

Draft Recommendations and Cumulative Notes

ASD Advisory Committee | Crisis Response Work Group

May 1, 2018 | 4:00-5:00 pm

AHCCCS | 801 E. Jefferson | Phoenix | 4th Floor, Arizona Room

Call-in Number: 1-877-820-7831 | Participant Passcode: 778195#

Facilitator: Sharon Flanagan-Hyde, sharon@flanagan-hyde.com

Work Group Objectives

Identify problems and generate concrete recommendations for the improving system of care for individuals with ASD experiencing a crisis and their families. The Work Group will be open, positive, respectful, constructive, collaborative, and solutions-focused.

Participants in May 1 Meeting

1. Bohdan Hrecznyj, MD, Child & Adolescent Psychiatrist, Health Choice Integrated Care
2. Brian van Meerten, MEd, BCBA, LBA, Director of Behavioral Health Services, Behavioral Consultation Services of Northern, Arizona, LLC (BCSNA)
3. Bryan Davey, PhD, BCBA-D, CEO, Touchstone Health Services
4. Diedra Freedman, JD, Board Secretary/Treasurer, Arizona Autism Coalition
5. Lauren Prole, Clinical Project Manager, Arizona Health Care Cost Containment System (AHCCCS)
6. Lindsey Zieder, Interim DDD Liaison & Special Projects Lead, Mercy Maricopa Integrated Care (MMIC), RBHA
7. Sara Salek, MD, Chief Medical Officer, Arizona Health Care Cost Containment System (AHCCCS)
8. Steven Leibensperger, Foster Care Community Liaison, Arizona Health Care Cost Containment System (AHCCCS)
9. Wendy Philpot, Manager of Crisis Services, La Frontera EMPACT-SPC

Draft Recommendations

The intent is for these recommendations to address the most urgent priorities, and be specific and able to be operationalized. Draft recommendations will be presented to the ASD Advisory Committee at the July 11, 2018 meeting.

1. AHCCCS should increase training for PCPs and behavioral health providers to identify individuals as soon as they begin to show signs of aggressive behavior and connect families to appropriate services. The 10-15 year-old male population is the group most likely to experience crisis situations, including aggression toward others, self-injury, and suicide. DDD should continue to fund peer-to-peer parent support programs.
2. DDD should continue to improve staff training and processes to identify children at risk for crisis, assess needs, and connect families to services early in the child's life (before adolescence). Approaches to identifying children at risk for crisis include:
 - a. The tool that DDD is developing to assess complex needs and identify and provide services to children and families at high risk for a crisis.

- b. Children with high scores (e.g., a 6) on the Child and Adolescent Service Intensity Instrument (CASII) because this may indicate higher levels of family stress. All AHCCCS behavioral health providers are required to do a CASII starting at age 6. AHCCCS should ensure that providers are actually doing this assessment.
 - c. Members who are elevated to the clinical resolution team.
 - d. Children who come to the attention of advocacy organizations.
3. The Autism Centers of Excellence and DDD should collaboratively formulate and share questions that network providers, DDD support coordinators, and behavioral health case managers and social workers can ask parents in order to identify the triggers that send families into crisis. (One example of a question: Have parents considered out-of-home placement?)
 4. To assess risk of caregiver burnout, AHCCCS should educate providers about the use of instruments such as Autism Parenting Stress Index (APSI), Questionnaire on Resources and Stress (QRS-F), Parent Motivation Inventory (PMI), and Child Outcome Rating Scale (assuming low ratings over time correlates with caregiver stress and burnout).
 5. AHCCCS should partner with community advocacy groups and conduct a survey and focus groups with parents who have gone through a crisis to find out what interventions and support worked and what didn't.
 6. Develop a mechanism for stakeholders (DDD, AHCCCS, the Autism Centers of Excellence, RBHAs, and community agencies) to identify the types of data that could help to identify patterns in the problems experienced by families in getting needed services. Once data types are identified, stakeholders should collect and periodically review these data in order to develop solutions across payors and providers.
 7. All providers should ensure that appropriate policies and crisis plans are in place and staff have proper training to respond appropriately when parents bring up a child's aggressive behavior. DCS should never be used as a threat in an attempt to de-escalate situations or to coerce compliance. Retaliation against families should never be tolerated. All professionals have a responsibility to take steps in order to protect the child, siblings, and other family members from harm, and also have a responsibility to connect families with needed services that can decrease aggressive behavior and prevent a crisis without escalating to the need for DCS involvement. Appropriate training should be provided in what it means to be a mandated reporter and how to talk with families before a call is made to DCS.
 8. DDD and other agencies should educate families about happens during a typical police response, police Crisis Intervention Team (CIT) training, and asking for a CIT-trained officer when calling for assistance. Multiple funders should collaborate to increase use of the BE SAFE Program.
 9. Develop a one-page information sheet and give to families as part of intake and the ISP—a flow chart with clear instructions about what to do in a crisis: who to call and in what order given the nature of the emergency (e.g., case manager, RBHA crisis line, 911 asking for a CIT-trained officer, etc.). Families should ensure that the child's emergency crisis plan is included in the crisis line's electronic health record.
 10. Building on the successful training conducted by some municipalities, the AHCCCS ASD Advisory Committee should encourage training for all law enforcement, fire, and EMT personnel throughout the state about the special needs of individuals with ASD.

Cumulative Notes

Incentivizing Providers

Providing care for more complex members is expensive. As payment models evolve and the system moves toward value-based purchasing, it is important to consider provider sustainability. Providers should be incentivized to ensure that professionals with appropriate qualifications and training are available to deliver services, and payments should reflect the additional training and expertise needed.

AHCCCS Complete Care and Centers of Excellence

In response to a question about services that Complete Care providers will deliver, Sara Salek shared the following contract reference:

https://www.azahcccs.gov/PlansProviders/Downloads/RFPInfo/YH19/ACC_RFP_11022017.pdf

Centers of Excellence

The Contractor shall contract with Centers of Excellence which implement evidence based practices and track outcomes for children with specialized healthcare needs:

- a. Children aged birth to five: Staffed with specialists who are endorsed by the Infant Toddler Mental Health Coalition of Arizona (ITMHCA) or other Endorsement program recognized under the Alliance for the Advancement of Infant Mental Health (formerly the League of States using the Michigan Association for Infant Mental Health Endorsement®),
- b. Children at risk of/with Autism Spectrum Disorder (ASD),
- c. Adolescents with substance use disorders, e.g.
 - i. Adolescent Community Reinforcement Approach (A-CRA),
 - ii. Assertive Community Care (ACC),
 - iii. Global Appraisal of Individual Needs (GAIN), and
- d. Transition Aged Youth:
 - i. First episode psychosis programs, and
 - ii. Transition to Independence (TIP) Model.

Assessing Needs

Sharon read the following e-mail from De Freedman, who was unable to attend the meeting:

“We need to encourage the MCOs, including DDD and the new Integrated Care Plans, to do a comprehensive needs assessment of member’s needs, including currently unmet needs, then a subsequent comprehensive cost assessment to meet all of these needs followed by a commitment by the MCOs to include the necessary resources in their budgets including funding to incentivize providers to develop appropriate innovative programs.”

Comments:

- DDD has looked at data and done value-stream mapping, following a case through, and has recognized that in some cases, families raise issues, and DDD’s assessment of needs and the services provided did not ameliorate or avoid crises. DDD recognizes the need to connect families with appropriate resources when children are younger, for example, peer-to-peer supports such as Raising Special Kids’ Positive Family Intervention (PFI). PFI data show that when parents begin hearing messages about available services earlier, they are more likely to be receptive to and connect with services that can help avoid crises.

Focus of Work Group Recommendations

- The priority group is 10-15 year olds, primarily males. This is the group that is most likely to experience crisis situations, including aggression toward others, self-injury, and suicide. We need to do a better job identifying young adolescents when they begin to show signs of these behaviors through PCPs and behavioral health providers.
- The second priority is ages 5-10: connecting families with services before children reach puberty can help avoid crises.
- The 0-5 group continues to be a priority for identification of children who need services.

Intervene with at-risk children and families before a crisis develops.

1. Target children at high risk for crisis:
 - a. Members who are elevated to the clinical resolution team.
 - b. Children who come to the attention of advocacy organizations.
 - c. Children with high scores (e.g., a 6) on instruments such as the Child and Adolescent Service Intensity Instrument (CASII) because this may indicate higher levels of family stress. All AHCCCS behavioral health providers are required to do a CASII starting at age 6. Are they actually doing this assessment?
 - d. Make sure that the tool that DDD is developing to assess complex needs is used to identify and provide services to children and families at high risk for a crisis.
2. Measure and track caregiver status to minimize burnout:
 - a. The Autism Centers of Excellence and DDD should collaboratively formulate and share questions that network providers, DDD support coordinators, and behavioral health case managers and social workers can ask parents in order to identify the triggers that send families into crisis. One example: Have parents considered out-of-home placement?
 - b. Note: TI dollars are going toward educating PCPs to increase expertise about normative behaviors and behaviors that warrant attention. This should help ameliorate situations in which families raise concerns and the PCP responds that the child "will grow out of it."
 - c. Find out from behavioral health providers whether families with more complex needs are being referred to the Centers of Excellence, or are seeing other providers who many not have sufficient expertise.
 - d. As the system moves towards integration, focus on creating a comprehensive team. Families say that services feel disjointed. The medical home/behavioral health integrated model should help.
 - e. Incorporate assessment of parental stress into 90-day ISP meetings and document to guide future support.
 - f. Consider use of instruments such as Autism Parenting Stress Index (APSI), Questionnaire on Resources and Stress (QRS-F), Parent Motivation Inventory (PMI), and Child Outcome Rating Scale (assuming low ratings over time correlates with caregiver stress and burnout).

3. Investigate what parents say they need and want:
 - a. AHCCCS should partner with community advocacy groups and conduct a survey and focus groups with parents who have gone through a crisis to find out what interventions and support worked and what didn't.
4. Encourage DDD and Behavioral Health to continue its efforts to provide additional training for support coordinators so they can more effectively identify at-risk families and provide appropriate supports to prevent or minimize crises. Online modules have been identified and will be provided to support coordinators. DDD should make sure that families know about the behavioral health services available to them. The Crisis Work Group supports DDD's efforts to streamline and combine the Child and Family Team (CFT) (behavioral health) and Individual Support Plan (ISP) (DDD) meetings and processes.
5. Develop a mechanism for stakeholders (DDD, AHCCCS, the Autism Centers of Excellence, RBHAs, and community agencies) to identify the types of data that could help to identify patterns in the problems experienced by families in getting needed services. Once data types are identified, stakeholders should collect and periodically review these data in order to develop solutions across payors and providers.
 - a. Data mining also can help to provide targeted interventions by identifying needed levels of care.
6. Reduce stigma through co-locating behavioral health providers with primary and specialty care providers. Integration of behavioral and physical health under one contract after October 1, 2018 will support this approach.
7. All providers should ensure that appropriate policies and crisis plans are in place and staff have proper training to respond appropriately when parents bring up a child's aggressive behavior. DCS should never be used as a threat in an attempt to de-escalate situations or to coerce compliance. Retaliation against families should never be tolerated. All professionals have a responsibility to take steps in order to protect the child, siblings, and other family members from harm, and also have a responsibility to connect families with needed services that can decrease aggressive behavior and prevent a crisis without escalating to the need for DCS involvement. Appropriate training should be provided in what it means to be a mandated reporter and how to talk with families before a call is made to DCS.
8. DDD and other agencies should educate families about happens during a typical police response, police Crisis Intervention Team (CIT) training, and asking for a CIT-trained officer when calling for assistance.
 - a. Encourage families to participate in BE SAFE programs.
9. Encourage and fund peer-to-peer parent support programs.
10. Provide advocacy groups and the public with data on AHCCCS customer service and substantiated quality of care concerns. Tracking trends over time on the types and severity of quality of care issues would provide insight into the effectiveness of agencies in addressing problems.
 - a. Questions for April meeting: What specifically? AHCCCS can provide high-level statewide trend data, but data are protected at the individual level. For example,

we could look at rates per 10,000 members, acute versus long-term care, etc.
What is the intention of looking at the data?

Design and implement a 24/7 ASD-Specific Crisis Response Model.

- As part of intake and the ISP, provide families with a one-page information sheet—a flow chart with clear instructions about what to do in a crisis: who to call and in what order given the nature of the emergency (e.g., case manager, RBHA crisis line, 911 asking for a CIT-trained officer, etc.).
- Improve crisis response line services statewide.
 - Gather data on capacity, policies, processes, and staff expertise of all crisis lines in the state.
 - Ensure that personnel staffing all crisis lines have the capacity, skill level, and expertise needed to handle calls quickly and appropriately.
 - Develop a database that crisis lines and first responders can access to identify insurance coverage and contracted providers who will provide care during a crisis.
 - Families should ensure that the child’s emergency crisis plan is included in the crisis line’s electronic health record.
- Develop “firefighter model” crisis response teams throughout the state to ensure that all individuals with ASD, regardless of insurance, have access to a trained team that is ready to go and respond in a crisis.
 - MMIC’s mobile crisis teams are available to everyone in Maricopa County. However, the team does not come if a child has been violent; they call the police. Further, this team may or may not have someone with familiarity when it comes to aggression, ASD or a combination of the two. MMIC should ensure that appropriate training and protocols are in place when making the decision to call the police regarding an individual with ASD who is aggressive.
- Access or encourage additional research on primary interventions that can prevent the use chemical and mechanical restraints during a crisis.

Law Enforcement

- Expand use of the BE SAFE Program.
 - There will be a BE SAFE presentation on Thursday morning, June 21 at the Ability 360 Center. All are welcome to attend— provider agency personnel can observe the BE SAFE program in action and decide whether to send provider agency personnel to the August BE SAFE Train the Trainer event the Greater Phoenix Autism Society hopes to offer in August. The AZ Autism Coalition will Facebook Live the meeting except for the BE SAFE Video presentation (that is prohibited) and will archive the Facebook Live video and make it available for later viewing
- Building on the successful training conducted by some municipalities, encourage training for all law enforcement, fire, and EMT personnel throughout the state about the special needs of individuals with ASD.

Hospital Emergency Departments

- Integrate medical and behavioral health care more effectively in emergency departments.
- Educate ED staff about the importance of contacting the case manager when a child with ASD receives care in an ED.
- When available, utilize developmental pediatricians, developmental behavioral pediatricians, behavior analysts, psychologists, psychiatrists, pediatric neurologists, and other providers with expertise in ASD, to help bridge the gap between medical and behavioral health providers.

Inpatient Treatment

- To improve quality of care for individuals with comorbid conditions, improve communication and case management when an individual is being served by multiple provider networks, such as DDD, behavioral health, and acute care.

Step-Down/Step-Up Services

- Develop more step-down and step-up facilities, intensive outpatient treatment programs, and in-home care programs to serve individuals as they move from inpatient to outpatient care. Step-up levels can provide services prior to an emergency department.

Support for Providers

- Assess needs and provide supports for providers, including crisis workers, support coordinators, direct care staff, behavior technicians, and respite workers, among others, to reduce stress levels. Provider burnout exacerbates workforce shortages.
- Identify additional training needs for crisis workers that are specific to the issues faced by families with a child or adult with ASD.