers. If two separate programs are providing services, providers need to be aware of one another in order to provide optimal care.

In response to a question about individuals with both commercial insurance and Medicaid eligibility, Sara followed up with this information after the meeting: As of July 28, 2017, we had 4,303 DDD ALTCS members with commercial insurance and 6,791 with Medicare. This represents ~36% of the population with either commercial or Medicare coverage (denominator of 30,724 ALTCS DDD members enrolled as of July 1, 2017).

Issues raised included: getting copays covered if going through primary insurance; coordination of benefits; copays that are somewhat unique to BCBA services, and shifting the family paradigm and how families view services. These issues will be addressed at the October quarterly meeting.

Announcements

- Vitalyst Health Foundation, formerly St. Luke's Health Initiatives, is continuing its interest in ASD by convening organizations that might partner to achieve system-level change for adults with ASD. Sharon Flanagan-Hyde will be facilitating the group. Please let Sharon know if your organization has an interest in being a partner (sharon@flanagan-hyde.com).
- Arizona Autism United will be conducting a community survey to gather input on needed services. They will send a link to this Committee. Please share the link with your networks.

Potential Future Agenda Topics

- Developmental screenings, early identification (before age 3), and early comprehensive ABA services
- Updates on ASD Centers of Excellence
- Parental burnout and network of providers who treat ASD members with complex co-occurring medical issues
- Coordination of Benefit/Third Party Liability
- Christopher Smith will give a presentation on the NODA tool

Please send additional suggested agenda items to Sharon: sharon@flanagan-hyde.com

AHCCCS
Arizona Health Care Cost Containment System

ASD ADVISORY COMMITTEE MEETING

Wednesday, October 4, 2017 3:00 pm - 5:00 pm
801 E. Jefferson Phoenix, AZ 85034, Arizona Room, 4th Floor
Teleconference: 1-877-820-7831 Participant Passcode: 778195#
Go-To-Meeting: https://global.gotomeeting.com/join/934000149

AGENDA

Time	Topic	Presenter
3:00 pm	Welcome and introductions	Sharon Flanagan-Hyde, Facilitator
3:15 pm	NODA™ (Naturalistic Observation Diagnostic Assessment) — Presentation and Q&A	Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)
3:35 pm	Discussion: • Respite and other support services for parents with children with ASD: the importance of preventing parental burn-out and avoiding out-of-home placement • Network of providers who treat ASD members with complex co-occurring medical issues • Crisis services • Meeting the needs of children/adults with developmental delay/ASD in Emergency Department and inpatient settings	Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix
3:50 pm	Developmental screenings, early identification (before age 3), and early comprehensive ABA services • Concern raised: Problems with the PAS Tool – identifying young children who are “at risk for institutionalization” (under-identifies those who need intervention the most)	Rene Bartos, MD, MPH, FAAP, Medical Director, Mercy Care Plan Robin Blitz, MD, FAAP, Chief, Developmental Pediatrics, Barrow Neurological Institute at Phoenix Children’s Hospital
4:05 pm	Updates on ASD Centers of Excellence	Bryan Davey, PhD, BCBA-D, CEO, Touchstone Health Services Ramiro Guillen, MD, Chief Medical Officer, Southwest Behavioral & Health

Continued on next page

Time	Topic	Presenter
4:15 pm	Lack of providers who can provide ASD interventions (ABA/Floortime/PRT, etc.) • Lack of consistency with training, supervision, and payment for providers. • Low reimbursement for Speech Therapists (communication problems are one of the primary deficits with ASD) • Hab workers require different skills for different/specific disabilities (e.g., ASD vs. CP) – Require hab workers to have training and skills specific to the disability of the individual they are working with	Sharon Flanagan-Hyde
4:30 pm	Discussion: DDD age limit for autism-specific treatments (some Committee members want to extend eligibility beyond age 5)	Sharon Flanagan-Hyde
4:40 pm	Services for Adults with ASD • Concern raised: continued lack of services for adults who have autism and the difficulties getting into the system after childhood • Innovation Group focus: Transition Years (14-30)	Sharon Flanagan-Hyde
4:50 pm	Coordination of Benefit/Third Party Liability	Sara Salek, M.D., Chief Medical Officer, AHCCCS
4:55 pm	Announcements and Future Agenda Topics	Sharon Flanagan-Hyde
5:00 pm	Adjourn	

Upcoming Meetings: January 10, 2018 and April 11, 2018

Raising Special Kids

ASD is the largest diagnostic category in the service population

30-32% of approximately 9,000 annual cases are parents of children with ASD.

ASD Case Issues 2016-2017

Issues by Frequency (Most frequent Sub-issues)

1,689 Special Education (Assessment, identification, evaluation; IEP; IEP Partner; Placement/Inclusion; FBA; Suspension/Expulsion; Seclusion/Restraint; Dispute resolution; Procedural safeguards; ESA; ESY)

833 Insurance (ALTCS; AHCCCS; Private insurance; DDD; CRS; AZEIP; Kids Care)

692 Behavior (Bx mgt/discipline/parenting; Behavioral health system navigation; PBS)

591 Youth to Adult Transition (Legal options at 18; Employment/Vocational services; Housing/Residential; Transition to adult services; Transportation)

440 Lack Access or Denial of Service (Access to HCBS; Access to Therapy; Appeal/Advocacy; Services not provided; Denial of Services not specified)

The Washington Post

Health & Science

Nowhere to go: Young people with severe autism languish weeks or longer in hospitals

By Christina Jewett | Kaiser Health News September 23

Teenagers and young adults with severe autism are spending weeks or even months in emergency rooms and acute-care hospitals because of a lack of community treatment programs able to deal with their outbursts, according to interviews with parents, advocates and physicians from Maine to California as well as federal and state data.

These young people — who may shout for hours, bang their heads on walls or lash out violently at home — are taken to the hospital after community social services and programs fall short and families call 911 for help. Once there, they sometimes are sedated or restrained for long periods as they wait for beds in specialized facilities or return home once families recover from the crisis or find additional support.

While the data on extended hospital stays are limited, national numbers on people with an autism diagnosis who were seen in hospital ERs nearly doubled over five years to 159,517 in 2014, according to the latest figures from the federal Agency for Healthcare Research and Quality. The total admitted for a behavioral or medical issues also nearly doubled, to 26,811 in 2014.

That same year, California recorded acute-care hospital stays of at least a month for 60 patients with an autism diagnosis. The longest were 211 and 333 days.

“As more children with autism are identified, and as the population is growing larger and older, we see a lot more mental-health needs in children and adolescents with autism," explained Aaron Nayfack, a developmental pediatrician at Sutter Health's Palo Alto Medical Foundation in California who has researched the rise in lengthy hospitalizations. "And we have nowhere near the resources in most communities to take care of these children in home settings."

Sixteen-year-old Ben Cohen spent 304 days in the ER of Erie County Medical Center in Buffalo. His room was retrofitted so the staff could view him through a windowpane and pass a tray of food through a slot in a locked door. His mother, who felt it wasn't safe to take him home, worried that staff "were all afraid of him . . . [and] not trained on his type of aggressive behaviors."

The problem parallels the issue known as psychiatric boarding, which has been an increasing concern in recent years for a range of mental illnesses. Both trace to the challenges of deinstitutionalization, the national movement that aimed to close large public facilities and provide care through community settings. But the resources to support that fell short long ago, exacerbated by the 2008 recession, when local, state and federal budget reductions forced sharp cuts in developmental and mental-health services.

The hospital "is the incredibly wrong place for these individuals to go in the beginning," said psychiatrist Michael Cummings, associate medical director at the Erie County facility. "It's a balancing act of trying to do the . . . least harm in a setting that is not meant for this situation."

Autism is a neurodevelopmental disorder typically diagnosed at a young age and characterized by impaired communication, difficulty with social interaction and repetitive behaviors that fall along a spectrum of mild to severe.

Adolescents and young adults with severe autism may still have the mental age of a child, and short-term care to stabilize those in crisis who are nonverbal or combative is practically nonexistent. Longer-term care can be almost as hard to find. It must be highly specialized, usually involving intensive behavioral therapy; someone with severe autism gets little benefit from traditional psychiatric services.

In New Hampshire this summer, 22-year-old Alex Sanok spent a month in Exeter

Hospital after he became violent at home, breaking windows and hurling objects at walls. His mother called 911, and paramedics spent half an hour trying to calm him before restraining him.

At the hospital, his wrists and ankles were strapped to an ER bed for the first week, and he spent several more weeks in a private room before he could be transferred, according to his mother, Ann Sanok. State agencies that handle developmental disabilities and mental health offered little help, she said.

As the days passed, she and her husband wondered: “What if [Alex] escalates again, what are we doing to do? We were getting no answers. Everyone seemed to kick the can down the road.”

Exeter Hospital said in a statement that its policy is not to use restraints unless there is an “imminent threat to patient or staff safety” and that any use is reviewed hourly. Sanok was moved in June to a special-needs residential school in Massachusetts, where his mother said he is doing well.

The federal government does no routine tracking of how autism is treated in ERs, but many experts say the problem of lengthy and inappropriate stays is nationwide and growing. Kaiser Health News identified some of the more extreme cases through interviews with autism and disability advocates, physicians and families in New Hampshire, New York, California and six other states — Maine, Connecticut, Rhode Island, Maryland, Michigan and Arizona.

Nancy Pineles, a managing attorney with the nonprofit group Disability Rights Maryland, said a group home took one young adult to a Baltimore ER earlier this year after he hit a staff member. And that’s where he remained for several weeks before the hospital moved him to a room in its hospice wing, she said — not because he was dying, but because there was nowhere else for him to go.

Such cases have been “on the increase,” Pineles said. “People with autism and more intense behavioral needs are just being frozen out.”

In Connecticut, the head of the state’s Office of the Child Advocate told lawmakers during a hearing on disability issues in May that the problem had reached a “crisis” level.

Private insurance data underscore the concerns. In a study published in February in the Journal of Autism and Developmental Disorders, researchers from Pennsylvania State University found that young people ages 12 to 21 with autism are four times likelier to go to the emergency room than peers without autism. They also are 3½ times more likely to be admitted to a hospital floor — at which point they stay in the hospital nearly 30 percent longer.

The analysis, based on a sample of 87,000 insurance claims, also showed that older adolescents with autism are in the ER more than their younger counterparts. The percentage of their visits for a mental-health crisis almost doubled from 2005 to 2013.

Tyler Stolz, a 26-year-old woman with autism and a seizure disorder, was stabilized after a few weeks in a Sacramento hospital. Yet she remained there for 10 months, according to Disability Rights California, an advocacy group that described her case in its 2015 annual report.

Ultimately, Mercy San Juan Medical Center went to court to demand that Stolz's public guardian move her. Although her conditions no longer required her hospitalization, they still "represent dangers to defendant and possibly to others if she were discharged to the community," the facility contended. "There is no safe place for the client to go."

The advocacy nonprofit helped place Stolz at a Northern California center that offered intensive behavioral therapy, recounted Katie Hornberger, the nonprofit's director of clients' rights. The medical center did not respond to a request for comment, but two years after an investigator found Stolz in a bed covered by a mesh tent, the case remains vivid in Hornberger's mind. "I don't believe we put people in cages," she said.

Across the country in Buffalo, Mary Cohen struggled to care for her teenage son. Ben's 6-foot-1, 240-pound body dwarfed her petite frame.

She began locking herself in a basement room to escape his outbursts, while still monitoring him via cameras she'd installed throughout the house to make sure he was safe. As the lock-ins became more frequent, she realized, "I can't keep going like this."

She found a nearby group home, covered by his disability and Medicaid payments, that could accommodate Ben.

On Aug. 1, 2016, it all imploded. Medication changes and an ear infection triggered a rage, Cohen said, and Ben hurt one of the staff members. Someone called 911, he was taken to the psychiatric emergency room at Erie County Medical Center, and a waiting room there is where he lived until early this summer.

Though a 304-day stay is a record there, cases like this have surged at the hospital, said Cummings, its executive director of behavioral health, who worked on Ben's case. They spurred him to launch a grant-funded home-visit program aimed at keeping families with autistic children from reaching a breaking point. He and his clinical partner have counseled nearly 400 families to help manage their youngsters' medications and find services, and their ER visits have dropped by nearly 50 percent, he said.

A bed finally opened up for Ben at Baltimore's Kennedy Krieger Institute — a private, highly regarded facility that offers intensive therapy, psychiatry and family coaching. Cohen held out for a placement there, hoping the staff could turn Ben's behavior around. The teen and his mother made the 360-mile trip in June by ambulance and plane.

"I want to do the right thing for him," Cohen said. "Because one day I'm not going to be there for him."

Kaiser Health News, a nonprofit health newsroom whose stories appear in news outlets nationwide, is an editorially independent part of the Kaiser Family Foundation.