# Behavioral Crisis Response Capacity of the Developmental Disability System
## *Summary of Stakeholder Input with Recommendations 8/2016*

The Division of Developmental Disabilities requested stakeholder input in identifying and prioritizing the next steps to further strengthen and improve the ability of the developmental disability system to respond to behavioral crisis.

Extensive written feedback was received, with many sending thoughtful multiple page papers and proposals. Division staff participated in many stakeholder meetings, where verbal feedback was shared by those in attendance. The Division thanks all who spent time thinking, writing and talking to us about their experiences and perspectives. Summary details regarding those who gave input is attached in charts following this report.

Input focused on preventing a behavioral crisis as well as intervention when there is a behavioral crisis. Several commenters shared what they saw as helpful in preventing crisis and supporting people in crisis and what is working in terms of structure, training and support. This report will start with those positive thoughts before addressing the difficulties and needs of the system as expressed in the input. Although there were variations and caveats to each of the items below, the intention is to capture the spirit of the collective comments.

## Strengths

Listed below are the resources most frequently identified as being beneficial in supporting people in a behavioral crisis. The tools that were most frequently mentioned as helpful, albeit with conditions and provisos, were:

1) Increased financial resources available to persons experiencing a higher level of need.
2) Referral to the Support Services Teams (SSTs), specifically their objective and timely involvement.
3) Staff's consistent approach and implementation of behavior plans.
4) Training to prevent, deescalate and manage behavior challenges, such as Safety Care.
5) Access to mental health inpatient and outpatient resources.
6) Access to specialty services, such as behavior analysis and pharmacology review.
7) Good communication among the service providers and with the individual, with careful attention to try to understand what the behavior might be expressing.
8) Thorough physical evaluation to ascertain if the behavior might be the result of an untreated illness or physical need.
9) Local community partnerships with first responders, hospitals, and mental health providers.

## Difficulties and Needs

The bulk of the input received focused on the difficulties and needs of staff, agencies and the system as a whole in preventing and intervening in a behavioral crisis. Comments were grouped and summarized

into larger categories based upon the nature of the comment. The identified categories are as follows: training, mental health, referral/matching/transition, State-Operated Developmental Centers (SODCs), and funding.

**Training.** Much commentary was provided about the need for training of front line staff. Commenters explained this means that all training should be funded and staffing patterns funded that allow for time to attend training on an ongoing basis, not just at the beginning of employment and not just training provided via computer. Recommended training topics for the direct service staff included: behavioral support techniques; building healthy relationships; understanding that behavior is often how people with developmental disabilities communicate; individual specific training such as - understanding the individual's preferences and what works best for them given their experiences and personality; coping skills; functional communication; social skills; dual diagnosis of developmental disability and mental illness; crisis prevention and crisis management systems; how environment can affect behavior; person focused supports; cultural differences; Registered Behavior Technician certification; mandated reporter; and various types of training focused on trauma informed care. It should be noted that some State-Operated Developmental Center staff, parents and community agencies shared the fact that such training is currently being provided.

Another specific area endorsed was additional training for other service entities in the community specifically first responders (police, fire and ambulance personnel) and medical providers (emergency room staff, medical school students, and mental health providers).

**Mental health.** Many urged the Division to address the mental health needs of persons with a developmental disability. A paper received as part of a comment quoted a national report from 2008-2009 that indicated 30% of the persons with a developmental disability also have a dual diagnosis of mental illness. SST service statistics show that each year the number of individuals receiving a referral who also have a mental health diagnosis is drastically increasing. Currently 99% of the total SST referrals received also have a mental illness. A theme with much feedback, specific areas suggested were:

1. Access to inpatient and outpatient mental health services that have professionals trained to meet the needs of a person with an intellectual or developmental disability.
2. Mobile crisis intervention and stabilization teams deployed during the crisis – similar to the Screening Assessment and Support Services (SASS).
3. 24-hour on call staff skilled in crisis intervention and available to quickly intervene in place of 911utilization.
4. Increased access to clinical pharmacology.
5. Support local physicians with access to psychiatric consultation with a psychiatrist experienced in serving persons with an intellectual or developmental disability. Specifically mentioned were psychotropic medication side effects and medication step down guidelines.

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**Referral/Matching/Transition.** A variety of concerns and suggestions were expressed related to the area and process of referral/placement and its impact on behavior crisis. Note that the word placement is a shorthand term for the process by which an individual and their family or guardian make an informed decision about their services and home and access those services. Those highlights are summarized below.

1. Offer to individuals residential service providers that have the experience, skills, and supports to meet their needs.
2. Screenings for placement need to be done by the day provider, as well as residential provider when they are not the same provider.
3. Screen person for compatibility with other residents in the home.
4. Improve the transition from special education into adult services.
5. Begin the guardianship process prior to the individual turning 18 (for those persons in need of a guardian) to allow better service planning and reduce crisis decision making in times of a behavior crisis.
6. Streamline the process for submission and review of request for alternate placement, consistent with draft rules on discontinuation of CILA services.
7. Consider a rating system that reflects the community provider's ability to manage challenging behaviors. Use the system in distribution of packets for placement consideration.

**State Operated Developmental Centers.** Several commenters spoke to the clinical resources at the SODCs and using improved local teamwork and partnerships with the SODCs to benefit the whole system. Specifically, contributors spoke to the potential opportunities for using the clinical expertise at the SODCs for training, clinical support on CART, and for consultation and crisis intervention. There was some input that SODCs could improve transition to and success in the community by changing the intervention philosophy to emphasize individual self-regulation and problem solving. It was also suggested that non-contingent medication reduction procedures often employed at SODCs be evaluated for their effectiveness.

**Funding.** Input was voluminous in this area, indicating responders saw this as a critical area. Suggestions for improvement were:

1. Increase the front line staff wage in the residential and day rates so providers can secure and retain adequate numbers and quality of staff, increasing experience and reducing turnover, to allow for relationship building between staff and individuals.
2. Funding for increased training described earlier.
3. Funding for property replacement and repair caused by physical aggression included in the rate.
4. Increase the amount and flexibility of the 53R/D funding to meet individual needs.

5. For individuals experiencing behavior challenges, reimburse long trial placement stays, as a way to allow sufficient time for the provider and individual to determine the appropriateness of the setting and services.
6. Fund all professional assessments and specialty services (Psychologist, Speech Pathologist, Occupational Therapist, Physical Therapist) in the waiver.
7. Enhanced rates to adequately fund and encourage development of smaller homes.
8. Funding to provide more thorough behavioral support so that behavior analysts can be helpful to the agencies in ways not currently billable.
9. Funding for an internal 24 hour responder who is available to the DSPs in an escalating or crisis situation.
10. Increased day program supports.
11. Increased and flexible nursing supports through rate changes.
12. Specialty service rates for persons with more complex medical or behavioral challenges.
13. Greater access to respite for persons with a behavior challenge and review of the process that determines who receives respite services.
14. Add funding in the CILA rate for middle managers to be on duty during second and third shift to provide oversight and be available for quick response for staff and individuals.

## Recommended priorities with next steps

The Division recognizes the expressed need to address rates for the direct service/front line staff as essential to improving the ability of the developmental disability system to prevent and respond to behavioral crisis. The administration continues to support the necessity for adequate numbers of trained and experienced front line staff and is exploring next steps.

Having said that and without rejecting any of the input, here are the recommended eight priorities that can be pursued immediately, along with a few next steps. A Division staff person will have to be assigned to each, with an advisory group, to develop a work plan.

1. **Work with the Department of Healthcare and Family Services (HFS) to ensure the managed care contractors meet the mental health needs of the enrolled persons with a developmental disability** (those not receiving Medicare, largely those 18-65 years old). Steps: Send HFS the summary of all the input received on the area of discrimination and unmet mental health needs. Meet with HFS to discuss mental health needs of persons with an intellectual or developmental disability and identify steps to assure required access to mental health services. Meet with managed care providers, as needed, in conjunction with HFS. Monitor access to mental health services by persons with an intellectual or developmental disability for HFS.
2. **Incorporate the needs of person with an intellectual or developmental disability in the Behavioral Health Transformation Initiative**. Steps: Share stakeholder input about the mental health issues and needs of persons with the dual diagnosis of developmental disability and mental illness with

the Behavior Health Transformation Initiative Working Team. Meet with the Working Team staff to explore best ways to include persons with a dual diagnosis. Involve intellectual or developmental disability stakeholders in the Working Team. Assure the mental health needs of individuals with an intellectual or developmental disability are covered in the development of the 1115 waiver.

3. **Develop services for persons with exceptional behavior needs.** Steps: Continue development of service for individuals with exceptional behavior needs. Identify a pool of potential providers, known for successfully serving persons with exceptional behavior needs, to assist in the development of this service, including service requirements. Develop a rate for needed services to include such potential components as higher QIDP and administrative allocation, higher overtime costs for an initial period, an allowance for property damage, and a reduced utilization rate to allow funding for vacancies.

4. **Improve the referral process** so that individuals get services from the appropriate provider that can meet their needs. In addition, make sure everyone knows where there are vacancies and that individuals are screened by both the day and residential provider, who also screens the individual for compatibility with others in the home. Steps: Implement the improved centralized vacancy tracking system which has been planned and requires computer programming. Develop a way to identify providers who are able to serve individuals with challenging behaviors based on their history, staffing, and internal options to handle crisis. Revise the placement process to require use of providers on this list for persons with challenging behaviors. Require screening by the day provider as well as residential when they are different and specifically assessing compatibility with housemates. Implement CILA and DT draft rule changes regarding discontinuation of services.

5. **Fund behavioral analysis as part of the CILA and day services rates** so that providers can hire BCBAs as team members to provide support to individuals as needed and to add value to the agency beyond hourly billing. Steps: Develop an estimate of the cost for behavior analysis services for each person to include hours and a salary that attracts BCBAs. This may be difficult to get approved through the waiver process.

6. **Fund ongoing across the board front line training** on emotional regulation skills, such as The Skills System, and competencies needed to prevent, minimize, and manage behavioral challenges, such as Safety Care. It is recommended that the cost of this new training and the costs of Direct Service Professional training (initial, in-service, and retraining) and Qualified Intellectual Disability Professional CEU training (initial and ongoing) be wrapped into the rate rather than separate billing and payment process. Steps: Determine how much is spent on initial, retraining and Q CEUs to fold into the rate. Establish standards for training related to the prevention and intervention with behavior challenges. Estimate the cost of the new ongoing training and add to the rate. Evaluate the necessity of adding monitoring for this training.

7. **Continue the process of strengthening 53R/D to increase flexibility about how the funds are used to meet the individual's needs.** Next step: A work group begins in July to address this area.

8. **Take advantage of the clinical expertise at the SODCs and in the community to develop best practices around prevention and intervention in a behavior crisis.** Steps: Involve SODC staff, Division clinical staff, community agency representatives and other stakeholders such as parents, in a partnership to develop best practices in prevention and intervention in behavior crisis across all settings. Infuse this best practice into rules, training, and other policy vehicles.

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UMMARY OF SOURCE OF WRITTEN INPUT RECEIVED

| TYPE OF COMMENTER | AREA OF THE STATE | NUMBER BY TYPE |
|---|---|---|
| TOTAL | 9 southern, 8 central, 21 northern | 38 |
| Providers | 2 southern, 3 central, 12 northern | 17 |
| Independent Service Coordination | 2 central, 1 northern | 3 |
| Parent/Family | 5 southern, 2 northern | 7 |
| Division of Developmental Disability staff | 2 southern, 2 central, 3 northern | 7 |
| Developmental Disability Council | 1 northern | 1 |
| Human Rights Authority | 1 central | 1 |
| American Federation of State, County, and Municipal Employees | 1 northern | 1 |
| Educator | 1 northern | 1 |

SUMMARY OF STAKEHOLDER INPUT SESSIONS ATTENDED

| NAME OF ENTITY | INTERNAL OR EXTERNAL STAKEHOLDERS | PRIMARY ROLES | VENUE | DATE | ESTIMATED PARTICIPANTS |
|---|---|---|---|---|---|
| TOTAL SESSIONS = 9 | | | | | 307 |
| IARF | External | Providers | In person | 5/25/16 | 25 |
| DDD Bureau of Quality Management | Internal | State staff | In person and phone | 5/25/16 | 20 |
| DDD Bureaus of Community Services and Transitional Services | Internal | State staff | In person and phone | 6/9/16 | 15 |
| The Institute, Executive Directors | External | Providers | On phone | 6/13/16 | 15 |
| Independent Service Coordination | External | Case coordinators | On phone | 6/13/16 | 9 |
| The Center for Developmental Disability Advocacy and Community Supports | External | Provider staff | In person | 6/15/16 | 145 |
| North/Northwest Cook County and Lake County DD workgroup | External | Families | On phone | 6/16/16 | 50 |
| ARC | External | | On phone | 6/17/16 | 16 |
| DHS Bureau of Accreditation and Licensure | Internal | State staff | In person and on phone | 6/17/16 | 12 |