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

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2020 Webinar

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Disclaimer Slide

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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

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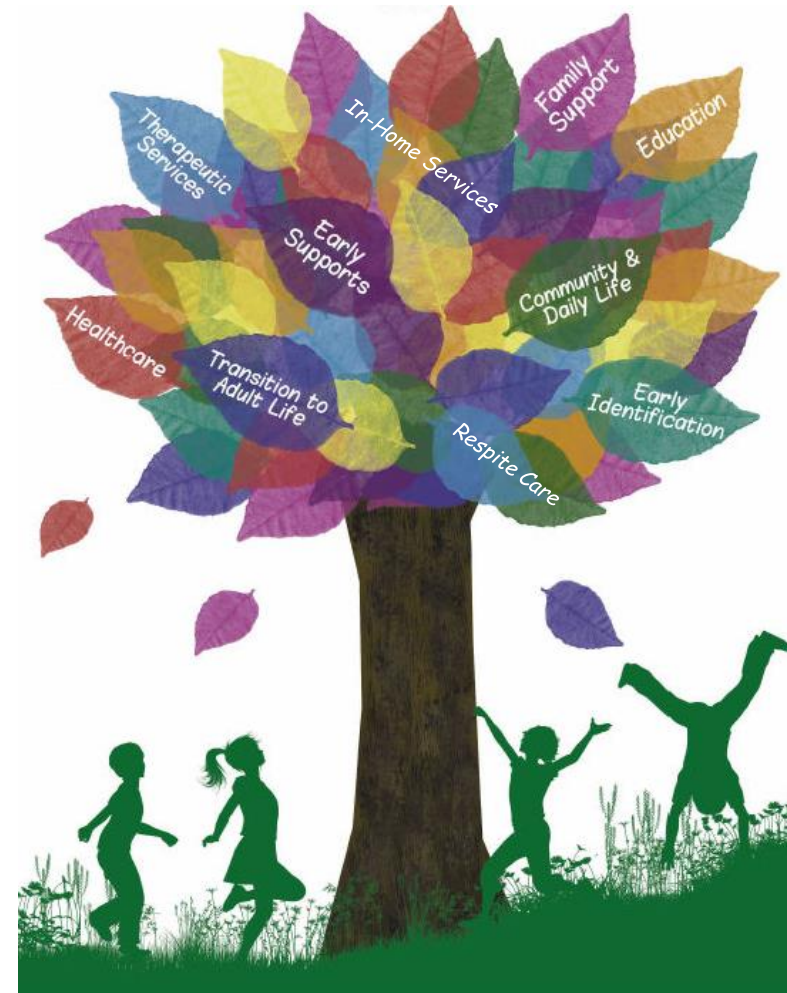
High Fidelity Wraparound in North Carolina

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

Eliminating Red Tape

While waiting for full complement of services:

- Family/Youth Peer Support <u>MUST</u> 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 my 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
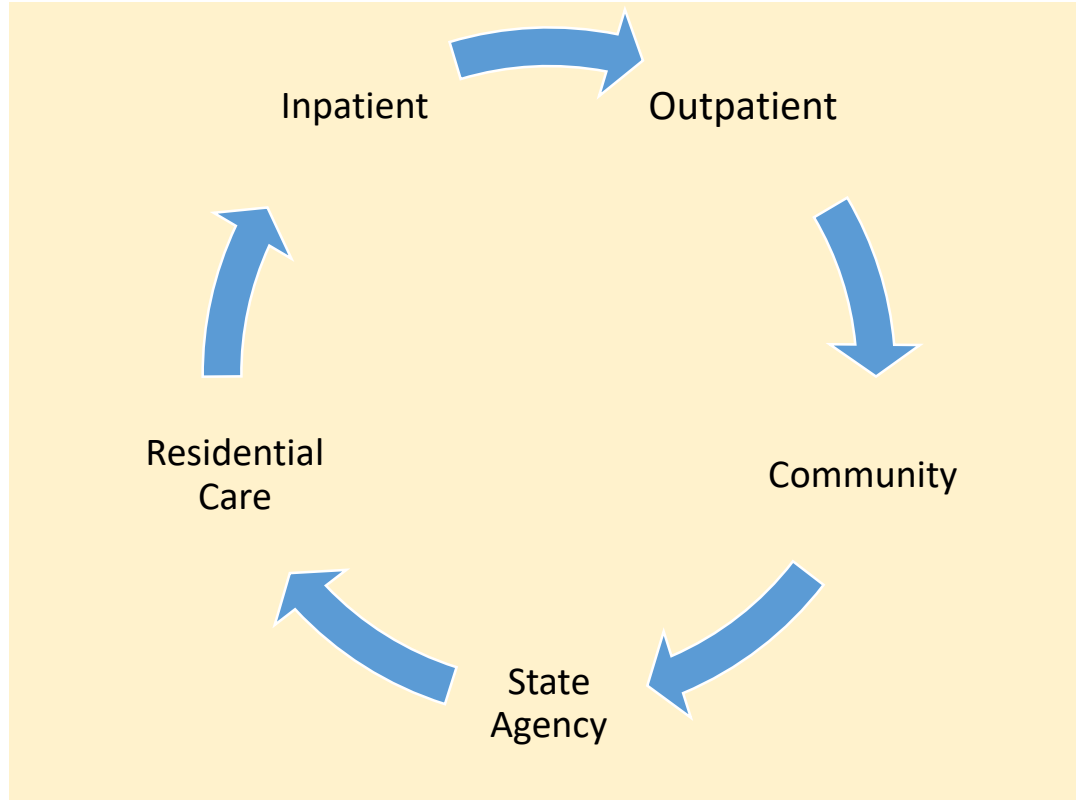
Respite

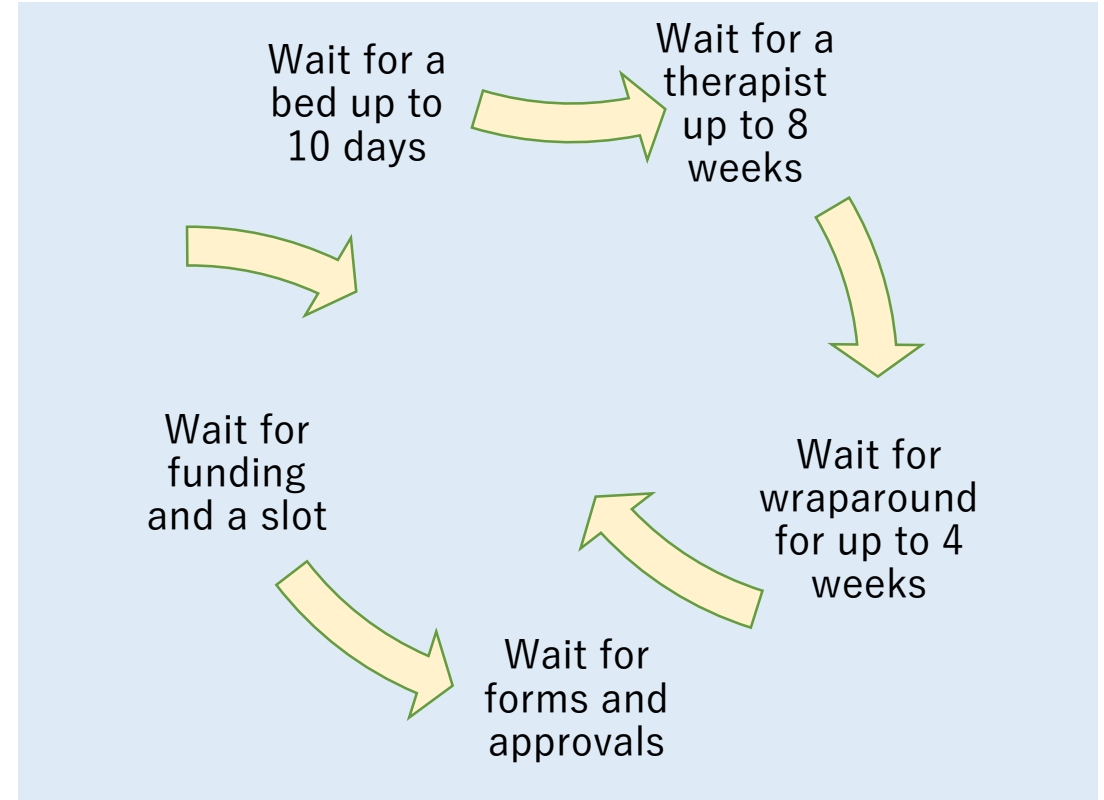# Providing Support Online

We can go virtual!

When Families Wait in Massachusetts

How families expect the system to work

Inpatient → Outpatient → Community → State Agency → Residential Care → Inpatient

How it actually works

Wait for a bed up to 10 days → Wait for a therapist up to 8 weeks → Wait for wraparound for up to 4 weeks → Wait for forms and approvals → Wait for funding and a slot → (back to Wait for a bed)

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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

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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
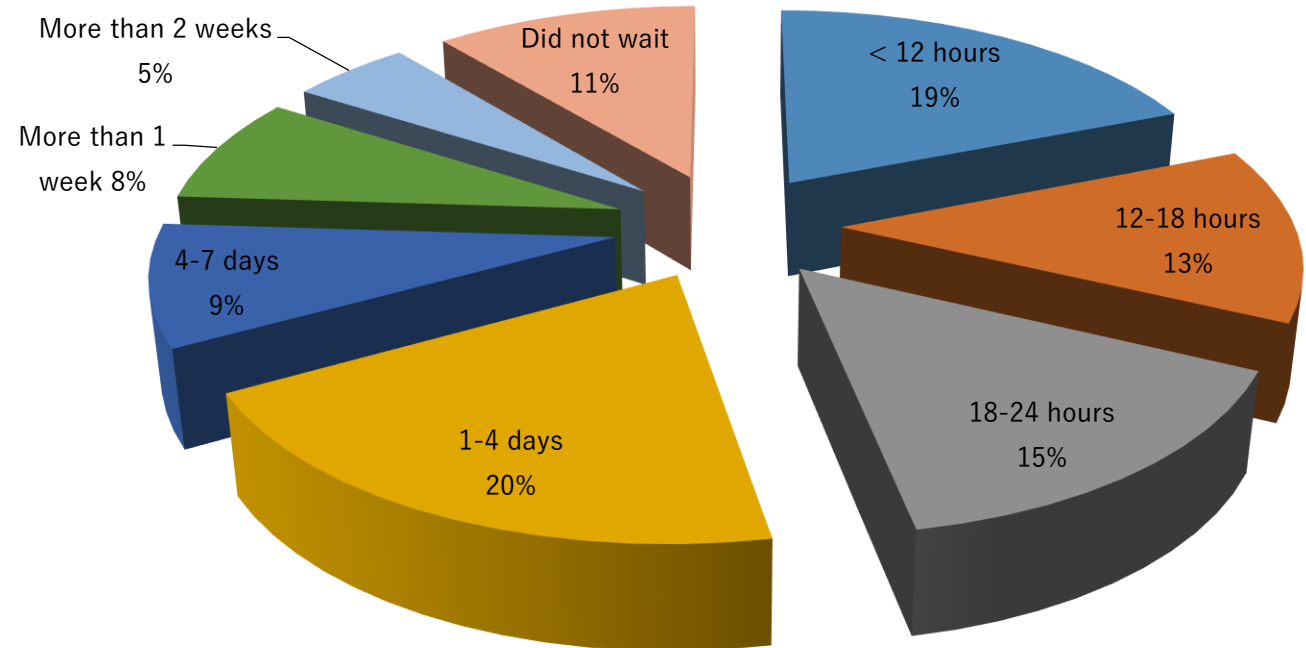- "Stuckness" of kids in child welfare
- Lack of advocacy and networking

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
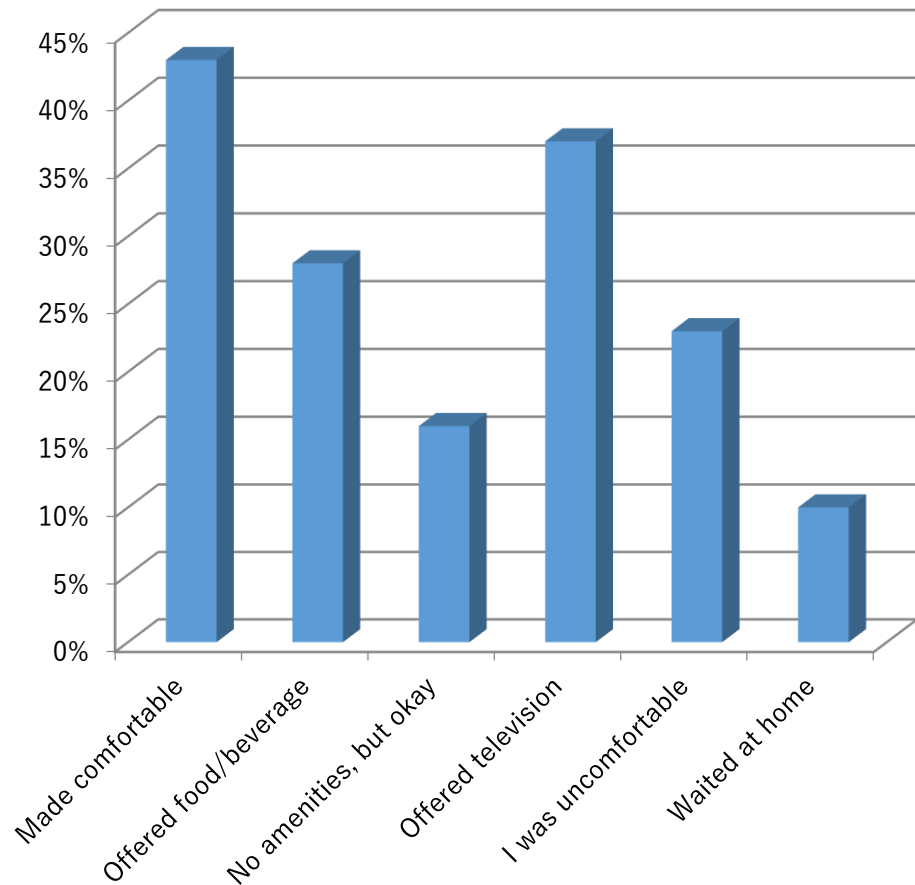3% > 1 race
2% American Indian
1% Asian

Length of Wait

- Did not wait 11%
- < 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%

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Key Survey Findings – Were You Made Comfortable?

How 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."

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Key Survey Finding: Impact of Race/Ethnicity of Parent

	White parents	Non-white parents
Offered amenities while waiting	31%	13%
51A threat changed my decisions	3%	15%
Staff member gave me a break and sat with my child	14%	6%
Came to ED because professional recommended it	14%	23%
I was told what insurer agreed to	24%	15%
Stigma affects whether I seek emergency services	27%	40%

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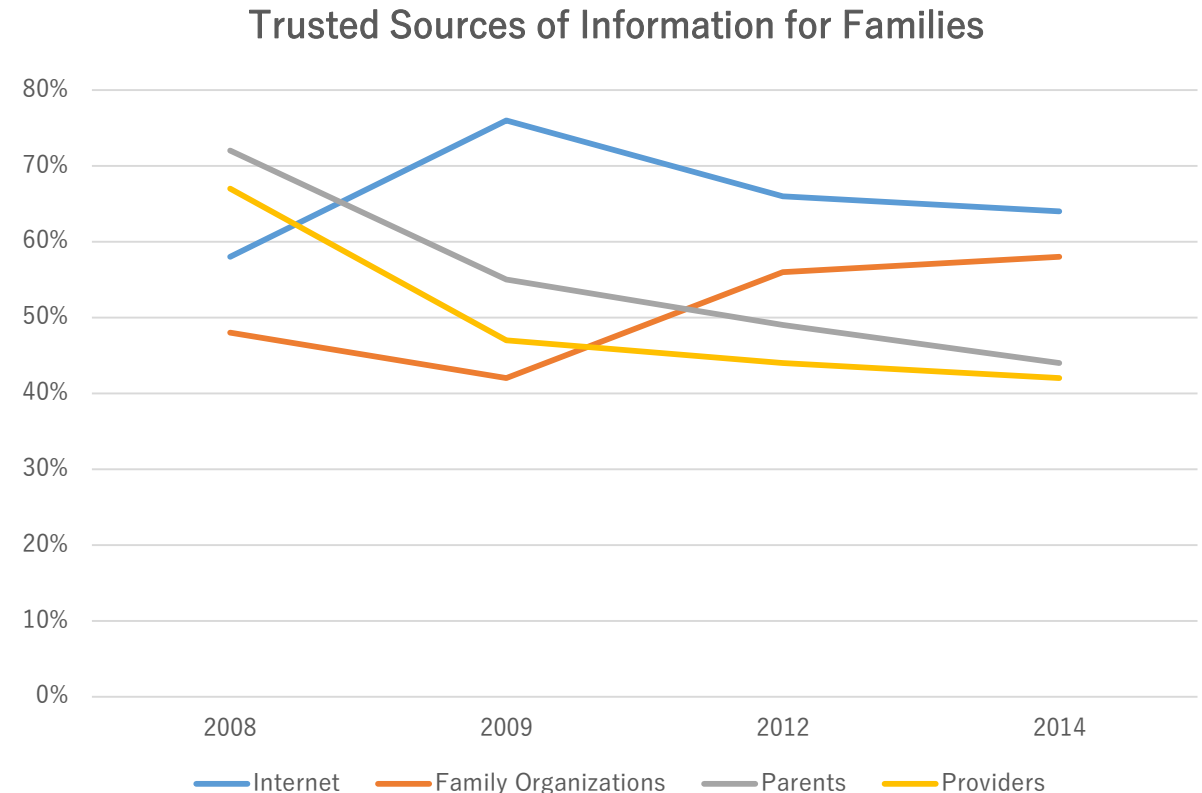Substance Abuse and Mental Health
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Data Leads to Change

- 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

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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

Legend: Internet — Family Organizations — Parents — Providers

Results of PPAL surveys 2008-2014

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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

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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

Who

What

When

Why

Where

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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