FAMILY ENGAGEMENT IN RESIDENTIAL PROGRAMS

A Group Concept Mapping Study Findings Report

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Acknowledged with permission (alphabetical order)

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Introduction

Supporting families during and after residential care is associated with a six-fold increased likelihood of sustained treatment gains. However, there is little research on the family engagement practices valued by families within the context of residential care.

Research and practice often define family engagement in terms of phone calls, visits, and family therapy. While these activities are important for communication, they represent a fraction of families' needs.

In fact, for decades, there have been calls by advocates to increase family engagement in residential care. While there has been progress, it has been limited to individual programs rather than the larger system.



A National Agenda

New federal legislation, the Family First Prevention Services Act (FFPSA), recognizes the importance of family engagement and mandates that residential programs engage families.

While this legislation promises to overhaul residential care, advocates have voiced concerns about the lack of clarity and uniformity around what family engagement will look like in practice.

As of January 2023, the federal government still has no definition or activities around family engagement in residential care.



Project Goals

The purpose of this study was to convene key stakeholders across the United States to:

1) Learn how families are engaged in residential care across the country.

2) Understand barriers and facilitators to effective family engagement.

3) Define family engagement and the associated supports.

4) Develop recommendations on what family engagement needs to look like in residential care.

5) Advocate for recommendations generated by this project be adopted.

Overall Project Timeline



Image: Constrained state stat

Thanks to the Family Run Executive Director Leadership Association, there were over 100 family partners interested in participating in this study.

- The final team included over 40 family partners and were parents with lived experience, residential program staff, and advocates.
- 79% of the team had lived experience having a child access a residential program.
- States represented on the project team include: Tennessee, Washington, Michigan, Pennsylvania, Oregon, Ohio, Virginia, Massachusetts, Florida, Texas, Georgia, New Mexico, North Carolina, New Jersey, Kentucky, Montana, Maryland, Wisconsin, New York, Minnesota, Arkansas, Delaware, Colorado, and Alaska.

Focus Group #1

In August 2022, we held ten 90-minute focus groups via Zoom. Each group answered the following questions:

1.Families need _____ when their child is in residential care.

2.Families need someone to talk to about _____.

3.It would be helpful if families could get education on ______.

4.It would be helpful families could build skills to _____.

5.Families need ______ after residential care.

Focus Group Findings



There is a need for greater transparency.

Families need to be fully informed about the following:

- Who cares for their child (e.g., name, qualifications, and training).
- Expected outcomes of residential care (there may be a need to dispel that residential will be a "fix").
- What the unit looks like and what the child's room looks like.
- What a typical day looks like for that child.





Peer support is an ideal method for engaging and supporting families

Peer support can help families to

- Realize that they may need to grieve
- Reaffirm the families decisions
- Think about what the future may look like
- Navigate the system
- Give them the space to say what they need to without judgment
- Engage in self-care and (re) build relationships

Peer support also normalizes experiences and feelings. Examples include:

- The feeling of relief after dropping a child off.
- Living on edge every day.
- Anxiety about home visits or discharge.

Families may benefit from enhanced education and skill building

- Hands on de-escalation training
- Learning about what educational services exist and how to get services
- How to effectively advocate for your child
- Transferable skills from residential care to home
- Oriented to the entire mental health system and where residential fits in
- Learning what is a mental health problem vs. normal development
- Trauma takes many forms; trauma influences behaviors; resilience factors





Must do's for Residential Programs

- Recognize families for the experts that they are.
- Engage and support the entire family (other children included).
- Stop the pervasive messaging that "children would be better if they had better parents."
- Staff would benefit from more training and engaging in "perspective taking" exercises.
- Families need to be engaged by providers and the system even before the residential stay.
- There needs to be ample support with discharge (e.g., cannot give 1 weeks notice; must have a crisis plan, therapy, medication management, school).
- Examine and address the home and community triggers (that aren't present in residential).
- Families need ample opportunity to practice skills and report back on what they're still struggling with.

Messages from Family Partners

"I moved my entire family across the country for better services. Turns out, it's no better here." "There's so much that goes into writing those initials on our children's clothes, knowing that someone else is going to be washing them."

"We need to heal together as a family unit"

"Who is taking care of my baby? Do they see the good side of him too or do they only see the problem side?" It was so traumatizing for all of us. They just need to slow down and deal with each family because this is not a routine thing."

"It doesn't really matter what things [providers] think we need or what plans they want to put in place for us, unless we are part of making that plan it's probably not going to work." "We're all working towards the same goal. We need to work collaboratively but also too, there needs to be trust in the experts who are the parents"

Group Wisdom Findings

The second phase of this project involved using a software called Group Wisdom.

Group Wisdom allowed the team to engage in a scientific method called group concept mapping. Group concept mapping is a community-based participatory method that allows for a wide range of ideas to be brainstormed, sorted, and ranked.

All Group Wisdom activities are centered around the focal prompt:

Effective family support for families with children in residential care should include...

The team brainstormed **over 200 ideas** for improving family support in residential care.

The Go Zone



This map represents the priorities for family support in residential programs.

Explanation:

- The numbers represent unique ideas generated by family partners, each corresponding to an idea.
- There are four quadrants in the Go Zone Map.
 - Orange: Ideas that are easy to implement but less important.
 - Example:
 - #41- Self care tips for the caregiver
 - Blue: Ideas that are difficult to implement and not important.
 - Example:
 - #40- Families can meet with funders, government, and credentialing agencies.
 - Yellow: Ideas that are very important but difficult to implement.
 - Example:
 - #68- Opportunities to practice new skills in a safe setting with support.
 - $\circ\;$ Green: Known as the Go Zone. These are the highest priority supports for families.



What's in the Go Zone?



Discharge Plans

- Family plan for discharge to include the entire family, such as parents (living together or separately), siblings, and other close family support (others living in the home or who frequently interact with the child, perhaps as a sitter or weekend visits).
- Discharge planning includes natural and community supports as well as a list of resources in the community.

High Priority: Preparing the family what discharge looks like, including making a plan to transition back to school and being transparent about how discharge is determined.

Aftercare Plans

- A strong discharge plan involves the entire family.
- Resolution of family issues before returning home.
- Support to parents in connecting with services and supports after the transition. This should happen before the youth returns home.

High Priority: Developing a strong safety plan and crisis plan in collaboration with the family.



Staff Training

- Communication and language that is traumainformed, culturally sensitive and humble, strengths-based
- An environment that is welcoming and nonjudgmental
- Strong communication with parents, including meetings for planning and updates
- Staff who are competent and trained in family engagement

High Priority: Taking the perspective of the family; Avoiding accusatory language; Recognizing families for the experts they are.

Communication

- Easily accessible direct contact information for staff, managers, and point person
- Consistent rules and expectations from all staff without mixed messages
- Programs addressing feedback and complaints in a timely and appropriate manner
- A venue for clear and frequent communication between daily caregivers and parents for collaboration on treatment goals
- A time set to meet and hear directly from parents what things/behaviors look like at home

High Priority: Ability to have contact with and check on their young person at any time and not used by the program as a reward or something to earn.



Facility Policies

- Opportunities for family input, suggestions, and recommendations for improvements in the facility and program, as well as a feedback loop on how that information is used.
- Communication with parents about what works well with their youth in residential and planning for how they might be able to do that in a home setting

Transparency

- Outreach and support from the facility to guide the family through the admission process.
- Information to parents and youth about what they can expect at intake, during discharge planning, and discharge
- Who's who, and what do they do on your child's treatment team

Supporting the Family

- Training needs: De-escalation, trauma education, coping techniques, crisis management
- Education on medications, side effects, and diagnoses
- Affirmations to the family that they're doing the best they can
- Information and education that encourages learning new skills as a family and opportunities to practice them with support

High Priority: Parent peer support was highly prioritized by family partners. Parent peer support bridges the gap between programs and families.



Dissemination Efforts

How are the results of this study being used?

The findings are being used to develop residential-specific parent-peer support training.

A family support tool (parent and staff version) is being developed to measure family support in residential programs.

Sharing of results with key advocacy organizations and legislators. Scientific publication and presentation of results.

Acknowledgement

A special thank you to the Family Run Executive Director Leadership Association for supporting the recruitment of family partners.

This project was supported, in part, by The Ohio State University College of Nursing seed grant and the National Center for Advancing Translational Sciences of the National Institutes of Health under Grant Numbers KL2TR002734 and UL1TR002733. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Suggested citation:

Herbell, K., 2023. Family Engagement in Residential Programs: A Group Concept Mapping Study Findings Report. Columbus, OH: The Ohio State University College of Nursing.

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