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Preface from Parent Advisor Board Members of ACRC *Redefining Residential: Becoming Family-Driven* is a vision for family-driven care. We are excited to have been asked to collaborate with ACRC in creating this document, as the association continues a series of policy papers that highlight new trends and promising practices in residential care. While our discussions at times were difficult, they were a necessary component of building mutual understanding and respect in our parent-provider partnership. The process of creating this paper is a good example of what ideally would happen on a daily basis in partnering with families in the care of their children. The collaborative work and open dialogue that created this document are essential elements of "becoming family-driven". This beginning dialogue must be continued if the redefinition of residential and true system transformation for our children individually and collectively is to become a reality. We hope that with this paper family-driven care has finally arrived, long overdue.

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This paper represents current thinking of the Association of Children's Residential Centers (ACRC) regarding the importance of family-driven care for youth placed in congregate facilities. ACRC is the longest standing national association focused on the needs of children in residential treatment and their families.

<u>Overview</u>

Residential treatment as a field has struggled with how to effectively respond to the familial needs of the youth in care. In the past the field tended to be youth centered, with family work as one of many identified treatment issues, typically focused on the youth's response to his/her parents and siblings. Parents' involvement ranged from none at all to very active involvement in their child's care; however in general the rights of family members to have access to and be central to their child's treatment was subject to contingency and question.

Residential treatment has not been alone in this clinical heritage; a dismissive approach to families of children with mental and behavioral disorders has also tended to characterize the culture of the child welfare, mental health, education, and juvenile justice communities. Nonetheless residential has a unique and unfortunate legacy of ambivalence about parents, rooted in its history as a service modality that evolved from the orphanage model. In its genesis the field was imbued with the residues of parent surrogacy, an orientation strongly reinforced by the prevailing mindset across the other child serving systems and training institutions- that parents were the cause of the child's problems. Residential became defined, and defined itself, as a placement, in which the staff individually and collectively took the place of parents in the day-to-day life of the child. The understanding and empathy offered the children was not consistently afforded to the parents, many of whom faced stigmatization and adversarial approaches.

In the last two decades, the thinking about family involvement across the child serving systems has begun to change. The Child and Adolescent Service System Program (1985) envisioned a central role for families in community systems of care for children with mental health problems. Wraparound, family decision making, and parent-professional partnerships have emerged in child welfare, education, medical, and juvenile justice arenas, as well as in mental health. Such service configurations have recently been supported by the research and heralded in salient mental health public policy studies, including the Surgeon General's and the President's New Freedom Commission reports. Research specific to residential care has also consistently identified improved child outcomes when parents and families are more involved. The response from the field to these developments has been slow but not insignificant, as residential centers across the country increasingly design processes and practices for more inclusion of parents and family members in the care of their children. The result has generally been improved outcomes for children and families.

Yet there remains a great deal to do. Residential facilities are faced with redefining their roles in local community systems of care and with the challenge of making the changes necessary to incorporate and support parents and families, often without additional resources, and within a framework of restrictive funding regulations. Many programs have been encountering this implicit or explicit expectation. For some it is transformative, but the task is complex and requires a shift in focus from treating the child in the context of the setting to treating the child in the context of the family and community. The complexity is compounded in responding to those children whose parents' rights have been terminated, who have bounced from temporary placement to temporary placement, and who consequently lack any real attachment to a community. This paper will review the emerging definition of family-driven care in children's mental health and discuss issues related to its implementation in residential programs. Some innovative practices will be referenced and organizational implications addressed.

Redefining Residential – Transforming to Family-Driven Care

ACRC, in a position paper entitled "Redefining Residential 2005", addressed the importance of residential programs reengineering themselves to become integral parts of local systems of care, and encouraged facilities to adopt and adapt transformative practices in keeping with the research and changing external environment. Of these, the move toward adopting and embracing family-driven care offers particular promise and leverage.

Family-driven care is defined by the Federation of Families for Children's Mental Health (<u>www.ffcmh.org</u>): "Family-driven means families have a primary decision making role in the care of their own children This includes: choosing supports, services, and provider; setting goals; designing and implementing programs; monitoring outcomes; partnering in funding decisions; ..." The definition delineates principles and characteristics of family-driven care, most notable of which is that <u>"administration and staff....share power, resources, authority, responsibility, and control..."</u> with families and youth.

There are many important reasons for residential facilities to embark on a path toward family-driven care.

- Children love and value their parents. The biological connection and the drive to heal any disruptions in attachment are powerful. To not explicitly and overtly value a child's parents may inadvertently symbolize not valuing the child. This can compromise the child's self-esteem and jeopardize treatment effectiveness. More importantly such an approach devalues the family relationship, a biological lifetime constant. Even youth who have been estranged and separated from their families often seek reconnection with family at some point in their lives. A treatment climate of shared responsibility, open communication, strengths-focus, and equal partnership facilitates healing and growth.
- The challenges children present in residential care often have genetic/biological components as well as environmental precursors. Children who have suffered trauma in their lives, regardless of source, often see themselves as helpless at the hands of external circumstances, for which they tend to blame others, including their parents. Marginalizing the participation of parents, in attitude or practice, causes staff to be caught up in the blame cycle, reinforcing the parents' sense of shame or guilt and making it difficult for the children to recover. Conversely, engaging with the family as full partners creates the opportunity for resolution of the losses and grief the child and family have experienced. Ensuring parents have the primary decision-making role supports or, in some instances helps them reassume, their parental responsibilities.
- Parents and families provide important information and feedback. An approach that engages them equally creates a shared responsibility for growth and change. It provides the opportunity for staff to work together with parents and to utilize family members' experience and expertise. This yields an increased ability to understand the child within the context of his/her family, culture and community,

and to develop realistic expectations, plans, and supports. The family is affirmed in having their strengths recognized and valued; the staff benefit from having support and assistance and from being relieved of the implicit, at times self-imposed, responsibility to be the ones who will "fix" the child. Family-driven care is a partnership.

- Parent-professional partnerships promote success. They overcome the fear, stigma, lack of support and encouragement, resource limitations, cultural dissonance, misunderstandings, and resistance that parents and professionals alike often experience with each other. They lead to shorter lengths of stay and more efficient utilization of resources.
- Parents are strong and effective voices, advocating in pragmatic and realistic ways for the needs of children on quality improvement, planning, and governance bodies. As political partners with professionals, parents are powerful advocates for the full continuum of care, inclusive of residential, and for efforts to meet the needs of children and families in local communities.
- The research in residential treatment consistently shows that the processes and outcomes of care improve in correlation with the degree of family involvement.

Residential programs have taken notable steps toward family-driven care, and it is probably safe to say that an evolutionary process has been occurring over the past decade. However, old habits, including mental habits, die hard. So despite the evolution that has occurred in the field, there still tends to be collective mindsets in the system and within individual organizations that diminish the importance of meaningful family involvement. The problem is exacerbated by residential's accustomed role as the placement of last resort. By the time families encounter residential providers, the parents are often angry, mistrustful, and/or hopeless, perhaps as a result of their experience in the system, but nonetheless tending to reinforce the "old" mindset where it exists. It is incumbent upon residential programs to develop a culture and practices that help staff to avoid or overcome this mindset and learn how to negotiate working relationships with families at the beginning of treatment in a way that establishes "ground rules", while engaging each family in quite the same manner as each "new" child, as possessing unique strengths upon which to draw in addressing their own particular challenges.

Making and Sustaining the Move Towards Family–Driven Care

Becoming family-driven has been described as "a journey", one that involves constantly addressing the belief systems of the staff, through leadership involvement, training, ongoing dialogue with family members, and self-monitoring (quality improvement). Organizations can consider encountering this challenge at multiple levels of partnership that bring alive the promise of family-driven care. For example:

- Care At the care level parents and/or family members can facilitate treatment planning meetings, work with staff in the milieu, shadow staff in facility and community settings, be the key decision maker in treatment plans, and be consulted over the phone at moments of impasse. Wraparound teams can be configured within residential programs and then follow the family and child back into the community. Focusing consistently on validating strengths can help parents and families reinforce and develop competencies, at times not identified in referral material or even clearly recognized by themselves. Listening carefully to and learning from parents and families can lead to better understanding of the child, increased cultural responsiveness, opportunities to address the needs of siblings, and the identification of respite and crisis plans for when their children return home.
- Hired Parents Many organizations are hiring parent advocates and parent partners as employees. These individuals can perform a variety of functions within the organization, for example family outreach, staff training, liaison, wraparound facilitation, and mentoring of other parents.
- Program At the program level parents have valuable contributions to offer into quality improvement activities, clinical policy, outreach, hiring, and many other arenas of organizational life. They can provide real life feedback regarding the strengths and gaps of the program.
- Governance At the governance level parents are valuable members of Boards of Directors, and offer critical input into strategic planning and resource allocation.
- System At the system level parents can have important voices on advisory committees and interagency collaboratives. Parents understand the importance of a full array of services and, in telling their stories, have a powerful influence on policy makers.

Such multi-level partnerships can help establish and reinforce a culture of family-driven care. They are more readily supported if the organization has made the leadership commitment to become family driven and can dedicate budgetary resources to supporting parent travel, paying stipends, or hiring parents as paid staff. The Board of Directors and CEO can ask themselves a series of key questions in assessing readiness to move in this direction, for example:

- ✓ Do the staff of the organization act, speak, and interact in ways that truly welcome, support, affirm, and incorporate the perspectives and wishes of parents?
- ✓ Do parents have to be "invited" into the organization or is it a baseline assumption of staff that parents are reciprocal partners?
- ✓ Is the organization committed to redefining itself as providing an intervention within a community continuum rather than as a placement of last resort?
- ✓ Does the organization believe that sharing decision-making, leadership, and power with parents yields better outcomes for children and youth?
- ✓ Is the organization willing to implement training and other practices that culturally reinforce the importance of parents and families in day to day actions, discussions, and care planning?

The responses to these questions can drive strategic planning and practice innovation. Changes in practice, even incremental, can and do lead to positive results.

The implementation of family-driven care in residential facilities is a transformational step that promises to yield better outcomes, increasingly shared responsibility, and exciting and rewarding partnerships between professionals, families, and communities. Agencies that have begun the path of innovation have reaped the reward of making their collective work more exciting and somewhat easier. Residential programs are urged to consider taking these steps and to develop practices to sustain them. For further information regarding ACRC, its position on family-driven care, or resources, please contact our national office at www.togetherthevoice.org