Children and Youth with Special Health Care Needs (CYSHCN) Family Forum 12/8/2021

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Agenda

- Background
- Lessons Learned from Families
- Support for LHDs & CYSHCN
- Your Comments and Suggestions
Background
Who are Children and Youth with Special Health Care Needs?

Birth to 21 years old, who:
- have or at increased risk for chronic physical, developmental, behavioral or emotional conditions and
- require health and related services beyond that required by children and youth generally.

Examples: Asthma, ADHD, anxiety, autism, diabetes, Down syndrome, epilepsy, food allergies, hearing impairment, muscular dystrophy, traumatic brain injury, visual impairment…
Children & Youth with Special Health Care Needs Programs

- Located at participating local health departments
- Provide information and referrals to families of CYSHCN to assist with medical and non-medical needs
  - Direct families to local, state and national resources
  - Share information about available services and supports
  - Promote opportunities for families to connect with each other
  - Direct families to organizations to assist with issues and concerns related to education/special education
  - Assist families in locating providers
  - Provide information about navigating various service systems
What do NYS Regional Support Centers do?

**FAMILY ENGAGEMENT**
Conversations with families of CYSHCN to learn from their lived experiences accessing the community, navigating service systems, obtaining necessary services and supports.

**EDUCATION & TRAINING**
Develop educational and training products for professionals and families.

**TECHNICAL ASSISTANCE**
Support local CYSHCN programs to improve connection with and support of families.
Family Sessions

Table 1. Family sessions and participants by RSC.

<table>
<thead>
<tr>
<th>RSC Site</th>
<th># Sessions</th>
<th>Total CYSHCN</th>
<th>Total Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>RFK</td>
<td>42</td>
<td>180</td>
<td>139</td>
</tr>
<tr>
<td>SCDD</td>
<td>83</td>
<td>148</td>
<td>114</td>
</tr>
<tr>
<td>WIHD</td>
<td>42</td>
<td>119</td>
<td>86</td>
</tr>
<tr>
<td>TOTAL</td>
<td>167</td>
<td>447</td>
<td>339</td>
</tr>
</tbody>
</table>

51/58 NYS counties represented

Community type
• 16% Rural
• 35% Urban
• 44% Suburban

63 group sessions, 104 individual interviews
• 4 participants in group sessions on average (range, 2 to 10)
• 144 English, 12 Spanish, 11 Mandarin sessions
CYSHCN

Conditions Represented

- Autism: 31.6%
- Behavioral: 23.1%
- Physical: 22.6%
- Learning Disability/Developmental Delay: 19.3%
- Mental Health: 15.9%
- Neurological: 13.7%
- Language: 10.3%
- Genetic: 6.3%
- Intellectual Disability: 4.5%
- Hearing/Visual: 4.9%
- Intellectual Disability: 4.5%
Lessons Learned from Families
Impact on the Family Unit

- Challenges to obtaining diagnosis
- Impact of diagnosis
- Parents as advocates
- Complexities adoptive/foster families
- Parents struggle with balance
Accessing Supports and Services

- Barriers to accessing services and supports
- Challenging education system
- Lack of transition services
- Poor Family-Professional Partnerships
- Confusing & Complex systems
Accessing the Community

Families of CYSHCN are accessing the community with varying levels of success.

Common barriers to community inclusion:
• Attitudes and understanding – creates hesitancy
• Inadequate supports or lack of accommodations
• Behavioral/sensory/physical barriers
• Lack of offerings
• Distance/travel and financial

Successful community inclusion addresses isolation and increases socialization and enrichment
Impact of COVID-19

- Exacerbate existing issues
- Disruption to services/evals
- Additional responsibilities placed on parents/caregivers
- Parent and child anxieties
- Increased mental health concerns
- Mixed experience with virtual services
- 33% indicated COVID-19 impacted their employment

The pandemic created some unexpected positive outcomes
Impact of COVID-19

Survey Link
Top Support Needs For CYSHCN Families

- Emotional & Social Supports: 20.9%
- Assistance from School System: 14.6%
- Access to Medical Care: 13.7%
- Financial Support: 13.3%
- Community Integration: 12.9%
- Transitioning to Adult Services: 9.8%
- Access to Childcare: 9%
- Transportation: 4.3%
- Other: 1.6%
Parent Recommendations

- Supports for whole family
- Information and coordination between systems
- Accessible care coordinators
- Guides & crisis hotline creation
- Disability awareness & other trainings
- Inclusive community opportunities
- Address staffing shortages
- Increase in mental health and trauma resources
Support for Families & LHDs
Educational Materials

Healthcare Transition Video

Parent Advocacy Webinar

Navigating Barriers to Community Integration

Mental Health

Effective Communication & more….

CYSHCN Website
Making Connections

Family Forums
Newsletters
Resource Directory
Networking Meetings
Family Connections
Questions and Discussion

- What are your thoughts on the findings? Surprising or expected?
- How do your experiences compare with those described?
- Are you aware of resources or supports that address the barriers highlighted?
- Do you have ideas/suggestions for some of the issues mentioned?
- Do you have thoughts on how to create more connections for families?
- Do you have ideas/suggestions for future educational topics for LHDs & families?
Contact Us

Feedback and suggestions: [survey link]

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CYSHCN Website