

Evidence Based Peer Support Models for Individuals with Intellectual Disabilities

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Elizabeth Janks, LMSW ACSW
Associate Director for Training and Community Support
Developmental Disabilities Institute
Wayne State University
e.janks@wayne.edu

Belinda Hawks, BS MPA
Program Coordinator
Livingston County CMH Authority
bhawks@cmhliv.org

Samantha Gardner, CFN
Family Navigator
Livingston County CMH Authority
sgardner@cmhliv.org

Origination of Peer Model

- Historical Data Supports Peer Models
- Pilot Parents Model (1973) Omaha, NB
- Parent to Parent (1975) International Organization
- Parent Training & Information Centers
- Parents Helping Parents (1976) San Jose
- Mentor Visiting Program (MVP)



Key Characteristics of Exemplary Peer Support Models

- Pre-screen potential Parent – Peer Mentors
- Informational meeting about their ROLE
- Written materials outlining responsibilities
- Realistic time commitment & compensation
- Competency Based Training
- Demonstration of Competency
- On-going support to Parent – Peer Mentor

Key Characteristics of Exemplary Peer Support Models

- Making the best match between parents or mentors
- Consider the Family Characteristics
- Personality Characteristics
- Disability match can be important
- Culture
- Values: strengths, positive outcomes, self-determination

Evolution of Family to Family Program Models

- Dr. Patricia Morrissey recognition from research & “real life” experiences of tenants of quality family support projects
- 20 Projects of National Significance
- 360 Models of Family Support
- 5 year projects
- Detroit 360 Family Support Project



Detroit 360 Family Support Project

- Serves 50 families per year, addresses needs of each family member, directs families to services and supports-process guided by a family support navigator (PEER Support)
- Family Support Events
- Reaching out to culturally diverse families
- Underserved families



Key Characteristics

- Detroit 360 Family Support Projects successful evaluation results supported the notion that parent to parent matching creates successful results
- Detroit 360 Family Support Project evaluation supported the valuable role a peer or mentor plays in the lives of families
- Competency based training is another key to successful mentor projects

Project 360 Evaluation Results

- 318 families received information & referrals
- 180 families were served
- Annual evaluations (N= 42), 76% reported participation in project strengthened their family unit
- 70% found family support events helpful
- 95% reported being very satisfied with the services provided by their family support navigator

Quarterly Evaluation Results

- (N=135) 82% reported being very or extremely satisfied with their navigator's ability to connect them with desired services & supports
- 95% reported being satisfied with the cultural competence of their FSN
- 75% reported being satisfied with the services they are receiving as a result of this project
- 66% reported Detroit 360 participation has strengthened their families

Lessons Learned

- Family Support Navigators, Community Liaisons, Parent Mentors, Peer Support Specialist = Individuals and Families believe their quality of life is improved
- The literature supports this finding, for individuals with many types of disabilities, aging, ill and individuals with mental health disabilities



DDI's Peer Support Training Events

- TA Institute for ADD in Gulfport, Mississippi for national recipients of family support projects
- TASH Tech Denver, Colorado
- Three Easter Seals national training events in Detroit
- Livingston County: Pilot site of the original training curriculum

Selecting Training Topics

- Literature review
- National focus groups of family support project staff
- Focus groups comprised of individuals with disabilities and family members
- DDI data from needs assessment
- In-put from the FSN's

Training Curriculum Topics

- History of Family Support & Family Systems Theory
- Initiating and Maintaining Parent & Professional partnerships
- Cultural Competency
- Effective Communication
- Family Support Service Systems: Federal, state & local
- Needs Assessment, Planning & Follow Along

Training Curriculum Topics

- Support Strategies & Service Brokering
- Teaching and Mentoring Access to Supports
- Self-Determination & Advocacy
- Family Support Activities
- Action Planning
- Demonstrating Competency of training



Evaluation of Training

- AUCD independent evaluation results
- 83% of participants were highly satisfied with the first day of training, 17 % were satisfied
- 92% of participants were highly satisfied with day 2 of the training, 8 % were satisfied
- 60% completed Action Plan and demonstrated competency in the field to become Nationally Certified as FSN's

The Michigan Connection 2009

- The Family Strengths Project Advisory Team
- We shared information about family support
- Belinda Hawks requested training for her new Family Strengths Project
- DDI pilot tested the Navigator Curriculum at the Community Mental Health Services of Livingston County

Family Strength Project

"Cultivating a connected community for families with special needs"





Origin

Inputs: Full array of Medicaid funded services and supports

Outputs: Family utilizes some services – overwhelmingly respite and CLS yet not others such as family training (counseling services)

Outcome: Absence of improved clinical outcomes of children

Outcome: Absence of improved family functioning in families



Current Best Practice Model

- **Together in Strength (San Antonio, Texas)** – Community Support for Families Caring for a Child with Special Needs. ([Respite Care of SanAntonio.org](http://RespiteCareofSanAntonio.org))
- **Wraparound services** - planning process that is designed to create an individualized plan to meet the needs of children and their families by utilizing their strengths. (www.michigan.gov/mdch)
- **Detroit Family Support 360 Project** - a one-stop support center for families with children who have disabilities. (www.wayne.edu/ddi)



Purpose and Intent

- **Purpose:** To help families that care for a child or adult with a developmental disability navigate through healthy decision making processes when considering the unique needs of their loved ones.
- **Vision:** To create a safe, stable, and nurturing family environment in which children can grow and develop. Help maintain and build upon primary family connections and family functions within the context of their family's culture and community.
- **Goals:** Access will be simple, user friendly, and centralized: will ensure fully informed choice, and will lead to timely access to services that address need in a holistic manner. To provide innovative parenting skills unique to the child's learning ability that will identify and promote family strengths. Institute individualized service approaches regarding length and availability of service matched to the urgency of family issues.



Components

- **FSP Clinical team**
 - Project Coordinator
 - Project Assistant
 - Project Case Manager
 - Project Peer Family Navigator Specialist
 - Participating Family
- **Functions of FSP team:**
 - Early Detection and Education
 - Intervention
 - Sustainability



Framework

Early Detection/Education

- Education and Outreach - promoting community wisdom
- Family specific trainings
- Safety awareness
- Professional community trainings
- Attends community collaborative groups

Build and Sustain Family Natural Support System

- Navigator meets the family where they are at as a peer, in all life domains impacting family functioning.



Framework

Intervention

- FSP meets with family to develop a family centered plan that will address their indicated need areas and strengths.
- Team meets monthly to discuss progress on goals outlined in the Family Plan.
- Family Navigator scheduled 1:1 time to meet with the family to implement aspects of the plan. Frequency for family contact is determined by the family.



Framework

Sustainability

- Navigator is a role model to promote independence and autonomy in the family.
- FSP team collects data to measure success routinely
 - Pre-scales: Brief COPE (assessing family functioning), CAFAS
 - Mid-scales: PSS-10 (assessing parental stress) , CAFAS
 - Post-scales: Brief COPE, CAFAS, Adaptation to disability (Dr. Darlene Groomes)
- Discharge planning meeting includes a family celebration and encourages a "pay it forward" plan.
- Navigator will value and support parents by facilitating a quarterly parent focus group that's purpose is to enhance parent leadership and networking opportunities.
- Graduated families are invited and encouraged to attend our focus group to exercise their new skills and share in the peer to peer community involvement opportunities within our community.
- Navigator is available to assist families for consultation if needs or concerns arise.



Billing for a Navigator

- **Family Training – CPT code S5111**
Parent-to-Parent training must be provided by a trained parent using the MDCH-endorsed curriculum. (MDCH –July 1,2011)



Achievements

The Family Strength Project has served 14 families since July of 2009.

Community Outreach and Education Initiatives

- 3 Sensory-friendly movies with local theater community partner
- Spring Symposium Series- 5 week series covering topics on Autism Wandering, Social Coaching, Sensory Integration, Challenging Behaviors, and the Play Project.
- Resource booths at Community Connect and Arc's Resource Expo
- Community Partners Meeting with Standing Agenda
- 3L's (Learning, Laughing, and Leadership) Focus Group with Standing Agenda
- Collaboration with Oakland University, OUCares, team developed measurement and survey tools to measure project outcomes, EMU-ACC who attends our partner mtgs and is in contract negotiations for clinic services, and Wayne State University-DDI.
- Meetings with the Department of Community Health-Mental Health Services- discussion on developing a curriculum for training family navigators.
- FSP Process Mapping Presentations to Livingston County Human Service Agency



FSP Family Testimonial

Mary - mother to 5 year old child diagnosed with ASD and ADD

"I agreed to join the FSP because I didn't want our lives to continue to revolve around my son's disorder. I am a single mother with 3 kids. My two oldest daughters are having a hard time understanding what autism is and how it effects their little brother. My son is 5 and was diagnosed with ASD when he was 3. My friends don't understand, they comment, "I don't know how you do it or I don't have the patience like you do." They would either pity me or ask why am I trying to do so much. I have no choice I am no longer with our children's father and he is in prison. I have a mom but she isn't always available to help out, I can't rely on her unfortunately. My brother is more reliable than my mom but he has a life of his own too.

The FSP helped me realize that I was doing everything right and headed in a good direction. There is so much to overcome and learn about my son's disability I often felt insecure, frustrated, defeated. I learned more about autism through the lectures hosted by FSP than I did any other way in the past. Through this process, I began to realize that I really did have it all together and learning made me want to keep going. It was nice to work with a team that appeared to be on my side for a change! The peer navigator and I bounced ideas off each other and I learned new things everyday it seemed. The FSP opened doors for me through out the community I never knew existed. Thank you FSP!"



Family Centered Practice Activity

- This activity can be used when working with families to help identify systems of support they will need in their lives. This is especially helpful when families are unaware of supports and can rely on your expertise to help them make those community connections. This process will be driven by them! You will coach them with examples if necessary. Sometimes when families are really overwhelmed they may need prompting to begin to identify what they need to thrive. In order for each individual to maximize their fullest potential, the family support navigator may have to guide the family, until they are fully empowered. Guiding the family as a partner means role modeling and teaching families to acquire skills to continue accessing and designing supports that strengthen all the individuals in their family.
- Referring back to Mary's testimonial lets work on this activity in groups. The person among your group who woke up the earliest this morning is Mary.



Family Centered Practice Activity

Materials: Pen and the Family Centered Activity Worksheet

Directions: In the center of your paper there is a circle. Have Mary put her name and her family member's name in the circle. Ask Mary to think about some of the strengths her family possesses; have Mary write down those strengths. For example, a family member might be a good problem solver or creative thinker. Perhaps her oldest daughter loves to read! In the blank circles ask Mary to identify needs they have as individuals or as a family member. In the blank lines below the circles have them write down the names of the people or agencies that can help them meet this need. Take a minute with Mary to look at what they have identified as important needs and supports.

Ask them to answer these questions:

1. Why do I need family involved with this specific activity?
2. Who benefits from this activity? And how do they benefit?
3. How can I make the connection to the support needed to meet the need?
4. How will I contact the support and what will I say to initiate the interaction?

References

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