



**Alliance for the Betterment of
Citizens with Disabilities**

Empowering People: Providers Shaping Policies

New Jersey Regional Family Support Planning Councils
Health and Safety Subcommittee

Recommendations to Improve Health and Safety of Individuals with Intellectual and Developmental Disabilities who Receive Services from the New Jersey Division of Developmental Disabilities

Feedback and Input Filed Electronically
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Thank you for the invitation to provide feedback and input on your November 2021 White Paper, *Recommendations to Improve Health and Safety of Individuals with Intellectual and Developmental Disabilities who Receive Services from the New Jersey Division of Developmental Disabilities*. ABCD agrees that information gathered over the last 5-7 years provides an opportunity to assess the initial stages of our system of care.

As providers we are discovering that person-centered care helps to improve the individual's health and safety and, so, strengthening the voice of the individual remains our rubric. Three principles applicable to all comments contained in this response are:

1. The individual, family, guardian, and provider are unique and distinct.
2. No process may erode the rights of the individual.
3. The individual has the right to their information, to confidentiality, and to permit or refuse another's request to access their information.

Some of our response builds on your recommendations while others provide a different perspective and are presented in that order. We also include a general assessment of the NJCAT, for your consideration. We look forward to continued dialogue and mutual efforts to enhance our system.

Collaboration

We are unsure how the "Team Meeting" would differ from the current annual ISP meetings. If these are not occurring as described, they should be, and we are in full support of ensuring that they take place.

Person-centered care sees people as equal partners in planning, developing, and monitoring care and services, which means putting the individual and their family at the center and working alongside agency professionals to get the best outcomes. Person-centered care is not just about giving people whatever they want or providing information, it is about considering the individual's desires, values, family situations, social circumstances, resources, and lifestyle and working together to develop appropriate solutions/plans. The support coordinator plays an important role as they are required to facilitate in such a way to verify that the individual's true desires are brought to light. If families desire that their input and involvement be accepted, we strongly encourage that providers be invited to the ISP meetings, so they can discuss and understand concerns and ideas, to arrive at satisfactory and workable protocols for all parties, particularly the individual.

To prevent retaliation, we must first agree on what it is. Retaliation occurs when an agency staff treat individuals, families and/or guardians, less favorably for reporting a complaint or problem, participating in investigations or lawsuits related to complaint or problem, or threatening to file a complaint or problem, regardless of whether the charge has merit. It is in the agency's best interest for individuals, families and/or guardians to feel comfortable to report concerns to the agency so that they can be investigated and addressed. To help prevent retaliation, agencies should inform staff that retaliation is prohibited, to respond to questions, concerns, and complaints promptly and effectively, ensure that managers and supervisors understand their responsibility to stop, address and prevent retaliation, and to hold staff accountable for complying with and enforcing rules and policies.¹

Transparency

DHS should consider the content of the Findings Letters to provide sufficient detail for the individual and family. A process currently exists for the family who desire additional information, outlined in DHS, *Reporting Suspected Abuse, Neglect or Exploitation Of an Individual with an Intellectual or Developmental Disability*, July 2019, attached.

Families should always have the opportunity to provide information and speak out of interest for their loved one.

Agencies may want to consider unaffiliated family for membership on their Human Rights Committee (HRC). Currently, many of our agencies wisely include family members on this committee, but the make-up of the HRC should ultimately be specific to the agency system and surrounding community and determined by the Executive and the Board, some of whom are family members.

External Oversight

We agree that government plays an active role in defining and enforcing basic standards. Before and since the advent of Home and Community Based Services in NJ in 2014 there have been improvements made to the interconnected agency/government network. As the system matures, agencies are adopting additional measures to increase accountability and quality through independent accreditation.

Nevertheless, while employing the most effective and efficient means to achieve our goals, we must also continue to develop and test ideas and protocols to improve upon these best practices; Furthering the design of the infrastructure to promote independence and self-determination and monitor health and safety, free from abuse, neglect, and exploitation.

- Agencies should consider an incident review process to ensure that a thorough investigation was conducted, recommendations were implemented, the corrective action plans were effective, and possible trends were analyzed.
- OPIA should reevaluate the current Risk Indicator Report to capture issues of concern.
- All audits should require observation and interview by DDD staff of all the individual residents while in their homes.
- Creation of the DDD Director's Best Practice Quality Roundtable, an apolitical think tank which includes thought leaders around developmental disabilities and related issues.
- Increased use of Remote Supports and Assistive Technology can help in connecting individuals to their communities and increase independence when partnered with ways in which to mitigate concerns related to privacy and safety.

¹ Based on the US EEOC, "What is Retaliation and How Can I Prevent It?" <https://www.eeoc.gov/employers/small-business/8-what-retaliation-and-how-can-i-prevent-it>

Records

Unfortunately, EHRs will not provide better insight into the health, life, and wellbeing of the individual. We also believe that the suggested process could lead to circumstances where staff are “treating the chart, rather than the person.”

As an alternative to meet the important goal expressed, we suggest structured opportunities for individuals, families, guardians and/or providers to communicate highlights of a person’s growth.

Grievance

Each agency is required to have a DDD approved grievance policy for individuals. Individuals and families should have a copy of the agency grievance policy to readily address and resolve issues of concern brought by the individual and/or their guardian.

There have been instances when family members insist on the implementation of procedures which:

- Would violate the agency’s mission and values;
- Would violate the rights of the individual;
- Are determined by the agency to be detrimental to the overall well-being of the agency system, staff, and other individuals and families; or
- Even in instances when the agency agrees, the agency is simply not in a position to provide the requests of the individual and family.

In these instances, the agency should cooperate with the individual and family to find an alternate program or placement.

There may come a time in some relationships when it is in the best interest of both parties to part ways.

DSP and Staff Training/Documentation

- Model of Care

Though there are certain protocols and tools suggested which may be of value, we wish to speak to the general direction of this section, which is of concern. The system described resembles that of a nursing home, rather than a group home. As we know, nursing homes are institutions, run by nurses using the medical model of care as opposed to group homes which are run by supervisors and DSPs using person-centered, humanistic model where things are done with people, rather than “to” them.

- DSP Role

DSPs work with individuals to teach them how to do things for themselves and how to live independently, helping them realize their potential and become integrated and engaged in their communities. The role of the DSP is to provide support which is different from caregiving.

- Clinical Staff Role

ABCD providers employ nurses, rehab therapists, psychiatrists, therapists, and behaviorists who provide clinical caregiving services and supports to individuals who have complex medical and behavioral issues to enable them to live in the community. To ensure that clinical staffing levels effectively match the needs of the individual with the knowledge, skills, and abilities of the clinician, more funding is required.

- Core Competencies

Based on the needs of the individuals they serve, many ABCD providers have core trainings in nutrition and mealtime management. On a universal level, ABCD believes that every few years core competencies should be reviewed on a statewide level to underpin the continuous evaluation, revision, and development by provider agencies of their training in the skill sets required of their DSP workforce.

- All stakeholders should be represented.
- Given that the IDD population is heterogenous, the working group must account for the possibility that not all competencies or levels of competencies are applicable in every situation.
- Many agencies have professional staff who are singularly responsible for employee training and development. The best trainings consider all that is necessary to maximize the learning of required skills by a specific audience. Provided that they meet the required outcome standards, agencies must be given the flexibility to create trainings that work for their system of care.

The Assessment of “The Assessment,” NJCAT

The assessment process must capture all the influential variables to not only plan but also allocate resources for the individual’s life choices and needs, see attached ABCD paper for details. Two issues of concern:

- The NJCAT largely disregards behavioral/mental health/dementia issues as a driver for additional care needs.

For mental health services and supports to be embedded on a systemic level to ensure that I/DD population has access to services along the continuum from promotion and prevention to treatment and rehabilitation, the NJCAT must be used to identify individuals at risk.

- The NJCAT findings are inconsistent; people with very similar support needs are put into different tiers and acuities.

These variances can contribute to wastefulness and inadequate resource allocation. When we provide too much in the way of support we can get in the way of the person’s personal growth as well as deplete limited resources for those who truly need them. When we provide too little, we limit the person’s opportunity to be fully actualized.