

THE “KEYS FOR NETWORKING”: TARGETED PARENT ASSISTANCE

Parents in Kansas whose children have or are at risk of emotional and/or behavioral problems call Keys for Networking seeking help. Parents call when they cannot get the response they need from agencies. Most report feeling isolated, alienated, disconnected, alone, or abandoned, even by family members. They often doubt their ability to help their own children. In the process of learning how to obtain effective plans and appropriate programming, however, they become connected with a statewide social support network that offers contact with other parents who have had similar experiences. Keys for Networking, or “Keys,” is this statewide organization. It is managed and staffed by parents.

Since 1987, Keys has offered peer-to-peer support to parents so they can advocate first for their own child, and then for other children. Not only do Keys’ parent staff meet callers’ immediate needs for information, they strive to connect parents to other parents so they can support each other. Keys develops and sustains the network by supporting long-term relationships between Keys and parents, among parents in the network, and between parents and their child’s providers.

With targets and benchmarks to engage parents at their level of experience and interest and to affirm their role as primary decision maker for their child, the Keys Targeted Parent Assistance (TPA) model includes procedures, interventions, and technology-based tracking mechanisms. Developed with support from the American Institutes for Research, TPA provides the system infrastructure to create



and sustain parent connections. With TPA, the parents who have received help and become connected to the network develop into help-givers and sustainers of the network: They hold the keys to networking.

TPA is based on a ten-level continuum that was developed from Dr. Barry Kibel’s Outcome Engineering (Kibel, 1996) and Journey Mapping (Kibel, 2000). The continuum describes the movement of parents toward family and system advocacy. Using the continuum, Keys staff details each parent’s progression from seeking help to emerging as a problem solver to becoming a systems change agent. Figure 1 depicts the continuum’s ten levels of parent engagement and groups them into three stages: *Initiation*, *Solution-Focused*, and *Expanding Interests*.

In the Initiation stage, the three levels are about “getting to know you.” Parents at level 1 call Keys seeking information about what Keys can do for them. Keys staff provide immediate answers to “What do I do know?” questions and offer Keys and local service contact information and emotional support. Parents remain at level 1 until they initiate a second contact. At level 2, parents may say,

“I am interested in more information. Tell me more about exactly what I can do.” Staff limit discussion to the questions asked and encourage parents to attend Keys’ trainings related to their interests. They offer mileage, childcare, lodging, and travel connections with other parents from their geographical area. Connecting families, with their permission, builds relationships and increases the likelihood that new

parents will attend. It sustains the commitment of experienced families and involves them as mentors to new families. Parents move to level 3 when their actions—such as completing training—indicate deepening involvement. The support relationship between Keys and parents at level 3 evolves into exploring larger system and family issues.

At the Solution-Focused stage (levels 4-6), parents work with staff on strategies to improve and monitor planning documents, secure necessary services, and integrate programming. At level 4, parents contact Keys frequently and Keys staff call them to revise Individualized Education Plans, mental health treatment plans, wraparound plans, and other formal service planning efforts. Staff may attend meetings to support the families. At level 5, parents report that some part of the original problem that brought them to Keys is resolved: “My child is back in school,” or “We have attendant care.” At level 6, parents have resolved their initial problem and decide to take on additional areas of concern. Parents at this level may say, “Help me think about how to do this.” During this stage, staff en-

gage parents to expand their skills and self-confidence. Staff members invite them to attend sophisticated trainings on topics such as IDEA legislation and wraparound facilitation.

The Expanding Interests stage (levels 7 through 10) focuses on outreach to others and system issues. This stage begins at level 7 when parents offer to help other families. They may say, "I would like to get involved. How can I help someone else?" or "I don't want what happened to me to happen to anyone else." These words denote expanding interest outside one's own family. Responding quickly to these statements with training and helping opportunities is critical. At level 8, parents complete training to help others. At level 9, parents assist other parents. They call Keys often, not for themselves, but for advice to further their work with others. They are attending meetings, revising plans, and sharing advice with other families. At level 10, parents ask for assignments to work on local and state committees, join boards, testify to legislative bodies, and participate in policy-making efforts. They serve as vocal and effective system advocates, offering testimony in very public forums. They support and organize other parents and sustain the family organization

and state services. They have come full circle, returning the help they got from Keys to other families in a wide variety of ways, facilitated by an organization whose mission is to build a statewide network of informed families.

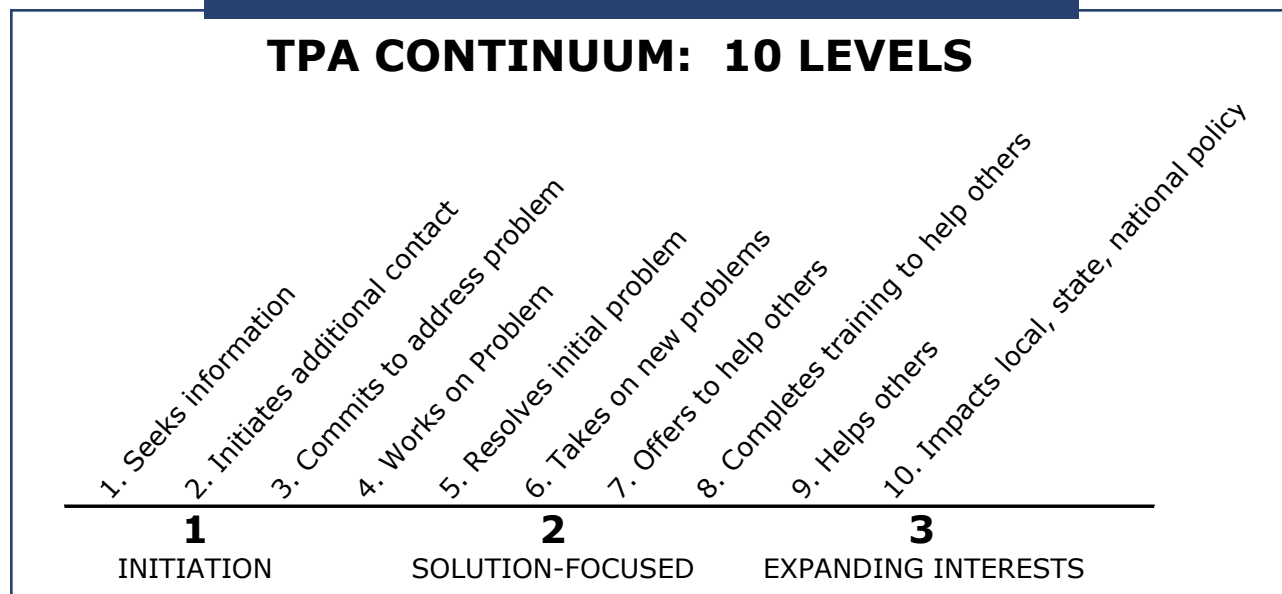
Monitoring individual parents and groups of parents along the TPA continuum, Keys staff members provide information and support appropriate to the parents' readiness level, while also promoting movement to higher levels. TPA marks change increments in parents' engagement with Keys and with service providers and systems. It documents the interventions offered and tracks the usefulness to parents of Keys' suggestions by check-in calls to parents at least monthly that allow staff to ask, "What is working?" When parents do not respond or do not show up at a meeting, staff members examine contact notes to identify problems with Keys' intervention. They may determine that the intervention was sound but was offered at the wrong level of the parents' readiness to use it.

The majority of parents move quickly through the first three levels (averaging 2.5 months per level), slowing when they reach level 4. Levels 4-6 average 4.6 months per level,

and levels 7-10 average 6.3 months per level. Graph 1 (adapted from Cheon & Chamberlain, 2003) shows the average duration of time at each level. Time is an important consideration in building relationships and establishing reasonable expectations when asking parents to deepen their involvement, complete training, attend meetings, advocate for their child, or commit to system change efforts.

The Keys TPA model provides the structure to document process and outcomes. Staff members track the interventions delivered and note which ones move parents forward. Data from a study conducted by the University of Kansas School of Social Welfare (Cheon and Chamberlain, 2003) show that parents move forward over time along the continuum. The data shows that parents who reach higher levels of engagement on the TPA continuum stay active with Keys over longer periods of time than parents scoring at lower levels. Only 26.3% of low-level (1-4) parents maintain contact with Keys for two years, compared to 67.2% of high-level (5-10) parents. Most parents who become inactive do so at level 1 (50.4%). The data shows that only 29% of minority parents remain active after two years compared to 44.5% of Cauca-

FIGURE 1: TPA CONTINUUM



sian parents.

To improve retention and promote depth of engagement, staff must respond quickly at lower levels (1-3) to parents needs with interventions that parents find useful and that are appropriate to parents' concerns and interests. Concerns vary by stage, as do parents' ability to use the information provided. At the Initiation stage (levels 1-3), 30.4% of parents ask about Keys program information, 20.3% have service system concerns (mental health, child welfare, juvenile justice), and 19.8% have specific school issues. They really want to know most what Keys can offer and what service providers should do. At this stage, the most useful intervention is to answer the specific questions asked. With very different interests at the Solution-Focused stage (levels 4-6), the majority of parents want help resolving specific service concerns. At the Expanding Interests stage, 30.3% of parents had questions about Keys' programs and services, 28.9% had no concerns, and 19.7% had service system concerns. In the Expanding Interests stage, parents want Keys to support them to assist other parents, to invite them to serve as spokespersons at events, and

to bring parent voice to boards. Keys staff link these parents to people and programs where they can serve, train them in sophisticated content areas, and encourage them to call when they need help with their own children.

Table 1 (also adapted from Cheon and Chamberlain, 2003) identifies the frequency of Keys' interventions offered by stage. In the Initiation Stage, when most parents call to learn what Keys can do for them, 46.6% of the interventions involve description of Keys' services and an invitation to Keys events. During the Solution-Focused stage, Keys' most frequent interventions are discussing options and following up to make sure issues are resolved. At the Expanding Interests stage, the interventions focus on linking these advanced parents to Keys activities where they can serve as spokespersons and following up to provide them with what they have asked of staff.

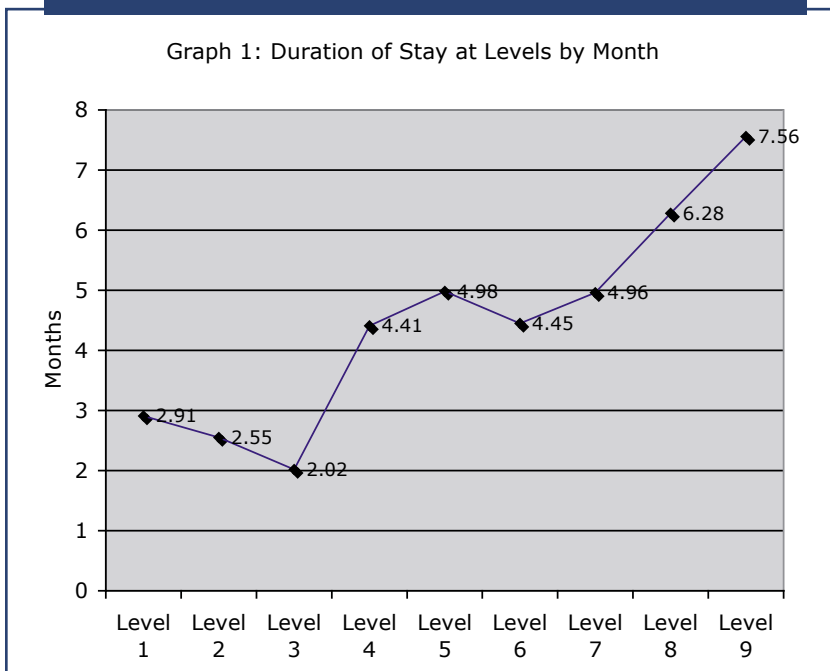
Bobbie's story illustrates the journey of one parent who has benefited from TPA and demonstrates her growth from family crisis to family and systems advocacy. Her testimony shows her commitment to her own children and her drive to learn,

to transfer what she knows to help other families, and to build service pathways across Kansas for families whose children have serious emotional and/or behavioral problems. Her children still have many problems, but her capacity to manage them and relate effectively to the service world has changed dramatically. She is a parent who Keys helped and who now helps Keys and all Kansas families.

My interest in advocacy began six years ago when I met the people at Keys for Networking. Before I knew the Keys staff, I was too afraid to leave my house. I was raising four children on my own. In May 1999, I attended a conference in Topeka. Keys staff held parent information meetings and provided childcare during these meetings. It was at this meeting that I got their phone number. I kept the number almost a year before I called to ask questions about why it was taking so long to get my son's testing done. I talked to Angie, who told me she was a parent of a child with serious emotional problems. She suggested I talk to the IEP team about my concerns. She called me back four days later to ask how I did. I could not believe it. She invited me to a training about my child's school rights. I said yes on the spot. She told me I could attend by phone and would not have to leave home. At that training I connected with other parents whose children had the same problems as mine. I learned that my son was eligible for additional services. I requested additional testing and the school agreed.

The Keys staff started calling me, to check on me, they said. For almost a year, I did not return their calls. They left messages to call if I needed help. In August of 2001, I attended the annual Keys Oscars event. I nominated my son's case manager for an award, which she won. In October 2002, Keys hired me to bring parents to a meeting with the Department of Education about the connection between NCLB [the federal No Child Left Behind Act] and reauthorization of IDEA [the Individuals with Disabilities Education Act]. About this time, my younger son started getting in trouble. I knew what to do. I asked for a special education evaluation and started him on an IEP. I started thinking maybe other parents could use my help. I attended

GRAPH 1: LEVEL ACHIEVEMENT SPEED



wraparound and parent support trainings and then called Keys for direction on how I could help a family get mental health services for their child. In March 2003, Keys called to give me information about legislative issues and encouraged me to talk to senators and representatives if I cared to discuss these topics. They gave me my legislators' names and phone numbers. I was invited to attend Mental Health Advocacy Day at the Capitol. In July of 2003, Keys invited me to serve on their NCLB state advisory council. In May 2004, Dr. Adams called to ask if I would help a family prepare for a wraparound meeting so their child could come home from the hospital. I did. Also, the Governor appointed me to the Mental Health Services Planning Council. At that point, I was feeling pretty connected.

Then in July my daughter tried to commit suicide. I was so overwhelmed I did not know where to turn. Keys staff came to my aid and fast. They kept telling me I was a good mother and that I knew what was best for my child. They said they were behind me all the way. They encouraged me to ask for a 504 Plan to help my daughter succeed in school. In September 2004, I testified at the Capitol, encouraging the legislature to develop policies against school seclusion and restraint. In May 2005, I facilitated a group at the Freedom Commission Goal 4 Summit with over 200 people. I brought my daughter and she participated. Recently, I called for help with my son's IEP and the wording for his behavior plan. The problems with my children don't stop. Most of the time I am able to handle them. I know where to get help when I need it. I am not afraid any more to ask for help. Other parents in my community see me as a resource when they need help. And, through me, they see Keys as a resource when I cannot help them.

Summary

TPA is a reciprocity model. Parents who seek help become help givers. By design, they join a state network of natural and professional supports that

TABLE 1: INTERVENTIONS OFFERED BY STAGE [MOST FREQUENT HIGHLIGHTED]

Interventions	Initiation	Solution-Focused	Expanding Interests	Total
Provide Information	6.8%	12.4%	14.3%	10.9%
Discuss options	13.2%	22.9%	15.6%	19.2%
Follow up issues	18.3%	35.0%	37.7%	30.2%
Refer to others	7.3%	7.7%	2.6%	7.0%
Provide advocacy & action	7.0%	9.1%	6.5%	8.4%
Describe and/or invite to Keys programs/events	46.6%	12.9%	23.4%	24.2%

benefits them and allows them to give back what they learn. TPA provides opportunities for parents to affiliate with a large body of Kansas parents who represent the 70,000 children (10% of Kansas' youth population) whom the Kansas State Department of Social and Rehabilitation Services estimates have serious emotional disturbance. They see that they are not alone. As parents grow in their self-advocacy abilities, they also experience a renewed (and in some cases new) sense of self-worth and capacity to help others. When parents take the step of offering to assist and advocate for other families with Keys' support, their sense of belonging and feelings of reciprocal services to Keys and to the community of parents is strengthened. Parents who experience success in helping other families recognize the magnitude of need on a system-wide level and are welcomed to the network of parent advocates through trainings and meetings, and they are given other opportunities to speak for children and families in policy-making activities.

References

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Jane Adams is Executive Director of Keys for Networking, the statewide organization of the Federation of Families for Children's Mental Health. Dr. Adams represented the child family consumer voice on the President's New Freedom Commission on Mental Health, 2003.

Elizabeth Westmoreland analyzes Keys' monthly TPA records and reviews them for progress and success/failure of interventions offered. Her adult sister and brother and her mother have chronic mental illnesses.

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