

## **Best Practices in Family Engagement and Advocacy to Meet the Devereux Family Standard**

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### **Abstract**

Devereux, a nonprofit organization that provides behavioral healthcare services, has established a comprehensive approach to family engagement that prioritizes trust, collaboration, and empowerment for individuals with behavioral, developmental, and intellectual challenges, as well as their families. Through initiatives such as the Family Engagement and Partnership Workgroup, National Family Advisory Board, Youth Advisory Council, and peer support programs, the organization provides tools, guides, assessments, and direct support to enhance communication, continuity of care, and overall outcomes. By integrating families' voices into decision-making, leveraging evidence-based practices, and continuously evaluating programs through nationally recognized assessments, Devereux fosters meaningful involvement, strengthens person-centered care, and advances a standard of excellence that ensures families feel supported, informed, and confident in the care of their loved ones.

### **Introduction**

When it comes to accessing behavioral health services, no one knows what an individual with emotional, behavioral, or cognitive differences needs more than their family members or caregivers. These family members and caregivers also deserve the highest levels of compassion, support, and communication to ensure peace of mind that their loved one is in the best possible hands for care.

A critical marker of success – for any human services organization – is gaining the trust of and actively engaging with the families and individuals served. And yet, among all human health service providers, a known obstacle is how to best engage families in their loved ones' care, particularly during challenging times.

### **The Importance of Family Engagement**

Active family engagement, meaning when a family member or caregiver is actively involved in their loved one's treatment journey, can lead to improved outcomes, services, and overall patient satisfaction.

Devereux, one of the nation's largest nonprofit behavioral health organizations, has implemented a myriad of ways to earn trust and deepen families' level of engagement throughout their loved ones' journeys, while in care and following discharge.

Specifically, through the role of Devereux's national director of family engagement, along with the organization's internal Family Engagement and Partnership Workgroup, connections, trust, and engagement are forged through ongoing meetings and communications, along with welcoming reports, toolkits, and guides developed by staff, family, and sibling advisors, and a multistate Youth Advisory Council.

### **About Devereux and the Family Standard**

Devereux is one of the nation's largest nonprofit organizations, providing services, insight, and leadership in the evolving field of behavioral healthcare. Founded in 1912, Devereux operates a comprehensive national network of clinical, therapeutic, educational, and employment programs that positively impact the lives of more than 10,000 individuals every year.

The nonprofit's families and loved ones are at the center of every decision and action made through the "**Devereux Family Standard.**" The Devereux Family Standard is the organization's touchstone principle that demands that, at all times, its programs and services match the high levels of quality and compassion that Devereux staff would choose for their own family members. Nothing less is acceptable. In fact, Devereux's National Board of Trustees is required to ensure the Board is comprised of a minimum of five family members (of individuals in care).

Meeting the Devereux Family Standard requires all employees to think through the lens of, "What would I want if I had a loved one in care?"

As the organization's National Director of Family Engagement, Amy Kelly, MBA, MNM, is tasked with doing just that with both national- and center-level family engagement initiatives. *Note: Kelly's daughter, Annie, has been in Devereux's care since 2007, which allows her to bring her personal and professional experience to her role.*

### **Family Engagement Workgroup**

Kelly leads Devereux's Family Engagement and Partnership Workgroup, which comprises staff (called Family Champions) from across the organization who meet monthly to share best practices and advance national initiatives to further family engagement and the Family Standard.

Over the past two years, the workgroup has spearheaded the following projects:

- **Welcome Books for families:** A guide about Devereux and their loved ones' specific program(s), various policies and procedures, etc.
- **"Devereux and Me" books for individuals:** Provided to all those participating in our children's/adult residential and foster care programs, these books are welcoming stories

or social stories with visuals to help individuals understand what they can expect from their Devereux experience

- **Family and Hospital Toolkit:**
  - **Adult personal care guide for families:** A guide on how to assist a loved one with personal care skills in an appropriate way when they are no longer in residential care
  - **“At a Glance” informational guide for families or hospital providers:** Provides information about a loved one in residential care so families are informed of any changes, likes, dislikes, etc., when the loved one visits home or if they are admitted to the hospital and have unfamiliar staff
  - **“Prevention and De-escalation Guide:”** A list of calming strategies, triggers, and warning signs of behaviors and/or safety concerns that Devereux staff highlight and send with the family during home visits to better assist in preventing and/or managing unwanted behaviors
- **A biannual assessment (Building Bridges Initiative Assessment) for children’s residential centers:** Devereux utilizes a SAMHSA-developed assessment to evaluate children’s residential programs from all constituents, including families, payors, and staff
- **A biannual assessment (Person-Centered Organizational Assessment) for adult residential programs:** This assessment is used to evaluate the person-centeredness of adult residential programs from all constituents, including individuals served, their families, payors, and staff

### **Engaging Families, Enhancing Care**

Devereux also generates increased family engagement through its National Family Advisory Board and Sibling Engagement Committee and subcommittees. These groups are comprised of family members whose loved ones receive services through Devereux, and are tasked to work together to advance and strengthen resources and supports for all Devereux families through various agreed-upon projects.

Over the past year, these teams partnered to create a comprehensive toolkit designed to support families when taking their loved ones home, on overnight visits, or during hospital stays. The toolkit includes information that goes beyond standard medical and clinical information by including personal preferences, such as likes and dislikes, calming strategies, and communication tips, all presented in a family-friendly, easy-to-understand format.

A key component of the Hospital Toolkit, for example, is a one-page overview, “At a Glance,” which can be posted in a hospital room or used by family members during hospital visits to help ensure consistent, person-centered care for that individual.

In addition, Devereux’s National Family Advisory Board and Sibling Engagement Committee identified the need for training on properly assisting with Activities of Daily Living when loved ones come home from residential care. As a result, an internal guide was adapted into a

simplified version for families, equipping them with the tools and confidence to provide thorough, appropriate care during home visits. This resource helps empower families to feel more comfortable taking loved ones home, assisting them with proper bathing techniques or other daily living skills typically administered during their residential stay.

### **Driving Quality Through Assessments**

Today, Devereux utilizes the following nationally recognized self-assessment tools to track progress toward best practices in care:

- SAMHSA-developed Building Bridges Initiative Self-Assessment for children’s residential programs
- Person-Centered Organizational Assessment (PCOA) for adult intellectual and developmental disabilities programs.

These assessments, conducted internally and externally every two years, engage individuals, families, staff, and funders. Assessment results help identify areas for improvement across programs and also provide Devereux centers that score well with the opportunity to share their practices with colleagues. Insights from the assessments are incorporated into each center’s quality improvement plans, with national support, to help standardize processes and enhance the overall quality of services. Previous improvements based on assessment findings include:

- Translating admission documents into the second-most-prevalent language
- Securing national contracts for translation services
- Establishing a Devereux Youth Advisory Committee
- Launching a healthy eating initiative

### **Turning Opportunities into Strengths**

In 2025, Devereux’s Building Bridges Initiative (BBI) assessment highlighted the need to further involve youth in organizational decision-making. As a result, Devereux is working to expand its Devereux Youth Advisory Committee to all child-serving centers, ensuring that youth voices and their recommendations continue to reach Devereux’s senior leadership team.

In addition, Devereux’s 2025 Person-Centered Organizational Assessment results pointed to opportunities for increasing person-centered decision-making among adults, specifically around community involvement, living arrangements, and fostering meaningful relationships. The organization’s center Quality Improvement (QI) teams are already incorporating this feedback into their immediate and future QI improvement goals.

Overall, Devereux showed strong performance on both assessments, with scores steadily improving over time. Past years’ reports have led to the creation of welcome baskets at admissions for families, the need for youth to have the opportunity to present directly to senior leadership, and collaboration between centers to understand successes and challenges more

thoroughly.

### **Hearing from Our Individuals and Families**

A true measure of Devereux's success is the satisfaction of the individuals and families served by the organization. While the BBI and PCOA assessments measure center-level successes and opportunities from the constituents' perspective, another evaluation focuses specifically on measuring individual customer service and satisfaction.

In 2024, Devereux partnered with Universal Stakeholder Participation and Experience Questionnaire (uSPEQ) – a growing branch of CARF International, a global accreditor advancing quality services for 50 years – as part of the nonprofit's efforts to gather reliable data from a third-party related to individual and family satisfaction. uSPEQ's Consumer Experience Survey gathers feedback from individuals and family members on their experience with Devereux's services and locations. The organization will continue to incorporate feedback from these uSPEQ surveys into its action plans.

### **The Importance of the Individual's Voice**

Kelly also spearheads Devereux's Youth Advisory Council, comprised of students from Arizona, Connecticut, Florida, Georgia, New York, and Pennsylvania. The group meets monthly and has previously focused on projects related to safety, healthy eating, proper hydration, and exercise. This national council leverages the voices of youth with autism spectrum disorders, intellectual and developmental disabilities, and behavioral challenges, fostering a deeper understanding of their unique experiences and helping to shape national projects.

Over the next two years, Devereux plans to expand participation to all children's programs and develop a similar initiative for adult programs.

### **The Power of Family Peer Support**

Devereux's centers in Arizona and Georgia are also participating in a National Institutes of Health research study with the Family-Run Executive Director Leadership Association (FREDLA) and The Ohio State University.

Research consistently shows overwhelmingly positive outcomes for individuals and families who receive peer support from people with lived experience. However, these services face significant barriers: they are not billable in every state, reimbursement rates are often low in states where billing codes do exist, and separate billing is typically prohibited when an individual is receiving bundled payment services in residential care.

Yet, it is often during these times, when families place their child in 24-hour care, that family peer support is most critical. The study was designed to demonstrate the impact of parent peer support in child residential settings, with the goal of securing funding for a larger study and

advocating for Medicaid reimbursement of parent peer services during residential treatment in all states.

Parent peer organizations, known as family-run organizations in Arizona and Georgia, partnered with Devereux to offer support from the time of admission through post-discharge. The preliminary results were outstanding, showing that 100% of Devereux parents said they: 1) received the support they wanted, 2) would recommend parent peer support, and 3) would come back to parent peer support in the future.

Results also found that clinicians were highly satisfied with the family peer support intervention and that the service is “able to improve parents’ willingness to engage in the child’s treatment” and has even lightened the clinicians' workload in some cases.

Devereux’s investment in Family Peer Support, an evidence-based model of care (similar to Peer Supports for substance use disorders), aligns with the Devereux Family Standard, and Devereux hopes to formally integrate parent peer support into its continuum of care in the future.

### **Helping Families Access Services**

In her role as national director of family engagement, Kelly assists parents, staff members, and those seeking Devereux’s services by helping them understand treatment alternatives, navigate systems of care, and advocate for their loved ones. She participates in Devereux’s Family Advisory Board and Sibling Advisory Board meetings, virtual center meetings with parents, and assists board members with special requests. Kelly’s oldest son, Danny Kelly, serves as co-chair of the Sibling Engagement Committee.

Through her role, Kelly promotes thought leadership at Devereux through her participation and partnership with the American Academy of Pediatrics Section on Developmental and Behavioral Pediatrics Executive Committee; American Academy of Child and Adolescent Psychiatry Advocacy Team; Autism Speaks; Autism Care Network; Patient-Centered Outcomes Research Institute; and The Children’s Hospital of Philadelphia. Kelly also publishes, speaks, and serves as an editor, contributor, and/or reviewer for several well-recognized journals and large grants for mental health, autism, and intellectual and developmental disabilities.

### **Eliminating the Challenge**

While family engagement remains a challenge across the human services industry, Devereux is ensuring it stands out as an innovative leader in this area through the appointment of a national position dedicated to assisting families and their loved ones; establishing family- and sibling-based committees; creating a Youth Advisory Council comprised of individuals served; and creating materials that not only support and empower program participants and families, but strengthen our communities.

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