Improving Access to Care by Using Creative Support to Address Families Waiting for Services

Gail Cormier, Executive Director, North Carolina Families United
Lisa Lambert, Executive Director, Parent Professional Advocacy League
Lynda Gargan, Executive Director, National Federation of Families
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services

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North Carolina’s Standards for Implementation
NC Families Wait for Identified Services and Supports

In areas such as:

• HIFI Wraparound
• Clinical Therapeutic Supports
• In-Home Behavioral Services
• Respite Care
• Family Peer Support
• Psychiatric Residential Beds
High Fidelity Wraparound in North Carolina

Expanding Program Across the State

a. Team must hold first meeting within 30 days of referral (may be waiver to 45 with verbal approval)

b. Implementation of wraparound plan must begin within 48 hours after first meeting. If identified services are not readily available, support services should be used until formalized services can be implemented

c. Every family gets the choice of a Family or Youth Peer Support Partner
While waiting for full complement of services:

• Family/Youth Peer Support **MUST** be available for each family on DAY ONE
• Family/Youth Peer Support can help by creating a family-centered Futures Plan
• Family-Run Organization can develop crises plan
• Family/Youth or Family-Run Organization can help families find natural supports
Hospitalization of a Child or Youth

**Admission Criteria**

- Child must meet the general criteria for admission to the NC Neuroscience Hospitals outlined in the Inpatient Psychiatry Policy.

- The patient must have a primary psychiatric illness and be in need of inpatient treatment or comprehensive diagnostic services not available or practical in a less restrictive environment.

- Patients should be at least 5 years old and under 18 years old.

- Patients should be at a developmental level and be medically stable enough to have some ability to participate in the unit programming.

- Unit conditions must be conducive to the provision of safe, comprehensive care. (The number of certain types of problems may be limited).

*Wait in Emergency Department Up to 3 Days*
While Waiting for Full Complement of Services

- Family/Youth Peer Support, if available in the area, can accompany a parent while in the Emergency Department
- Crisis Plan development by Family-Run Organization or Family/Youth Peer Support
- Family/Youth Peer Support can help by creating a family-centered Futures Plan
- Connect with families | Provide online Family Peer Support
Wait Times and Lists

- Clinical Therapeutic Supports
- In Home Behavioral Services

Wait lists vary by region.
- Rural areas more likely have longer wait list and less culturally appropriate services
- Urban areas may also experience a wait list
Respite
Providing Support Online

We can go virtual!
When Families Wait in Massachusetts

How families expect the system to work

- Inpatient
- Residential Care
- State Agency
- Community
- Outpatient

How it actually works

- Wait for a bed up to 10 days
- Wait for a therapist up to 8 weeks
- Wait for funding and a slot
- Wait for forms and approvals
- Wait for wraparound for up to 4 weeks
What Kinds of Help Families Need

• Quick, cut-to-the-chase information
• A customized strategy for their family
• Someone to network for and with them
• Understanding of what “should” happen and what “can” happen
• Coaching
• Advocacy
The Roles of the Family-Run Organization

- Support, education, coaching
- Individual advocacy for the family
- Identifying themes, trends and patterns
- Systems advocacy
- Collecting data and anecdotes
- Persistent bumping up of issues
Factors That Increase Wait Times

- Workforce issues
- Confusion over who funds what service
- Complexity of child’s presentation
- How parent is perceived
- Accuracy of provider listings, especially for private insurance
- Time of year – seasonality
- “Stuckness” of kids in child welfare
- Lack of advocacy and networking
Key Findings on Wait Times for Inpatient Beds

PPAL 2018 Survey on Experience of Families Waiting in Emergency Departments

411 families
Child mean age = 14 years
70% had a sibling at home

84% White
8% Latino
3% African American
3% > 1 race
2% American Indian
1% Asian

Length of Wait

- < 12 hours: 19%
- 12-18 hours: 13%
- 18-24 hours: 15%
- 1-4 days: 20%
- 4-7 days: 9%
- More than 1 week: 8%
- More than 2 weeks: 5%
- Did not wait: 11%
Key Survey Findings – Were You Made Comfortable?

Parents of younger children were more likely to be offered amenities.

Parents more satisfied when they were kept in the loop and had input.

“We waited 2 days for a bed. It was extremely uncomfortable and difficult for my son and me.”
## Key Survey Finding: Impact of Race/Ethnicity of Parent

<table>
<thead>
<tr>
<th></th>
<th>White parents</th>
<th>Non-white parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offered amenities while waiting</td>
<td>31%</td>
<td>13%</td>
</tr>
<tr>
<td>51A threat changed my decisions</td>
<td>3%</td>
<td>15%</td>
</tr>
<tr>
<td>Staff member gave me a break and sat with my child</td>
<td>14%</td>
<td>6%</td>
</tr>
<tr>
<td>Came to ED because professional recommended it</td>
<td>14%</td>
<td>23%</td>
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<tr>
<td>I was told what insurer agreed to</td>
<td>24%</td>
<td>15%</td>
</tr>
<tr>
<td>Stigma affects whether I seek emergency services</td>
<td>27%</td>
<td>40%</td>
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• System change – Department of Mental Health creates expedited admission policy
• PPAL works closely with Department of Mental Health and state Medicaid to troubleshoot individual family problems
• Forum to educate Emergency Department providers – one key message is the impact on families, including siblings
How Families Communicate

- Families began communicating with us via social media.
- In the past, we communicated information to them, via newsletters, Facebook pages, printed materials.
- They began contacting us through texting, Facebook messenger, apps, email, Instagram and Facebook groups, where they tagged us.
- Inevitably, we began getting texts, messages, tags on Facebook groups when they were experiencing Wait Times.
- We explained, passed on information.
- We advocated, helped them choose options.

Trusted Sources of Information for Families

Results of PPAL surveys 2008-2014
Using Social Media Changes How Families Wait

- While waiting, families are posing questions about providers, wait times, satisfaction ratings.
- While waiting, families are describing how they are treated, often to an online group of other families.
- If families are given incomplete or inaccurate information, we correct it in real time.
- We are using verbal releases (followed by forms) similar to telehealth.
- Our state partners find out more in-real-time information.
Using Social Media Changes How We Collect Data

- We pose questions and gather info and anecdote
- We use polls
- We use social media to link families to quick surveys
- We “ask” for specific data (insurance, satisfaction)
- We ask for suggestions for improvement
Impact of COVID-19 on Wait Times and Communication

Less demand for all children’s mental health services
  • Parents worried about entering medical buildings
  • Parents interpret “emergency” as DIRE emergency

Nearly all clinical interactions via telehealth
  • Barriers for some parents
  • Not all parents comfortable, able to work out details at home

Parents on social media to compare notes, especially about school
  • When asked, parents very observant about what works or not