Parent and Community Supports

Community of Practice on Autism Spectrum Disorder and other Developmental Disabilities

March 8, 2017
How do the Worlds of Autism / DD Interact with Mental Health?

- Inability to focus / attend
- Inability to regulate emotions
- Intermittently incapable of controlling behavior
- Inflexibility
- Impaired ability to engage in reciprocal, appropriate social interactions
- Atypical response to requests / stimuli in terms of time, content or intensity
- Often sabotage efforts to help
How do the Worlds of Autism / DD Interact with Mental Health?

• Difficulties they face are primarily due to skill deficits / delays (Ross Greene, John Maags)

• At Wisconsin Family Ties, we refer to the population we serve as “families that include children or adolescents with social, emotional, or behavioral challenges”

• WFT was an early promoter of autism interventions in mental health
  – Social Thinking / Understanding
  – Perspective Taking (Michelle Garcia Winner)
  – Sensory Approaches (Occupational Therapy)
  – Response to Agitation (Rebecca Klaw)
Parenting Can Be A Challenge

- The vast majority of families raising children with mental health needs are **healthy families** who are experiencing a particularly stressful challenge.

- “Good parenting” **skills don’t usually work** when a child has mental health needs – when they hear voices, are extremely depressed or anxious, have compulsive behaviors, or harm themselves.

- Disciplinary strategies that work with typically-developing children **are not effective** for behavior problems related to mental health.
Parent Support

All parents **need support**, including support from family, friends, systems, professionals and the community. This includes being:

- Given accurate, understandable, and complete information necessary to make choices for their family
- Recognized as the expert on their children
- Supported to make decisions for their families
- Encouraged to share their experiences and ideas
- Consulted to plan and evaluate programs and services
What can we all do to better support parents?

- Learn their stories
- Listen with intent
- Suspend judgment
- Present alternatives to assumptions
What is Parent Peer Support?

- Parent Peer Support programs help to provide social support, information about community resources, and coping assistance to parents who are struggling with the challenges of parenthood. (University of Iowa, National Resource Center for In-Home Services)

- Peer support provides a wide array of benefits to parents and can help prevent the removal of children from the home.

- Key element of peer support is “lived experience”

- Pioneered by family-run organizations
<table>
<thead>
<tr>
<th>Study</th>
<th>Method</th>
<th>Key Findings</th>
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</thead>
<tbody>
<tr>
<td>Parent Support: Building Structures That Support and Assist Children (Davis-Groves, et al., Univ. of Kansas, 2007)</td>
<td>Mixed-methods approach consisting of focus groups, interviews, questionnaires, and secondary analysis of an existing database</td>
<td>Children whose parents received peer support specialist services have better outcomes in terms of residential status, law enforcement contact, academic performance, and school attendance. In addition, these children demonstrated fewer externalizing behaviors than children whose parents were not receiving support.</td>
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### Evidence Base – Research Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Parent Peer Support and Outcomes for Children with Mental Illness (Ramacher, UW-Stout, 2010)</th>
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<tbody>
<tr>
<td><strong>Method</strong></td>
<td>Non-random pilot study with self-administered online surveys with five demographic and eight closed-ended statements, based on the Likert Scale</td>
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<tr>
<td><strong>Key Findings</strong></td>
<td>Parents receiving peer specialist services experienced improvement in coping skills, emotional health and confidence, as well as increased knowledge, improved management of children’s behavior, and more confidence in advocacy skills. While the data do not as strongly support a link to improvement in children’s behavior, there is some indication that improvements for the parents impacted the children, as evidenced by better school grades.</td>
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## Evidence Base – Research Studies

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<thead>
<tr>
<th>Study</th>
<th>Peer Support &amp; Parent Peer Support: Impact and Relative Importance as Reported by Service Recipients (Ruffalo, Davis, et al., Medical College of Wisconsin, 2016)</th>
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<td><strong>Method</strong></td>
<td>Self-administered online surveys disseminated through multiple distribution channels</td>
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</table>
| **Key Findings**                                                   | • Of 11 services options, peer support was most frequently ranked #1 in importance (41%). 73% ranked peer support in their top 3 services.  
• Respondents indicated peer support 1) helped them feel less alone/isolated, 2) connected them to resources, 3) empowered them to find solutions  
• Peer specialists connected 72% of respondents to other services. Engagement rate in referred mental health services was 96%.  
• 89.5% of respondents said that peer support was “essential” or “important” to them. |
# Current Research

<table>
<thead>
<tr>
<th>Study</th>
<th>Parent Peer Specialists and Educational Outcomes (2017-18)</th>
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<tbody>
<tr>
<td><strong>Partners</strong></td>
<td>Wisconsin Family Ties, Wisconsin Department of Public Instruction</td>
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<tr>
<td><strong>Research Questions</strong></td>
<td>What is the degree to which parent peer specialist services improve:</td>
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<tr>
<td></td>
<td>• parental involvement in educational services?</td>
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<tr>
<td></td>
<td>• parental perception of educational services?</td>
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<td></td>
<td>• parental satisfaction with their child’s school plan?</td>
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<td></td>
<td>• student educational outcomes?</td>
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<tr>
<td></td>
<td>• teacher perception of the student?</td>
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<td>• teacher perception of the family?</td>
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# Current Research

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<th>Study</th>
<th>National Data Collection Project</th>
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<td>Partners</td>
<td>Family Run Executive Director Leadership Association (FREDLA), University of Washington, NYU, University of Maryland, Georgetown University</td>
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</table>
| Project Goals | • Development of standard definitions for services/supports typically offered by family-run organizations (FROs)  
• Collect information on what services are offered and how these are funded in FROs  
• Establish a set of standard data measures for use by family-run organizations  
• Develop a national repository for the standard data  
• Suggest ways to use the data to demonstrate the impact of the organization and their services |
## Current Research

<table>
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<tr>
<th>Study</th>
<th>Improving Outcomes for Children with Mental Health Challenges and Their Families through Parent-to-Parent Peer Support</th>
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<tr>
<td>Partners</td>
<td>FREDLA; Dr. Eric Bruns, Univ. of Washington (PI), Dr. Kimberly Hoagwood, IDEAS Center, NYU</td>
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</table>
| Project Description | • Patient-Centered Outcomes Research Institute (PCORI) Pipeline to Proposal Tier 1 project  
• Building the community and capacity necessary to develop a patient-centered comparative effectiveness research project  
• Project will study the effect of parent-to-parent support on child and family outcomes |
Parent Support Organizations in Wisconsin

- Children & Youth w/ Special Health Care Needs (CYSHCN) - https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm
- Family Voices of Wisconsin - http://www.familyvoicesofwisconsin.com/
- National Alliance on Mental Illness (NAMI)
- Wisconsin FACETS - http://www.wifacets.org/
- WSPEI (Wisconsin Statewide Parent-Educator Initiative) - http://wspei.org/
Wisconsin Family Ties Services

• **Information & Assistance**
  – Information on a variety of topics, including disorders, treatment options, service programs, providers, child and parental rights, mental health system and special education

• **Education & Training**
  – Conducting courses and workshops, presenting at conferences, providing scholarships for families to attend training events, and individual parent coaching / mentoring

• **Advocacy**
  – Helping families develop healthy working relationships with the systems that serve their children

• **Support**
  – Providing emotional support to help families rekindle hope by finding steps they can take to receive the help they need
Parent Peer Specialist

A Wisconsin Family Ties parent peer specialist is an individual who has:

• at least one year of experience as a parent or primary caregiver involved in the day-to-day care of a child or adolescent with social, emotional or behavioral challenges;

• successfully navigated the process of obtaining mental health services for his/her child, the need for which has persisted for a period of at least one year;

• received specific training to provide support to families and to help equip parents with the confidence and tools to better meet their families’ needs.
WFT Parent Peer Specialist Services

• Supplying information so families can better understand and participate in the systems serving their children
• Helping families get their needs met
• Giving emotional support and guidance through a maze of services
• Helping families to identify strategies that they can use in their homes to reduce conflict and encourage pro-social behavior
• Helping families identify and implement strategies to develop collaborative working relationships with the systems serving them
• Acting as an objective liaison between families, schools, case managers and service providers
• Advocating for filling gaps in services and supports
• Ensuring that school plans are effective and appropriate
• Providing telephone support at times needed by families
• Offering hope and encouragement in challenging times
• Helping families become better advocates for their children
Systems Navigation

• Mental Health System
• County Human Services
• Medicaid / other funding sources
• Public Education
• Juvenile Justice
• Child Welfare
• Division of Vocational Rehabilitation
How PPSs are Utilized

With families that include kids with social, emotional or behavioral challenges...

• Experiencing communication issues or conflict with providers / service systems
• Whose child’s school plan is not working
• That have few natural supports in the community
• That include a child at risk of, or returning from, an out-of-home placement
• Whose child exhibits challenging behavior at school, home or in the community
• Whose child is receiving exclusionary discipline at school
• Whose child is experiencing incidents of restraint or seclusion
• Whose child is not connected to adults or peers at school or in the community
• On a wait list for services
• That have been difficult to engage
• Whose child has been evaluated but does not meet eligibility criteria
WFT PPS Training

• Assessment upon hiring
• Develop individualized training plan
• Multi-faceted training approach
  – Formal coursework, self-paced learning, group book review, coaching, on-the-job skill acquisition
• Proficiency measured against core competencies
WFT Key Practice Values

- Respect for individual family culture
- Ethics and boundaries developed specifically for this role
- Nonjudgmental approach
- Trauma-effective approach
- Best way to address challenging behavior is to prevent it
- Youth outcomes can improve with increased focus on opportunities and skill development
How to Get a WFT Parent Peer Specialist in Your Community

• Advocate with systems, counties, school districts, community foundations and providers for funding through:
  – Grants
  – Medicaid-reimbursed services - Comprehensive Community Services (CCS), Children’s Long-term Support Waiver (CLTS)
  – County levy
  – School district discretionary funding
  – Other ideas?
Discussion Questions