Issue: **DDAN ISSUE REPORT: COMMUNICATION**

Issue Description:

Ultimately, many of the challenges individuals with intellectual and developmental disabilities (I/DD) and families experience in obtaining support and services have their root in an inadequate line of communication between state agencies, policymakers, and individual and family advocates. Well before the state decides to implement new policies, there must be regular, in-depth, and systematic communication with the individuals and families who will be affected by the system of policy changes in question.

Messaging to individuals with I/DD and families should be written in clear and cognitively accessible language. Input from individuals and families should be actively sought. Far too many families have not even a vague idea of how the "system" works, let alone how to successfully navigate it. Messaging should also be available in multiple languages.

It is important for the state to understand that individuals with I/DD and their families are the state's greatest asset in terms of gaining a greater understanding of what works and what does not work. The state should further utilize advocacy groups such as the <u>Regional Family Support Planning Councils</u>, the <u>Family Advisory Council</u>, and an as-yet-to-be-established Self-Advocate Advisory Council as a way of disseminating information and obtaining direct feedback from our community.

1. Many of the challenges individuals with I/DD and families experience in obtaining supports and services stem from an inadequate line of communication between state agencies, policymakers and individuals and families. Well before the state decides to implement new policies, there must be regular, in-depth and systematic communication with the individuals and families who will be affected by the system and/or proposed policy changes.

2. Messaging to individuals with I/DD and families should be written in clear and cognitively accessible language with input by individuals and families. Far too many families have no idea how the "system" works, let alone how to successfully navigate the system. Messaging should also be available in multiple languages.

3. It is important for the state to understand that individuals with I/DD and their families are the state's greatest asset in terms of gaining a greater understanding of what works and what does not work. The state should further utilize advocacy groups such as the Regional Family Support Planning Councils and the Family Advisory Council, and recently established Self Advocate Advisory group as a way to gather input, disseminate information and obtain direct feedback from our community.

Issue Action Items:

The DDAN Communication Committee continues to recognize the importance of improving communication and interaction between Division of Developmental Disabilities (DDD) within the Department of Human Services (DHS) and the Children's System of Care (CSOC) within the Department of Children and Families (DCF). In order to improve communication; we make the following statements/recommendations:

<u>Division of Developmental Disabilities (DDD)</u>

1. Use effective and timely communication. Examples include but are not limited to:
   a. Send announcement letters to all individuals, parents and guardians prior to major changes
   b. Inform and educate Support Coordinators about upcoming changes prior to implementation, or at least simultaneously
   c. Monitor DDD's performance on information dissemination
2. Continue formal monthly meetings with the Family Advisory Council (FAC)
   a. Rotate agenda focus each month between DDD and FAC
   b. Review all proposed policy chances and new policy implementation with the FAC
   c. Accept FAC policy changes and provide direct feedback as to what will be accepted and if feedback is not accepted, provide specific reasons for rejecting suggestions
   d. Provide FAC with pertinent background materials when suggesting policy changes and review pertinent background materials the FAC may provide
   e. Conduct pilot group(s) prior to significant changes in order that new policy practices can be "field tested." Utilize feedback from the pilot to strengthen the new practice. Develop clear written communication

that details the new/changed practice and allow for ample input from individuals/families/ support coordinators/agencies before final changes are made. Consider using FAQ's and additionally run parallel systems until full transitions can be implemented.

3. Conduct Quarterly Statewide Family Update meetings with expanded options for families/caregivers to call in and rotate meetings geographically throughout the state
    a. Offer at least 2 different locations for each Quarterly Family Update meeting, for example- one Family Update meeting in the South and one in the North within a week of each other. Rotate this schedule across the state four times per year for a total of 8 in person meetings

4. Begin formal monthly meetings with individual Advocates (self-advocates) by July 1, 2019

5. Provide general education for individuals and families regarding the DDD service system, with specific guidance on the NJCAT and Goods and Service requests since these are the two areas with the most complaints

6. Establish an Internal Appeal process to address disagreements between individuals and/or families and DDD with a time limited turn around

7. Use a Fair Hearing process when Internal Appeals are not satisfactorily resolved

8. Provide education and resources to individuals and families that details the DDD Internal Appeal and Fair Hearing process when individuals/families disagree with DDD decision making, for example, the NJCAT Tier, Goods and Service Request, etc.

9. Provide a greater level of information/education to individuals and families as to the way in which they operate, system design and changes that are implemented

10. Seek formal input from individuals and families as it relates to the overall operation of services before services are modified.

11. Maintain a 24-hour return call policy

12. Deliver at least two direct mailings per year with DDD updates as well as eSignature verification and use these mailings to update accurate basic information

Children's System of Care (CSOC)
1. Use effective and timely communication. Examples include but are not limited to:

     a. Send announcement letters to all individuals, parents and guardians prior to major changes

     b. Inform and educate PerformCare/Care Management Organizations/Family Support Organizations about upcoming changes prior to implementation, or at least simultaneously

     c. Monitor CSOC's performance on information dissemination

2. Continue formal bi-monthly meetings with DCF/CSOC Collaboration Committee

     a. Review all proposed policy chances and new policy implementation with the Committee

     b. Accept Committee policy changes and provide direct feedback as to what will be accepted and if feedback is not accepted, provide specific reasons for rejecting suggestions

     c. Provide Committee with pertinent background materials when suggesting policy changes

3. Participate in bi-annual listening sessions with individuals and families of children/young adults with Intellectual/Developmental Disabilities

     a. Offer at least 2 different locations for bi-annual listening sessions

4. Begin formal bi-monthly meetings with individual Advocates (self-advocates)

5. Provide education and resources to individuals and families that details the DCF CSOC Appeal process when individuals/families disagree with CSOC decision making

6. Seek formal input from individuals and families as it relates to the overall operation of services before services are modified

7. Maintain a 24-hour return call policy

8. Deliver at least two direct mailings per year with CSOC updates and these mailing to update accurate basic information

DDD and CSOC should maintain a single point of entry and automatically process applications for children exiting CSOC for DDD eligibility.

Next Steps:

1. Share the recommendations with DDD and CSOC
2. Have a follow up conversation with DDD and CSOC

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[1] 2015 DDD Quality Improvement Stakeholder Report
(https://www.state.nj.us/humanservices/ddd/documents/stakeholder_input_report_on_quality_improvement.pdf)
[2] CQL – 5 Factors of Quality (https://c-q-l.org/files/2017Documents/CQL-Personal-Outcome-Measures-Factors-And-Indicators.pdf)