



Summary of the 2017 Community Conversations Regarding Consumer Perspectives of the Connecticut Network of Care



Between December 2016 and March 2017, a second round of Community Conversations was completed to gather input from families and youth regarding the Network of Care in Connecticut. A total of 30 conversations including 333 adults and 151 youth were facilitated by the Family Systems Managers from FAVOR. Family Systems Managers are family members who provide leadership and support to the development of the local, regional and statewide integrated family-driven network of care. As was done in 2014, participants were asked the following questions:

1. What are the strengths of Connecticut's service system for children and families?
 - a. What is working well?
 - b. What needs are being met?
 - c. In what ways are services accessible for families? Do people know about the services that are available?
2. What are the major areas of concern within Connecticut's service system for children and families?
 - a. What is missing from our system?
 - b. What needs are not being met?
 - c. What are some of the barriers families encounter when trying to access appropriate services?
 - d. Which populations within our communities experience greater difficulties accessing services? (ask about: race/ethnicity, language, gender, sexual orientation/identity)
3. How should we fix these problems? What are your suggestions to improve our system of care?
 - a. How would you like the system to work?
 - b. What services are most important so that all of our children and families have the supports they need?
 - c. What do we need to do to improve access to care for all of Connecticut's children and families?

Information from the Community Conversations was gathered through careful notes taken by network of care staff and then analyzed using standard procedures for analyzing qualitative data (Krueger, 1994); data was coded, aggregated and synthesized by FAVOR Family Systems Managers and an evaluator from Yale University. Only comments made by participants across different meetings or by consensus of one group of participants are included in the summary. Thus, not everything said in the community meetings were included in the results.

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Children and Families to Care

2017 CONNECT Community Conversations Summary

Strengths of the Network of Care

Community conversation participants report significant strengths in Connecticut's Network of Care.

Family Voice. Community members report that there are increased opportunities for them to share their concerns and ideas regarding the behavioral health system. They stated that some entities, especially DCF, are listening to them. Opportunities for input include the Community Conversations and the increased openness to having families at some decision-making tables. Some remarked that there has been an attitude change from DCF and from families and that these entities are now more willing to come to the table to talk.

Parent Education. Parents and caregivers report that they highly value the educational opportunities that are available to them to increase their leadership skills and to prepare them to have meaningful and impactful roles at decision making tables. They highlight the Network of Care - Agents of Transformation Training (NOC-AOT) and the Parent Leadership Training Institute (PLTI) as examples. Families report that as a result of these trainings, they are finding their voices and are looking for opportunities to contribute to the network of care.

Peer-to-Peer Support. Parents and caregivers report that peer-to-peer support is effective, authentic and valued. They receive this support through family advocates, support groups and family organizations.

Department of Children and Families. Community members note that their relationships with DCF are significantly improved. They report that DCF has become more strength-based in their approach to working with families, that staff are more responsive to the needs of families, and that DCF is clearly listening to families both at the individual family and at the systems levels.

Care Coordination. Families report high levels of satisfaction with care coordination services and value that the service plans are driven by the desires of each family and focus on the strengths and needs of that family.

School Resources. Some family members report high levels of satisfaction with the schools indicating that the staff is well-trained and provide needed supports, services and information to students with mental health needs and their families.

Juvenile Review Boards. Community members report that the Juvenile Review Boards have led to significant improvements in how the system responds to youth. They note that positive youth outcomes have resulted from the utilization of restorative justice practices in Connecticut.

Community Resources. Caregivers and youth report that community resources such as youth sports, after-school programs, libraries and youth programming in churches provide important and impactful supports for youth.

Resources Needed

Information about Services. While there are places to find information regarding services such as Infoline, the system remains difficult for families to utilize. Many report that they feel overwhelmed by the large volume of information provided and that they do not know how to navigate the Infoline website. Families request the following: 1) data on quality of services be made available to help families choose services for their child; 2) up-to-date written information on the services available in each region be provided in English and Spanish; and, 3) presentations and/or resource fairs be provided in each region on a regular basis to assist caregivers in identifying supports for their family.

Culturally Competent and Linguistically Appropriate Services. Across the network of care there is a need for additional staff who are fluent in the languages spoken by families seeking services. In addition, training is needed for all staff on how to deliver services in a manner that respects the culture (e.g., family composition, religion, customs) of each family they work with.

Peer-to-Peer Support for Youth. There is a need for development of the structures for youth to engage in peer-to-peer support so that they can enhance their natural supports.

Peer-to-Peer Support for Caregivers. Additional peer-to-peer support is needed for caregivers whose families are newly accessing the service array to serve as mentors and to help these families to navigate the system.

School Resources. While parents and caregivers indicate that there have been positive changes within schools, areas of significant concern remain. Funding cuts have resulted in some schools not having the staff support (e.g., social workers, nurses, paraprofessionals) needed to effectively work with students who have behavioral health concerns. These cuts have resulted in school staff primarily having time to respond to crises and frequently unable to be proactive in initiating planning (e.g., IEPs), providing needed services or offering information and resources that would be helpful to families.

School Communication. Parents and caregivers expressed that schools need to focus on engaging families in the school community through respectful and effective communication that provides the information that families need in the languages spoken by members of the school community. Schools should also develop mechanisms through which students can communicate their needs and desires and to do so in a manner where they feel respected and that their voices are being heard.

System-level Focus on Bullying. Families advocate that the State Department of Education recognize that bullying is traumatic for students and assist local schools in publicly acknowledging both the existence of bullying and the comprehensive action steps that need to be taken to respond to bullying and to prevent future incidents.

Transportation. Transportation to services remains a significant issue throughout the state from the rural areas where public transportation is very limited to the urban areas where many families report not having the financial means to pay for public transportation.

Transitions between Treatment Providers. Families report that transitions between levels of care, service providers and between the child and adult systems can be quite problematic resulting in increased stress to families and disruptions in care. Caregivers and youth suggest that transition planning begin early (e.g., at admission for inpatient or residential care), involve caregivers (and youth as appropriate), and include ongoing communication between providers so that youth and families are not burdened with repeating the same information numerous times.

Stable Workforce. There is a need to develop a more stable workforce of individuals who work with children and families in need of services. High staff turnover leads to a lack of continuity of care that is detrimental to families.

Supports for Foster Families. The network of care relies on foster families to provide care when a child's family cannot. Peer-to-peer and other support structures are needed for these families so that they and their children can continue to provide this vital resource.

Autism Spectrum Disorders. There is a need for additional treatment and supports for children and youth on the autism spectrum and their families.

Structures that Need Improvement

Families as Full Partners. In order for the network of care to be effective, families need to be full partners at all decision-making tables and meeting times need to be flexible to accommodate work, school and family responsibilities. While progress has been made in families feeling heard, there are still places in the system (e.g., schools; foster care) where caregivers and youth report expressing their opinions but feel their perspectives are not considered as system changes are made.

More Accountability is Needed. There is an expressed need for increased accountability throughout the system including child welfare, education, and behavioral health providers. This includes: enhanced communication with parents and caregivers in general and specifically around a child's progress; timely and comprehensive responses to questions; greater assistance during transitions between levels of care or providers; increased responsiveness when families have a grievance; and, the provision of outcome data for families to use when choosing a provider.

Insurance Coverage. Parents and caregivers report frustration that the services available for their child and family are dictated by their health insurance. They report that some services are available only for families who have Husky (e.g., in-home services) and not for families who have commercial insurance. In addition, those families who live close to state borders are not able to access the services that are closest to their homes if they are located across the state border as their insurance will not pay for out of state care.

Cost of Care. Parents and caregivers report that even when they have insurance the costs associated with their child receiving appropriate and needed care including co-pays for services and medications leave them having to decide between obtaining needed care or providing for the basic needs of their family.

Time Limits on Services. Many services have time-limits that do not take into consideration the needs of the family. Often these time-limits result in disruption of service and a change in providers causing the family to have to "start over" versus continuing the course of treatment. When services do end it is important for the referring provider to follow-up with families to determine if their service needs are being adequately met.

Rights for Children/Youth in Foster Care. Youth in care voiced significant concerns regarding their rights and request that they have a voice in decisions that directly affect them. Youth report that placement decisions are often made without their input and without notice resulting in sudden moves to new communities and new schools. Youth also request that appointments are structured so that they can speak with their DCF workers and medical providers without their foster parent present. Youth request that workers prioritize building a trusting and supportive relationship with them that is characterized by open communication so that they not only receive timely information from their workers but feel comfortable sharing their concerns.

Policies Regarding Foster Parents. Youth report that the process to screen foster parents needs improvement as some have been placed with foster parents who are not able to or do not provide adequate care and others have been placed in over-crowded or unsafe homes. Youth request increased accountability in the foster care system including a mechanism for youth to file grievances without fear of repercussions.

Appropriate Placement in Evidenced-based Services. While families appreciate the move to evidenced based services as they want the best care for their children, some report that more attention is needed in determining the most appropriate fit between the family and the treatment. As one family member stated "sometimes it feels like they are trying to fit square pegs into round holes".

EMPS Services. Families report that they appreciate and value the EMPS service describing the workers as helpful, prompt and discrete. However, some feel that workers prioritize the completion of required paperwork over diffusing the crisis. Families suggest restructuring the work schedule for EMPS clinicians to allow time for the completion of paperwork after the crisis is diffused.

Professional Development

Staff Training to Engage Families. Across the board training is needed for state department, community agency and school staff who interact with families to enhance their awareness and skills in interacting with families in a way that is respectful and responsive. This training should be provided to all staff including service providers, educators, office staff, security staff and agency leadership.

Trauma Informed Care. Training is needed for all providers working with children and families regarding how to provide trauma-informed care and how to identify children and families impacted by trauma.

Training for School Staff. While community members recognize improvements in how school staff support students with behavioral health concerns, there continues to be a significant need for educators to enhance their skills in effectively responding when students exhibit behavioral difficulties in the classroom with the goal of enabling students to remain in the educational setting. This training should be ongoing for school staff and required for individuals who work as substitute teachers.

Training for DCF Staff. While community members recognize the significant progress that has been made in DCF staff's approach to their work with families, they highlight areas for ongoing training specifically in the area of working to build closer relationships with the children and youth on their caseloads so that these children and youth are comfortable expressing their needs to their worker. It is hoped that these enhanced relationships and communication can lead to the needs of the children/youth being more closely considered as placement and other decisions are made.

Training for First Responders. Ongoing training is needed for first responders regarding how to approach and work with children and youth who have emotional and behavioral difficulties.

Training for Clinicians. There is a need for more clinicians who are trained to work with children with the most severe psychiatric disabilities.

Training for Primary Care Providers. Given that early intervention is essential to prevent the development of more serious issues, families report that there is a need for primary care providers to receive training on behavioral health as they are instrumental in the identification of children in need of services.

Parent Education. While parents and caregivers report high levels of satisfaction with the training opportunities that are available, parents request that these training opportunities continue and that they be expanded. As one parent stated "When families are informed, they have better outcomes".

Child Psychiatry and Medication Management. There is a significant need for more psychiatrists trained to work with children and youth and a need for more professionals, including psychiatrists, APRNs and physician assistants trained to manage psychiatric medications for children and youth.