

AGENCY READINESS TO EMPLOY PARENT SUPPORT PROVIDERS

This brief reviews the steps an agency might take in preparation for beginning a parent-to-parent program and hiring Parent Support Providers. As part of the steps, the agency readiness includes developing a structure for the on-going support, supervision and evaluation of the program.

GETTING STARTED WITH A PLAN

The first step in the preparation for beginning a program employing Parent Support Providers¹ is to decide on the scope of the program:

Identify the goal. Parent Support Providers can be utilized in many ways, for example, as one-to-one support for parents and family members, group support, seminar or instructional leaders, team members and change agents as part of another agency and change agents as part of systems level advocacy. The goal selected can be as broad as a child's access to a continuum of care without having to leave the state or as narrow as a specific segment of care, such as engagement with the XYZ community mental health center programs.

Establish a guiding team. Form a small guiding team of 4 to 6 people who are committed, enthusiastic, and organized family members, professionals and/or current staff/board members to serve as champions. They will serve as the primary communicators for developing or expanding the parent support program and transformation process. The guiding team will likely need to meet initially for 4-8 hours to draft the outline of the plan.

Develop the outline of a plan. The guiding team needs to decide on the primary goal of the program. Agreeing on the goal will help determine what other partners or technical assistance may be needed to implement the plan. While it may not be self-evident at first, people interested in helping individual families may not be interested in embarking on system level change of children's mental health services delivery. Anticipating problems and developing strategies for these two tasks will require different skills and experiences.

Establish a coordinator or "go to" person for the team. Someone needs to be charged with coordinating and communicating information to all involved in the Parent Support Provider program. The person who coordinates and communicates internally must be someone who can adhere to a timeline, ensures that everyone follows through with their tasks and most importantly remains enthusiastically articulate about the end product. The "cheerleader" portion of this role is critical since many good ideas just end up being stymied by little barriers or inertia.

DEVELOPING THE PLAN

The first concrete step in developing the plan is ensuring there is agreement about the value and use of the definition of family-driven care and youth-guided care. The guiding team members must be absolutely clear about the benefits of parents of children to 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.

¹A Parent Support Provider is a peer of the parent that is being supported. Their relationship is based on the sharing of "lived experience." The Parent Support Provider is a person who is parenting or has parented a child experiencing mental, emotional or behavioral health disorders and can articulate the understanding of their experience with another parent or family member. This person may be a birth parent, adoptive parent, family member standing in for an absent parent or a person chosen by the family or youth to have the role of parent.



Reaching an agreement on the value of parents' involvement will lay the foundation for the acceptance of the involvement of the child until, as a youth, s/he becomes progressively a primary decision-maker in his or her own care and the policies and procedures governing the care.

The second step in developing the plan is to review the "current state" performance. The guiding team is in the best position to begin to identify what is working and what is not working for parents of children/youth with emotional, behavioral (including substance use) or mental health challenges. A useful prompt, "My (son or daughter) is getting what (he/she) needs because we have XYZ" or "I wish we had had access to XYZ when my (son or daughter) needed it." In other words, consider the current state of children's mental health services performance through the eyes of the parent and family members. If the group does not have enough day to day experience, consider doing a focus group with a handful of parents, youth or case managers to develop a care experience flow map (how family members practically access services and any barriers they encounter). You may also find it beneficial to have a candid interview with the community mental health director or mental health program manager for the state or local government about how services can be improved for children and youth. The idea is to assess this information with an eye toward identifying opportunities for improvement.

If you are planning in a large community, develop and empower a working group. Members of the guiding team should invite individuals to serve on a working group to transform care. Caregivers and administrators should be picked from each segment of the continuum of care to serve on the working group. Working group members may number between 10 and 40 caregivers and include physicians (including psychiatrists), psychologists (including those from the school), clinicians from residential and outpatients services, private therapists and managed care organization staff, care coordinators or case managers, social workers from the child protection and juvenile justice systems, after hours crisis team member, social service providers and administrators, head start or day care providers, and do not forget parents of children and youth with emotional, behavioral

(including substance use) and mental health challenges. Invite a few outspoken people who pride themselves at "saying it like it is." The mental health program manager or administrator involved in planning or evaluating children's mental health services should also be invited to join in. It is essential for working group members to come from a cross section of the community. At this point, members of the guiding team become part of the larger working group and may handle the note keeping and coordinating function for the group.

If you are planning in a small or isolated community, develop and empower a working group by adding a few key people to the guiding team. The people invited to join the guiding team should be a balance of people who will need to "buy in" to the program and supporters, similarly to the working group in a larger community.

Create a shared vision. The working group should first create a shared vision. This can be accomplished by writing a story of the ideal continuum of care for children and their families and then comparing the ideal with the reality; if the real and the ideal are not the same, focus in on what will need to be done with children, youth and their parents to make the real and the ideal align. This will help to identify the tasks that can be assigned to Parent Support Providers, either at the individual family level or the system level.

Review the definition of family-driven care and youth-guided care. The working group members need to be proponents for the principle and practice that family members parenting a child with emotional, behavioral (including substance use) or mental health challenges have the 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. Reaching an agreement on the value of parents' and family member involvement will ease the way to the acceptance of the involvement of the child until, as a youth, s/he becomes progressively the primary decision-maker in his or her own care and the policies and procedures governing the care.



Without an agreement, designing this program should slow since it will be necessary for the working group to review the research and publications on the benefits and outcomes of family-driven and youth-guided approach to care.

Identify the details of how Parent Support Providers can fill the gaps identified. Identify potential improvement projects by comparing the "current state" of care with the ideal experience; prioritize these projects based on children's and family's needs and feedback. Be sure to keep separate the activities that assist individual family members from those that are systems changes. This will make it easier to track the progress.

KEY ELEMENTS OF THE PLAN

Structure and location. Implementation of Parent Support Provider services involves making decisions about the source of the personnel support, training and supervision, and the location and placement of the Parent Support Providers. Location or placement of the Parent Support Provider is likely to impact their ability to teach family members how to advocate for themselves without censure as to its use, teach advocate across more than one agency or funding source, provide complete and unbiased information about the family's choices, and the availability or duration of the services. The source of the on-going training and supervision may also influence the availability or structure of the peer to peer supervision and clinical supervision. While there is little published research on the long-term effects of these decisions, there needs to be concern and thought given to them when designing the program. There are four basic models for the structure and location of Parent Support Provider services:

- Personnel and services located and provided by a family-run organization and available broadly in the community.
- Personnel and services provided by a family-run organization and available through a contract to a community-based organization, such as, out-patient community behavioral health center, residential treatment services, school, pediatrician office, or a community center.

- A community-based organization employs Parent Support Providers and contracts with a family-run organization to provide peer-to-peer supervision and training.
- A community-based organization employs Parent Support Providers in a department devoted solely to parent or peer support, with its own Parent Support Providers supervisors, training staff, and advisory board/committee.

Key elements in the implementation of the philosophical structure of the Parent Support Provider services. The elements to consider in planning the structure of Parent Support Providers services are:

- Initial contacts that can be done over the phone and do not involve taking a lengthy history
- Initial contacts that solve some part of the identified problem or provide some of the information the parent is calling about. The initial contact should have an end product in which the caller feels some relief or resolve
- Parent Support Providers should be able to identify themselves in that first conversation as a parent of child with emotional, behavioral (including substance use) or mental health challenges.
- Parents should be able to receive information about possible resources over the telephone, by e-mail or be met at their home or at a time and location where they normally transport their child without having to make a trip to an office or other location.
- Parents do not need to agree to a use a specific service before or as a condition to having access to a Parent Support Provider.
- Parents do not need to agree to a specific number of meetings, tasks, or goals as a condition to having access to a Parent Support Provider
- Parents set their own goals



- Parent Support Providers should be able to assist a parent with issues or concerns that effect more than one agency or more than one funding source, such as, completing a public housing application form, preparing or attending an IEP meeting and choosing to receive therapeutic services from more than one agency

These are the key elements because their presence in the structure of the program allows the Parent Support Provider to utilize the lessons learned from their lived experience of parenting, offer hope and support, and have the flexibility to be complementary with the parent based on that parent's need and tempo. When evaluating the four models for implementing these elements, it is evident that each of the four models creates its own advantages and difficulties.

Key elements in the implementation of the placement or location of the Parent Support Provider services. Location has two components: physical location and administrative component of the agency.

Physical location is the easiest to address: the place must be accessible at the time the parent can get there. The physical location needs to be totally accessible since a wheelchair, stroller or someone with mobility concerns may need to use the room, chairs, writing surface, baby changing area, telephone and restroom. Lastly, the physical location should also have a "child friendly" area or child care so the parent can interact with the Parent Support Provider without simultaneously needing to care for babies, children or youth who also came with the parent. It is also possible that the actual physical location may be moot, if Parent Support Services, other than support groups or classes, will be provided in the parent's home or anywhere in the community. Some of the better public locations for individual meetings are social gathering spots with internet access, such as, coffee shops, community centers, and the parent's own place of worship.

To adequately assess the organizational placement, the administrative readiness can be addressed through the following questions:

- Do the organization's vision, mission and philosophy of care statements reflect the principles of family-driven care and youth guided?
- Does the organization promote professional-family partnerships with the parents of the children it serves?
- Does the organization promote professional partnership with Parent Support Providers or use of the family-run organization for the parents of the children it serves?
- Has the definition and application of quality and philosophy of family-driven and youth guided care been communicated clearly throughout the organization?
- Does the organization staff's language and actions communicate that parents know their own children better than professionals and want to do what is best for their children?
- Do the organization's leaders model collaboration with children and youth and their families?
- Are the organization's policies, programs and staff practices consistent with a family-driven and youth-guided approach?
- Are family members encouraged to review their records and work with staff to correct inaccuracies?
- Are professionals committed to providing practical information to parents and youth in order for them to give informed consent about treatment and alternatives?

Before beginning a placement of a Parent Support Provider or beginning a program with Parent Support Providers, the following questions need to be discussed with the entire team that will interact with the families and the Parent Support Providers. This discussion is most beneficial if all team members are present, including the staff from accounting, billing, medical records, physicians, janitorial, and so on.

- Do I believe that children, youth and their parents bring unique perspectives and expertise to the clinical relationship?
- Do I encourage children, youth and their parents to speak freely?



- Do I listen respectfully to the opinions of children, youth and their parents?
- Do I encourage children, youth and their parents to participate in decision-making about the planning and evaluation of care?
- Do I encourage children, youth and their parents to be active partners in assuring the safety and quality of their own care?

When the Parent Support Provider is out-stationed, embedded in another agency or there is a separate department for Parent Support Providers in a non-family-run organization, the following issues must be addressed:

Parent Support Providers often utilize the same services for their own children that are used by the parents they are helping. This raises a number of logistical concerns. These concerns are generally procedural and often have already been discussed and resolved in relationship to other staff members.

- How can the privacy of the children, youth and other family members of the Parent Support Provider be protected?
- Will the Parent Support Provider with a behavioral health challenge be treated similarly than a clinician who also has behavioral health challenges?
- Can I socialize with a Parent Support Provider as I would another colleague since they, their child, or their family member might be or become a client of the agency?

Parent Support Providers come from all types of backgrounds. They have common competencies and experiences as parents. Some have very minimal formal education but some have extensive experience in coordinating services and some also have advanced degrees. Some have their own emotional, behavioral (including substance use) or mental health challenges. This results in conflicts that are predictable and often are fear-generated. There is benefit in addressing these questions directly before the program begins.

- Will they have a relapse?

- Will they keep information confidential?
- Will they have the same access to information as clinical staff or other team members?
- Will they respect professional and personal boundaries with me?
- How will they handle professional and personal boundaries with our mutual clients?
- Will they change the way I work?
- Will they take my job?
- How am I expected to treat them? Are they a client or a colleague? Do I socialize with them?

In designing the program to address system-level advocacy or transformation of policies, procedures and evaluation of programs, the preparation is different than in setting a program for individual or group support. Involvement with groups or committees whose task is to plan or evaluate are by definition not of “one mind” and may often have divergent ideas about solutions. The focus of the preparation is organizing the background information and coaching the Parent Support Provider how to respond rather than priming the organization to accept or add a new service. The following questions will need to be addressed by the supervisor or mentor of the Parent Support Provider who will be doing policy or system level work:

- Are there orientation or education programs to prepare the committee members or attendees (legislators, administrators, clinical staff, paraprofessional staff, physicians, students, and family members) about family-driven and youth-guided wellness oriented practice and collaboration with children, youth, parents and Parent Support Providers?
- Do committee members let colleagues know that they value the insights of families?
- Do committee members believe that families can play an important role in improving quality within organizations?
- Do committee members believe in the importance of family participation in planning and decision-making at programs and policy level?
- Do committee members believe that families bring a perspective to a project that no one else can provide?



- Do committee members believe that family members can look beyond their own experiences and issues?
- Do committee members believe that the perspectives and opinions of families and providers are equally valid in planning and decision-making at the program and policy level?

Parent Support Providers working with families as advisors and/or preparing themselves to be members of policy committees, should answer and discuss these additional questions:

- Do I understand what is required and expected of families who serve as advisors and/or members of committee members?
- How do I set clear goals for their roles or myself?
- Am I prepared to advocate a position in a win-win manner?
- Do I feel comfortable mentoring family members to address policy or transformation issues?
- How do we prepare for a family member to take time off from their responsibilities on these committees because of an illness or other family demands?
- How do we plan for, debrief from and distribute information about these meetings?

IMPLEMENTATION OF PLAN

Once the goals are identified, the steps for providing individual parent-to-parent support in the family-run organization are as follows:

- Put in place a training curriculum which includes
 - Initial training on all domains of competencies before beginning to speak with families
 - On-going weekly training needs to increase competencies and continue focus on wellness and empowerment
- Develop a supervision schedule which includes

- Weekly peer-to-peer review of how the Parent Support Provider is supporting family members
- Monthly clinical review of issues the Parent Support Provider is encountering
- Develop an outcome data base² that at minimum addresses
 - Type (phone, in person etc), location (parent's home, office etc), and duration (travel, contact and note writing time) of contact with the parent and family members
 - Subject matter (emergency housing, IEP, medication, etc) and methodology (support, coaching, etc) of the contact
 - Resources used (WebMD, DSMIVR, etc) or connections (parent support group, intake at CMHC, etc)
 - Demographics about family (age and sex of siblings, address, etc)
 - Demographics base for later outcomes (child in school, # of past hospitalizations, etc)
 - Other indicators regarding effectiveness of the Parent Support Provider work (empowerment measure, parenting stress level, etc)
- Ensure that there is appropriate administrative support, such as, liability insurance; six months of cash flow for personnel costs; electronic communication and IT equipment and support; HIPAA and other electronic confidentiality, and other compliance; system for grievances; and
- Develop an outreach or referral mechanism for the new Parent Support Provider. In many locales, just announcing the availability will provide enough requests for assistance. In areas unfamiliar with the service, the Guiding Team or Working Group should be prepared to reach out to schools, churches, health and social services agencies and community groups.

² The content of a functional data base is the subject of another brief.



To implement the parent-to-parent support service as a stand-alone department in a non-family-run organization, the organization will also need to

- Identify ten to twelve individuals to become the advisory group or committee to the program. These individuals should be parents who have utilized Parent Support Provider services or wish they had had access to them.
- Develop a contract with a family-run organization or other agency that has operated a Parent Support Provider program to provide supervisory and training services until the department can be self-reliant.
- Develop a reciprocal communication mechanism with the family-run organization to ensure there is a safety-net or secondary referral for parents and connection with the broader field of parent-to-parent and peer-to-peer support.

To implement a contracted or imbedded Parent Support Provider program in an organization, like a community mental health center or pediatrician office or residential treatment facility,

- Contact a family-run organization that has contracted their Parent Support Provider services. Some statewide family networks have years of experience, such as, Association for Children's Mental Health in East Lansing, Michigan, Families Together in Albany, New York, UPLIFT in Cheyenne, Wyoming and Oregon Family Support Network in Maryhurst, Oregon.
- Develop an internal hourly pricing structure that includes recruiting, training, supervising, data collection, IT support, insurance, transportation, time spent coordinating with the contracted agency, and time spent preparing and being with the family member. Most agencies do not find it possible to recoup total cost of the service from a third party payer such as Medicaid or private insurance. Normally, up to 75% of the actual cost is supported by grants or donations.

Once the goals are identified for system-level advocacy or transformation policies, the steps for implementing the Parent Support Provider program are as follows:

- Begin a contact list of parents, behavioral health professionals, community members interested in children's mental health, legislators and policy-makers. This list will be updated regularly. The list should include the name, address, phone, e-communication contact and the subject matter or reason for their interest, for example, daughter's friend, special education teacher, board member of XYZ organization, etc.
- Develop an input mechanism to ensure the advocacy and representations made by the Parent Support Provider program represent both broad opinions without impinging on the needs of some families. Some programs use Survey Monkey, Twitter or telephone polls to gather information.
- Develop a reporting mechanism to disseminate information, for example, an electronic newsletter or phone tree.
- Develop a database for tracking the time, effort, and results of the advocacy. This should include, at minimum, the
 - Number and types of contacts with advocacy groups or individuals
 - Number and type of contacts with groups or individuals who are the object of the transformation
 - Dates and description of modification to the policy
 - Number of people or costs effected by this policy

ACHIEVING THE GOALS OF THE PLAN

Developing a good plan and implementing it is the first part of readiness. Unless there is a goal to start the process over after the subsequent administrative or personnel turnover, the final part of readiness is to develop the plan for permanency.

- Identify the successes and improvements of the work by Parent Support Providers



- Publicize the successes as improvements made as part of the team effort
- Use the working group to highlight the connection between Parent Support Providers and the successes
- Promote the successes as part of a short and well articulated vision statement
- Develop new champions and leaders for continuing implementation of the vision
- Publish the effort and result through mailing lists, in the newspapers, on radio and television and in professional journals

THE RESULT

Parent Support Providers are change agents: they empower individuals by supporting and coaching them to be more empowered. The result is that parents and family member develop their own “voice” and advocate better for the needs of their children. Professionals are empowered to work collaboratively with family members thereby achieving better outcomes for children. Policy makers utilize the information and energy leveraged by the Parent Support Providers to develop and implement policies and programs that best fit the needs of children with emotional, behavioral (including substance use) and mental health challenges.

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