

## What a Difference Family-Driven Makes: Stories of Success and Lessons Learned

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**Abstract** Community Psychology’s emphasis on citizen participation aligns with the nationwide children’s mental health family movement and is clearly evident in communities that have made sustainable system changes. The national family movement has long advocated for the meaningful engagement of families and youth who are the focus population of the federal Children’s Mental Health Initiative. Little rigorous research about the experience of families in leadership positions or of their impact on systems of care has been done. In the absence of scientifically acquired evidence, this article offers the reader a glimpse into the authority, influence and credibility earned by four family leaders as well as their impact on local system of care communities. Their stories occur in four distinct macro level arenas: governance, evaluation, legislative advocacy, and workforce development. In the end, common attributes emerge from their stories, providing anecdotal information useful to identifying the qualities of successful family leadership and their impact on sustainable macro level changes.

**Keywords** Family · Involvement · Engagement · Empowerment · Family-driven · Governance · Workforce · Policy · Evaluation · Authority · Influence

The concept of family involvement has evolved hand-in-hand with system of care theory over the past 30 years. Initially conceived as family-focused, the federal Children’s Mental Health Initiative (CMHI) eventually aligned with Goal Two of the Final Report of the President’s New Freedom Commission on Mental Health: that “mental health care is consumer and family driven”. (2003. Page 22) Family driven as defined by the family movement means that “families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes: choosing culturally and linguistically competent supports, services, and providers; setting goals; designing, implementing and evaluating programs; monitoring outcomes; and partnering in funding decisions.” ([www.ffcmh.org](http://www.ffcmh.org))

Despite the progressive movement toward a more purposeful engagement of families in all aspects of system of care, there is little rigorous exploration of the experience of families in leadership positions or of the impact of their involvement on systems of care. In the absence of scientifically acquired evidence, this article offers the reader a glimpse into the authority, influence and credibility achieved by four family leaders as well as their impact on local system of care communities. Their four distinct perspectives represent specific vantage points from within the system of care: governance, evaluation, legislative advocacy, and workforce development.

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## One Family Leader's Story of Involvement in System Governance

Systems of care include families in their governance structures in a variety of ways. In some communities that takes the form of majority family representation on a governance board and in others experienced family leaders have been hired in leadership positions such as Co-Project Director and Project Director. Family leaders who have had the greatest success ensuring that the family perspective is included in governance processes are empowered through the respect, authority and influence they have acquired with local leaders. Following is the story of one mother's leadership as the Executive Director of a family-run organization in a system of care community. Her experience highlights six important messages for other systems of care.

I am the Executive Director of Kentucky Partnership for Families and Children, Inc. (KPFC), a family-run organization that has been involved with several system of care initiatives. The core competencies I have found critical to my work include the lived experience of raising a child with mental health needs, good communication skills, and non-profit management. KPFC considers the lived experience to be a non-negotiable requirement for the Executive Director. To a system of care, a parent's lived experience brings an intimate knowledge of the workings of multiple systems: special education, child welfare, private clinicians, community mental health centers, primary care physicians, transitional services and the courts. This includes an understanding of the various acronyms, mandates and processes of all of these systems. In addition, my previous professional experience gave me strong communication skills, enhanced curriculum development and training skills, an understanding of working for a bureaucracy, and an ability to recognize personal-professional boundaries. After coming to this position, I also completed a certification program in nonprofit management that included a focus on financial management, administration and supervision, social marketing, and honoring the vision. The first recommendation I would make to a system of care initiative is to fill family leadership positions with people who have the "lived experience" and to ensure they have access to training programs to build knowledge, skills and abilities necessary for them to be effective in their roles.

My second important message: all family-run organizations engaged with systems of care must have broad local representation and be connected to strong state and nationwide networks. KPFC includes diverse people who have a vested interest in helping youth who have severe emotional disabilities and their families to be successful in their home communities. This includes youth with severe emotional disabilities, their parents, KPFC's board

members, and other partnering agencies: school, mental health, courts, juvenile justice, etc. The board of directors is made up of a minimum of: 51% parents, 9.5% transitional-age youth, and 33% providers from child-family serving agencies. This makeup builds the family-run organization's credibility and connects it to many agencies that provide services to children, youth and families. A state chapter of the National Federation of Families for Children's Mental Health, KPFC is at the center of the national family movement. KPFC is the recipient of a Substance Abuse and Mental Health Services Administration's Statewide Family Network grant as well as the state vendor for providing family-driven and youth-guided support and infrastructure. A majority board makeup of parents plus leadership with the lived experience of raising a child with mental health problems ensures KPFC is a family-run organization.

I would also emphasize that an active board of directors is critical to supporting the family-run organization's leadership and position within the system of care. When I became the Executive Director for KPFC, the board was passive and abdicated most of their responsibility to the board chair and me. They would often "rubber stamp" any action item I took to them and lacked a demonstrated passion for KPFC's mission and vision. The untimely death of the board chair threw the organization into crisis, exposing the dearth of active leadership on the board. An external facilitator from the Center for Nonprofit Excellence was contracted to conduct a board retreat and training. That event strengthened the board's commitment to its roles and responsibilities. It also enabled individual board members to embrace the mission and vision of the organization and helped them to see the difference KPFC was making in the lives of children and families. A new and charismatic board chair built strong relationships and increased leadership among the board members. Today the board has grown into becoming strengths-based and solution-focused, and works to resolve barriers and address gaps in services to children and their families. Further, a strong bond of trust and transparency has developed between the board and the Executive Director. This support from the board enables both me, as the Executive Director, and the staff to creatively solve problems for children and families. Further, it supports KPFC to serve as a strong and credible statewide partner to all those working in systems of care.

My fourth message: a family-driven system requires strategic placement of family leaders into all decision making bodies of the system of care. KPFC as the family-run organization and system of care partner oversees this to guarantee family members have the information, preparation, and support they need to be effective in their various roles. As of 2010, our state is on its third system of care

cooperative agreement with the federal Substance Abuse and Mental Health Services Administration. Being the family-run organization's executive director, I have partnered as the state-level parent, sitting on the state administration team that works to ensure the initiatives are being implemented in a manner that is true to the objectives of the cooperative agreement. This team also focuses on budgetary needs. With each SOC initiative a state-level implementation team is also developed that includes team members from all child-family serving agencies. Our family-run organization has had a minimum of two staff members (including the executive director) at each of these quarterly meetings that drive the programming within the SOC initiatives. Instead of placing all the parent leaders on the committee that focuses on family involvement, we strategically place a parent leader on each committee. This allows us to have a parent voice on each committee and provides us the opportunity to educate all participants in better understanding family-driven care. I believe that this strategy has worked well because we, as parent leaders, are integrated instead of segregated. Often times, partnering agencies want to say they are modeling "family-driven" because they have one work group or initiative working to increase family involvement. While family involvement is important, family-driven is much bigger than that. This strategy models for these community partners that parent voice and parent leadership are important on all committees regardless of focus—not just the workgroup for family-driven or family involvement.

Like all partnering organizations, KPFC as the family-run organization in Kentucky's system of care initiatives was charged with helping to sustain system of care principles beyond the federal cooperative agreements. We succeeded in this, which leads to another key message to system of care communities: support the creation of a strong leadership development structure with employment opportunities for Peer Support Specialists and their supervisors. Parent peer support providers have been used informally throughout the US since the children's mental health family movement began in the 1980s. With an opportunity to formalize and support this service with a sustainable infrastructure throughout Kentucky, we needed to define the steps to build a family-driven system of care. We turned to a facilitator trained in using Dean Fixsen's Implementation Drivers<sup>1</sup> to help us understand what was needed to create sustainable change in the system. The process helped us refine four goals or components of our plan:

- (1) Help parents and transitional-age youth become leaders within their own lives,

<sup>1</sup> Dean L. Fixsen of University of North Carolina and the National Implementation Research Network.

- (2) Recognize Family Peer Support Specialist as a real and viable service for families that have children with behavioral health issues (this includes writing regulations, passing state level legislation that recognizes this support as a legitimate service covered by Medicaid, and developing training on identified core competencies),
- (3) Support Family Peer Support infrastructure by having experienced specialists that can also act as coaches and mentors for new specialists, and
- (4) Expand the understanding of providers on what "family-driven" means and the steps their agencies can implement to move in that direction.

Sustainability comes from having a strong infrastructure with depth and breadth; it doesn't depend on one person or one role, but the blending of many roles, multiple partners and a multitude of skills.

Finally, as a family leader in three system of care initiatives and as the Executive Director of the family-run organization, KPFC, I want to offer my sixth important message to others in this work. It is imperative to keep hope alive, to help families and others see the long-term picture and to understand change takes time. It is often difficult for parent and youth leaders to believe change is occurring. I hear questions like: "why don't people get it," "why do we just keep doing the same thing," and "are we really making a difference." I strive to explain that system change is a long, arduous journey and is not for the faint of heart. Just because we have not "arrived" at a destination, I assure the parents and youth leaders that this is all part of the journey in changing system philosophies, values, beliefs, and functions. I recognize that these efforts to build and sustain a family-driven system of care will not necessarily assist my children and the children of other parent leaders, but it is our responsibility to move it forward as best we can. It is my belief that we will reach our collective destination and a family-driven system of care will eventually become "business as usual". To do this, we cannot lose hope.

Our state continues to clearly demonstrate its commitment to helping families and youth who experience the challenges of dealing with severe emotional disabilities by establishing a strong sense of community and partnership. Our family-run organization along with the Department of Behavioral Health, Developmental and Intellectual Disabilities, the System of Care cooperative agreements, and other community partners continues building an infrastructure that will allow parent leaders to have a voice in governance issues across our state. As our journey continues, our hope is that this will build a family-driven infrastructure that is strong and sustainable.

## One Family Leader's Story of Involvement in Legislative Policy

One of the greatest benefits communities enjoy from strong family-run organizations is their ability to harness the voices of families who have benefited from systems of care and engage legislators to advance policies that support and sustain them. Following is the story of a very successful family leader who found her own voice in this process and, in doing so, guided her family-run organization to do the same.

Twelve years ago I was part of a coalition working to pass mental health parity legislation in Massachusetts. Although I had never done it before, I met with several key legislators and told them about my son's significant mental health needs and how I had tried unsuccessfully to make a limited mental health benefit pay for the many treatments he needed. As I passionately told my story to one powerful legislator, he listened, nodded and said, "In most families, the apple doesn't fall very far from the tree, you know." I was stunned, mumbled a few words and left his office. That encounter was a pivotal moment for me. That legislator did not see parents as important allies, strong community leaders or key sources of information. He heard my story as a single story, not representative of hundreds of families. He assumed, as many do, that any failure negotiating with my insurer was due to my lack of skills rather than an inadequate insurance benefit. He believed that it was my family that was dysfunctional, not the system.

Since that day, I have worked to develop strategies to help families educate their legislators. These are all best done through the support of family-run organization. I work for Parent/Professional Advocacy League (PPAL), a statewide family-run organization where we employ multiple avenues for families to become involved, provide families with regularly updated information, build and sustain relationships with legislators and other allies as well as use media stories to focus attention on the needs and strengths of parents and youth. Following are six recommendations other communities and family-run organizations can use.

First, use data to increase the impact of personal stories when trying to educate legislators. Legislators tend to underestimate the number of families in their districts whose children have mental health needs. They might hear the occasional horror story but they have little idea about the actual numbers. By combining the national prevalence rate of mental health disorders with the actual numbers of students in their districts, I have been able to help them see how mental health parity (and later, other bills) affected families in their districts. I would point out that if 1 in 10 children have mental health needs and if there were 9,000 students in a town, at least 900 students would be affected.

I also emphasized that the families of those 900 students were constituents and I was representing them. Now, when I recount an individual experience, whether it is my own or belongs to another parent, legislators and policy makers understand that it is something that thousands of parents experience.

Second, parents should ask their state legislator to make a call on their behalf to the insurance company, hospital, state agency or whatever entity may have created a barrier to care for their child. I used this while working to pass legislation to form a children's mental health commission in my state. Over the period of a year many parents called and legislators found that they were no more successful than parents in obtaining needed services; when they were successful, it was only with great effort. They had renewed respect and compassion for families of children and youth with mental health needs. This strategy was fairly easy for parents wanting to use their experience to make a difference for the parent coming behind them, but with little time on their hands. By reporting a barrier affecting their family and asking for much needed help, they served to enlighten legislators who found that helping their constituent meant grappling with a complicated child-serving system.

In addition, the family-run organization should design a range of simple ways for parents to directly contact their legislators about pending bills. First and foremost, the family-run organization must ensure parents understand the bill and its implications on their own family. Then, with an outline of the provisions of the bill and suggested talking points, parents can easily make a difference through other supports of the family-run organization. For example, I have often ignored the common wisdom that letter writing or calling are the most effective ways to contact legislators and encourage parents to email, which they could do quickly and late at night. At times, we have printed and distributed postcards parents can sign with a handwritten line about their family. This has been extremely effective in our state. Once PPAL began this, legislators began hearing directly from families, some for the first time.

Fourth, devise ways to funnel information from large numbers of parents into the family-run organization's public statements. Any initiative needs a public face and I have long made sure to regularly show up at hearings, public events and at scheduled meetings. While I often bring another parent with me, I always bring information from as many parents as possible. Before writing testimony I frequently conduct a short poll to gather information and recently asked parents whether they knew that there was no parent-child privilege in our state and they could be called to testify against their child in a court of law. Later, speaking to legislators about a pending bill on this matter, I was able to tell them that I had polled parents and 94% of those surveyed were shocked and dismayed by this and

therefore considered this a priority bill. Using devices such as the poll above or outlining the top five ways a change will help children can frame issues and highlight experiences in a way that is immediate, powerful and compelling. These methods have ensured that legislators understand that my public statement includes information from hundreds of families as well as their endorsement. Over the years, I have stated that families are the experts on their children so often that some legislators now repeat it back to me as well as to their colleagues. When legislators repeat key points, it is clear that they have aligned their thinking with your own.

Because changes in policy and statute can progress at a snail's pace, one of the most effective strategies can be to work with the media. Long ago, an influential state representative said to me, "There are 50 priority issues on my desk at any given time. If you want your issue to jump to the top of the list, make it visible." For the first few media stories, I used my own experience, partly because other parents were reluctant to be interviewed. Those experiences have helped me form a number of guidelines to help parents tell their stories more effectively and ensure that reporters treat them with respect and patience. I remind reporters that parents are not professional spokespeople; they are talking about their own children and lives. I explain that families need to be thanked for their contribution and informed that stories will be shortened. For families, I coach them to approach an interview as if it were a book report (state your point, then offer a story or two to strengthen it) not a lengthy biography. Over the years we have helped create dozens of media stories that have led to reform in both statute and practice around custody relinquishment, lengthy hospitalizations, mental health parity and access to care and we have shifted from simply responding to media questions to actively pitching stories. This active relationship with newspapers, radio and television has also made our family run organization more influential and powerful. This leads to my next recommendation: to create relationships with media outlets and maximize opportunities to get your messages out.

Finally, working with other groups in a coalition can be an extremely effective strategy. Family run organizations are often seen as desirable allies, and I am approached often to work on a variety of issues. It is important to ask pivotal questions such as whether our organization's strategic priorities align with an issue or whether it directly impacts families. Sometimes a concern will emerge from the collective experience of families in our network; other times I will be approached to see if we have interest in working on a different issue altogether. Because the issues that affect children with mental health needs are so vast, many important policy matters come to my attention this way, including work on school suspension guidelines,

parent-child privilege and insurance reform. If I can work in a coalition, we can often get far more accomplished since each organization brings different skills and resources to the table. I am careful to avoid "mission creep" and ask myself if children with mental health needs and their families will directly benefit from policy, regulation or statute changes before I make a commitment. As a result, legislators and policy makers know that our organization will consistently and exclusively advocate for improvements in children's mental health. Some have even asked where the families stand on an emerging issue. Our ability to clearly state the perspective of families while collaborating with others has been crucial to moving many policy issues forward.

A lot has changed since my meeting with that legislator 12 years ago. Today legislators call and ask for parents to testify at oversight hearings, to work on reforming practice or to talk about the state budget. Many even direct their staffs to call our organization to better understand how certain provisions will affect children with mental health needs and their families. Other parents and I have been invited six times to see legislation we've worked on signed by the governor. We've shared stories within our network to gauge what kind of impact a law actually has after it has been enacted. Most of all, we know that change is possible.

### **One Family Leader's Story of Involvement in Evaluation**

CMHI system of care sites are expected to engage families in both their Congressionally mandated national cross site evaluation and their local evaluation activities. This arena of family involvement has been particularly successful. This success may be attributed in part to the general ease with which family leaders and evaluators can see benefits to working together. Family leaders often see the benefit of having a researcher as their ally; for example, to help find and prepare data to inform legislators about the size and relevance of problems among their constituents, as mentioned in the previous section. Likewise, evaluators are able to see the value of family involvement in their work, for example offering their perspective on all stages of program and system evaluation, applying real-life meaning to their results, and ensuring the findings are disseminated and used. In the following family leader's story, her outreach to seek an evaluator's assistance led to something more significant than either had hoped. Her influence on the system of care's local evaluation helped raise visibility and build sustainability for the local parent peer support program. She tells about four key strategies she believes supported their success.

When I was hired as the key family contact, a required position in SAMHSA funded system of care communities, I was asked to sign a form indicating that I understood I was being paid from grant funds. The form said there was no guarantee of continued employment or program sustainability when the federal funding ended. Having previously worked in private industry as a sales representative, I knew the burden was on my shoulders to “sell” what needed to be sustained. And, as the parent of a child with mental health challenges and firsthand experience in the effectiveness of parent-to-parent support (called “peer navigators” in our community), signing this form was motivation enough for me to get focused on how to sell parent-to-parent support to our local funders and decision makers.

One of the first opportunities I was given in our system of care was to travel to an evaluation training provided by the National Federation of Families for Children’s Mental Health and the national CMHI evaluation team. As per the National Federation’s invitation, our system of care sent the lead evaluator and me as a team. This proved to be an invaluable step as we sat next to each other for 2 full days discussing how families and evaluators could partner to strengthen systems of care. The course included basic evaluation concepts and processes which our evaluator helped me understand. It also included concepts of family involvement, family voice and family choice, all of which I helped our evaluator understand. My first recommendation: provide joint training to families and evaluators early in the life of any system of care. This is also where we started our bonding process, building trust with one another.

Once we were back from the joint evaluation training, we knew how to talk to each other and were ready to take on a task together. I asked the evaluator to help me figure out how to showcase the value of the peer navigators in order to find support to sustain their work. Our evaluator needed to produce data useful to decisions makers in our community, as well as to the national CMHI evaluation. We needed each other in order to be successful in our own roles. I believe this interdependence added to our ability to trust and respect each other. My second recommendation: find tangible ways evaluators and family leaders can help one another. Our work together not only helped sustain parent peer support, but also led to some of the first documentation of parent peer support outcomes.

My third recommendation: any evaluator who wants access to authentic family voices should be willing to go where the families are, to spend time with them, and to listen carefully. To begin our project, the evaluator met with me and the other parents serving as peer navigators. The fact that I already had a relationship with him gave him entry into our world, a place far from his university office. The fact that I trusted him reassured the other

parents who opened up to him and shared their information. He listened deeply to the work we did as peer navigators on a daily basis. Using this information, he created categories of our work and developed a checklist for us to use to gather data.

The evaluator reported back to the peer navigators often so they could better understand what we were learning about the benefits of their work. He also told them what he was reporting quarterly to the community decision makers showcasing the value of their work. Transparency, sharing data with other stakeholders, built a stronger bond between everyone in the system of care. So, my fourth recommendation is to be as transparent as possible with families and other community stakeholders. It helps to build trust.

We were able to tell the story of success through data. We showed that peer navigators help parents cope with the stress and strain of raising a child with behavior issues and maintain basic living necessities, such as keeping their jobs. They help parents find community based supports for the whole family not just the child receiving services. The data showed that peer navigators bring information, empathy, and connections to the community, which are important supports to the families.

Finally, we showed that when a family member shares their personal story of struggle and success, it inspires families who are just beginning their journey. Each of the navigators and I shared our stories of raising children involved in various child serving systems to help inspire families with encouragement and hope. As a parent of a youth with mental health challenges, I had to navigate my way through child welfare, juvenile justice, education, and a mental health institution to get my child the help he needed. My story also served to help providers, policy makers, and other system leaders understand what families need and how they need it.

Sustaining peer navigators beyond the federal system of care funding is due largely to the partnership of the evaluator and me, the key family contact. It is one of the accomplishments I am most proud of.

### **One Family Leader’s Story of Involvement in Workforce Development**

The following story is that of a parent who is the Executive Director of a statewide family-run organization and, as such, has a key role in the state’s mental health workforce. She shares her own journey into this workforce and how she helped to develop a sustainable statewide program for parents hired to provide peer support to other parents. She offers four recommendations.

My journey as a family leader within the children’s mental health field began over 12 years ago when my

oldest son began having difficulties coping with day to day stressors. As I worked harder to find answers, identify professionals who could help, and looked to systems for services and supports, I began to experience stigma, blame, judgment, shame, and hopelessness. What I found was not help; it was hurdles, hoops and heartache.

I knew then that there was a need for the professionals who worked within the child serving systems to have an ability to better understand: to see what we see, to know what we know, and to feel what we feel. I knew that if they could experience what it was like to hold your child who raged for hours and wanted nothing more in the world than not to hurt, they would change the way they looked at me as a mother and the way they blamed me and my child for why things had gone so wrong.

In the early years, I drew support from the Association for Children's Mental Health (ACMH), Michigan's state-wide family-run organization. The peer support and opportunities to network with other families and learn about the systems and services that could support us helped me address the challenges that affected my child and my family. When my son continued to rotate through psychiatric hospitals with little to no improvement and the systems began to consider removing him from my care, ACMH provided guidance for me to talk with the county mental health agency directors and supervisors to explore what other options existed. I also spoke with the state psychologist and legislators about the lack of community based options. For each and every person I met with, I made sure they knew how much I loved my child, how committed I was to doing whatever it took to keep him at home and in the community, and that I saw myself as being the primary force for making things happen. My first recommendation is to ensure systems of care provide opportunities to parents to get involved with a family-run organization. This kind of support is critical to our ability to advocate for our child and to help our family recover its well-being.

My second recommendation is to ensure systems of care link families to educational materials and support them to attend trainings about children's mental health, systems of care and other knowledge they may need or want to work toward healing. I began by attending trainings, conferences, and seminars as often as I could find time, money, and childcare. I researched at the library, read books, and talked to as many other parents as would talk to me. Much of this was available through the family-run organization and the federally funded system of care. It furthered my sense of self-efficacy and hope.

The third message I want to impart is that relationships based on mutual respect, understanding and accountability are critical. My own credibility with administrators, providers, and families alike depended on using my lived

experiences to empower everyone to be part of the solution. Assuming that people who worked with families wanted to be helpful, but just did not know how, prevented me from blaming them. Keeping my attitudes and beliefs focused on the hope that things would ultimately get better helped in all of my relationships.

My connection to the family-run organization, other parents, information, and respectful relationships led to my ability to impact the children's mental health workforce in several ways.

In 2005, as the Lead Family Contact for a federally funded system of care site, I helped develop, implement and evaluate cross-systems trainings at a local level aimed at increasing provider awareness about how to deliver services through a family-driven, youth-guided, individualized approach. I also presented at conferences about strategies for developing meaningful family involvement, effectively engaging parents, and family driven care and the impact it has at a systems level. My fourth recommendation is to ensure system of care communities offer families and providers opportunities to be trained by one another: across agencies, across disciplines, and across cultures. This should include sharing responsibility for developing, implementing and evaluating the training they provide. We found great success using this approach in our community.

In addition to training, in this Lead Family Contact role I oversaw a Family Advocacy Support Program that employs 8 family members. Over 80% of the Family Advocates are former recipients of Family Advocacy Support services through the system of care and are now providing peer delivered parent to parent support to over 500 families throughout the county. These family members are integrated within the treatment teams, housed within the child serving systems, and involved from the first point of contact with a family. During my time operating this program, part of my role was to collaborate with the child serving systems to initially understand the importance of family support, family involvement and family empowerment. Later it was to trouble shoot the complex challenges of integrating family members as service providers within the mental health workforce. Through it all, the key was to listen to the concerns of everyone, appreciate the barriers as it related to partnering with family members in an employment capacity, and develop creative solutions that took into consideration the needs of families, systems and the family members employed as providers.

My success implementing a peer delivered parent support program at a local level, led to me being asked by the Michigan Department of Community Health, Michigan's state mental health department, to participate in the development of a training curriculum and certification process for family members. This was an enormous

success. This created a mechanism to afford families of children with mental health needs currently involved in the public mental health system access to parent to parent support as a Medicaid covered service.

Currently, I am working in partnership with the Michigan Department of Community Health as they roll out the statewide Family-Driven/Youth-Guided Policy and Practice Brief developed as a result of the Family-Driven Policy Academy hosted by the National Federation of Families for Children's Mental Health in 2009. I was one of a small group of authors of this policy and am eager to see how this policy strengthens the role of family members in the workforce as well as the increased skills and awareness of the provider workforce through family empowerment, engagement and involvement. This policy will be included in the contract requirements for all community mental health service programs for FY 2011.

In March of 2010, I became the fourth Executive Director of the Association for Children's Mental Health. I can honestly say it was one of the proudest days of my life! As a family leader, I owe my success to always staying true to the lessons I learned along the way. Never give up no matter how much resistance you encounter—the consequence is too great to families. Always remember where you come from—I am a parent of a child with mental health needs first and foremost—that is what equips me to do what I do. Stay focused on the big picture—long-term, sustainable change takes time. And maintain a commitment to parent/professional partnerships being the answer—parents and professionals who experience one another as adversaries lose valuable opportunities for positive outcomes.

## Conclusion

Each of these first person accounts demonstrates citizen participation at its best. Each citizen/family member was of the focus population and, in each story, their leadership led to sustainable macro-level improvements in their children's mental health system. Yet, in the 20 years of the federal CMHI, family-driven at the system level continues to lag.

These four stories provide anecdotal information about specific developmental pathways and common indicators for family leadership that succeeds at making improvements to local children's mental health services and programs.

(1) Each of these four family leaders began their journey with the experience of stigma, blame, judgment, shame and hopelessness in the face of raising their child with significant mental health needs in their community. This factor alone helped give them

credibility with other family members as well as with policy decision makers.

- (2) Each had at least some prior work and/or study experience that gave them knowledge, skills and competencies useful to their advocacy work.
- (3) They were each lifelong learners: especially about intangible things like power, strategy, political will and discretion.
- (4) Each understood trust, credibility and informal authority to be earned characteristics.
- (5) Their personal characteristics included tolerance for delayed gratification and for risk-taking. For example, they understood that the changes they were effecting would take perhaps a full generation to impact the children in their community, eliminating the possibility that their own children would benefit. And they were each willing to risk failure. They did not limit their efforts to only the obvious wins.
- (6) Each displayed empathy for all stakeholders, including legislators, providers, and evaluators. They were therefore able to develop and nurture relationships with everyone, and to change peoples' minds.
- (7) Each had a strong desire to improve the lot of children, youth and families in society as demonstrated by their skilled mentoring of other family members to empowerment and some to leadership positions.

Their stories also lead to conclusions about community strategies that support effective family leadership that makes a difference. Each of these women had paid positions within their system of care at the points in time when their influence was most significant. They were provided with training and networking opportunities. And, there is evidence of professionals, providers, and evaluators who were willing to listen and to eventually be supportive collaborators. Critical elements, we learn from these four stories, to replicate in system of care communities are:

- Hire family members with the above mentioned capacities and characteristics into leadership positions;
- Provide them, as you would any promising employee, with on-going education, supportive supervision, training and networking opportunities;
- Be innovative in helping staff without the lived experience gain respect for the value of it and the contributions it can make to the community overall.

It would be useful to conduct a broader and more rigorous study of the most influential family leaders of the past few decades. We need to better understand how to support and engage these most significant stakeholders to facilitate authentic citizen participation and sustainable systems' improvements.