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Developing a family engagement training strategy

Phase 1 Final Report

October 2011

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS 3
OVERVIEW 4
OBJECTIVES 5
METHOD 5
LITERATURE REVIEW 5
ENVIRONMENTAL SCAN 6
DEFINITIONS: WHAT DO WE MEAN BY FAMILY ENGAGEMENT? 7
KEY INGREDIENTS OF A FAMILY ENGAGEMENT TRAINING PROGRAM 9
WHY IS FAMILY ENGAGEMENT IMPORTANT? 9
PRINCIPLES OF FAMILY ENGAGEMENT – USING A FAMILY CENTRED MODEL 10
ROLE AND PRACTICE STANDARDS 12
ORGANIZATIONAL COMMITMENT AND READINESS 14
INVOLVING FAMILIES IN THE DESIGN, DELIVERY AND EVALUATION OF TRAINING 15
OVERVIEW OF BARRIERS AND FACILITATORS OF FAMILY ENGAGEMENT 16
Diverse backgrounds of service providers and settings 17
Lack of perceived “fit” between training and real life 17
Cultural competency 19
The importance of relationships – A sense of collaboration 19
Architectural design 21
STRENGTHS, WEAKNESSES, OPPORTUNITIES, THREATS (SWOT) ANALYSIS 22
PROMISING MODELS 24
INVOLVING FAMILIES ACROSS MENTAL HEALTH CARE 24
HIGHLIGHTS OF EXISTING TRAINING 28
SETTING THE STAGE FOR EVIDENCE-INFORMED TRAINING IN COMMUNITY-BASED ORGANIZATIONS 31
SUMMARY – KEY COMPONENTS OF A FAMILY ENGAGEMENT TRAINING PROGRAM 36
RECOMMENDATIONS AND NEXT STEPS 38
REFERENCES 40
APPENDIX A – HEADINGS IN ENVIRONMENTAL SCAN 43
APPENDIX B – SUMMARY OF QUESTIONS ON E-MAIL SURVEY 44
APPENDIX C – E-MAIL SURVEY: HIGHLIGHTS OF FEEDBACK 50

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OVERVIEW

> *"Parents feel that they know best for their children, and as much as we appreciate care sometimes we feel that we are not being heard at all." – Parent*

Family engagement in community child and youth mental health services is increasingly accepted as a best practice for providing quality service and support (Chovil, 2009). Despite the acknowledged importance of family engagement, community mental health organizations vary in the implementation of training for front-line service providers to more effectively engage families. The Ontario Centre of Excellence for Child and Youth Mental Health (the Centre) has a six-year mandate to deliver programs and activities designed to foster the sharing and use of knowledge in the daily practice of front-line service providers. In an effort to build capacity among stakeholders and provide evidence-informed services and tools the Centre is exploring ways to develop a comprehensive strategy and training approach to family engagement.

This report is the final deliverable in the Family Engagement Training Strategy Development: Environmental Scan (Phase 1) project undertaken to assist the Centre in the collection of information and strategies as the family engagement training strategy is developed. Specifically, a literature review was conducted, working definitions and models in the area of family engagement were explored through both the literature review and discussions with the family engagement steering committee, both parent and service provider key informants were contacted for interviews, and a set of recommendations for the development of parent/family engagement training and tools for service providers working in the child and youth mental health was developed.

OBJECTIVES

The current report is a summary of information gathered during Phase 1 of the family engagement training strategy project. The objectives for the current report are to:

1. Provide a summary of key ingredients of and considerations for a family engagement training program for front-line service providers

2. Outline working definitions for relevant terms that will form the basis of shared communication around family engagement

3. Provide examples of models, tools and resources to include in a training toolkit

METHOD

Triangulation, or the use of multiple methods and sources of information, was employed in Phase 1 of the family engagement training strategy project. Processes and consultations that use only one method and/or source are more vulnerable to errors or omissions while consultations that use multiple methods for gathering data and information provide cross-data validity checks and ensure the voice of all stakeholders can be heard. When possible, a participatory approach was employed to ensure that the best information was gathered from the best experts, those that provide or use the services. The following methods for gathering information were employed in Phase 1:

LITERATURE REVIEW

Relevant literature that was published primarily since 2005 was reviewed and summarized. When relevant articles that were published prior to 2005 were mentioned in the literature they were also retrieved and reviewed if they contributed to the topics discussed. A literature search was conducted through PsychInfo and Sociofile using relevant search terms such as “family engagement, family involvement, family focused, family centred, mental health, mental illness, psychiatric disability, children and youth.” More than 2000 articles were returned in the search and were then sorted based on relevance leaving approximately 90 articles for review. Though the focus was on Canadian and North American literature, international research was also examined. Due to the short timeline for this review,

an exhaustive search was not conducted and the review captured only a snapshot of available literature. A number of relevant articles may have been missed since the search was limited to literature published since 2005. This paper will outline relevant definitions, models and key themes surrounding engaging/involving families in child and youth mental health care.

ENVIRONMENTAL SCAN

An environmental scan is the acquisition and use of information about events, trends and relationships in an organization's external environment (Choo, 1999). Organizations can then use this information to assist in planning a future course of action. In addition to the literature review, the environmental scan conducted for Phase 1 included:

Web Search

Key terms similar to those used in the literature review were employed in major search engines to find organizations, experts and existing training opportunities and resources related to training front-line service providers in family engagement. Relevant information was recorded in two main spreadsheets (see Addendum 1). The first spreadsheet captures relevant training opportunities that exist, while the second captures relevant organizations, websites and area experts related to family engagement (Appendix A shows headings used in each spreadsheet). In many cases contact was made with organizations or experts and additional information or resources were requested. When possible, links to courses, resources or information are included in the spreadsheets. Hardcopies of documents were also maintained.

Key Informant Interviews

The Phase 1 steering committee, in consultation with project managers, identified six to 10 family members and front-line service providers to contact and ask questions specific to family engagement, existing training, facilitators and barriers. Six family members and six service providers were contacted and provided feedback to be included in this report. When possible, telephone interviews were conducted to gather information; however, scheduling difficulties and the comfort level of some families meant that information was gathered through e-mail when necessary. Additional experts identified through the environmental scan were contacted, and information was included in both the spreadsheets and this report.

E-mail Survey

In order to capture information from the largest number of families possible in a short timeframe, a brief feedback form was developed whereby questions related to service preferences, barriers and facilitators (see Appendix B) could be sent out in an e-mail link to families of children and youth using community mental health services. Questions on the feedback form were developed in conjunction with the Centre and reviewed by the steering committee. The form was then developed in SurveyMonkey and a link was sent to steering committee members who were in turn asked to circulate the link to families they knew. A total of 40 responses were received in just over four days of gathering feedback. Highlights of responses are shared throughout this report, while additional results are shared in Appendix C.

DEFINITIONS: WHAT DO WE MEAN BY FAMILY ENGAGEMENT?

One of the most challenging aspects of family engagement training is the varying methods and definitions used to describe what exactly is meant by family engagement. For example, the web search and literature review uncovered many different definitions of family and some sectors appear to switch the terms "involvement" and "engagement". In addition, families point out that what service providers perceive as engaging, and what families *experience* as *meaningful engagement* can be two completely different things. Finding a common language to discuss family engagement was an objective of Phase 1, and is essential to contributing to a positive discourse and shared understanding.

The following working definitions were developed after reviewing several different definitions gathered through the literature review and environmental scan. These definitions were then taken forward to the steering committee, where they were revised to meet common understanding and the objectives of this study.

> FAMILY: A circle of care and support offering enduring commitment to care for one another related either biologically, emotionally or legally and takes into account those who the "client" identifies as significant to his/her well-being.

FAMILY CENTRED is a philosophy and evidence-informed approach to practice focused on meeting the needs of both clients and families (family as defined) where the family is seen as a primary component and unit of attention. Family centred care is based on the following principles:

- Recognition that families are experts in the needs of their loved ones
- Practices that promote equal partnerships between family members, service providers and the client
- Supports the family's role in decision making and contributions to ongoing care and planning for the client

FAMILY INVOLVEMENT: Families are involved when they support and participate in their child's mental health care, create home environments that support the child and collaborate with the broader community to provide resources/services to help community mental health agencies succeed.

FAMILY ENGAGEMENT: The term "engagement" implies a more active partnership between families and service providers. For service providers, this means listening to what families think, engaging them in two-way communication and involving them as essential allies in decision making so that their involvement is meaningful and having a purpose. Effective family engagement requires the service provider to develop a relationship-building process focused on listening.

Steib (2004) provides a helpful distinction between family involvement and family engagement:

> *"Engagement is often synonymous with involvement. Involvement of families in child welfare services is important, but real engagement goes beyond that. Families can be involved and compliant without being engaged. Engagement is about motivating and empowering families to recognize their own needs, strengths, and resources and to take an active role in changing things for the better. Engagement is what keeps families working in the long and sometimes slow process of positive change". (Steib 2004)*

DIVERSITY: Diversity is a commitment to inclusion that recognizes and appreciates the variety of characteristics that make individuals unique in an atmosphere that promotes and celebrates individual and collective achievement. Examples of these characteristics are: age, cognitive style, culture, disability (mental, learning, physical), economic background, education, ethnicity, gender identity, geographic background, language(s) spoken, marital/partnered status, physical appearance, political affiliation, race, religious beliefs and sexual orientation.

CULTURAL COMPETENCE: Cultural competence refers to the ability to interact effectively with diversity. Cultural competency refers to an awareness of one's own worldview of characteristics of diversity, and potential limitations of that worldview. It refers to one's attitude towards differences, knowledge of different practices and worldviews, and cross-cultural skills.

Key informant interviews with both families and front-line service providers confirmed that family engagement terminology can be confusing, and several requested clarification on "what do you consider engagement". Families were especially adamant that engagement must be meaningful from the family's point of view. Moving forward, it will be important to include a mental health literacy component to a training strategy for front-line service providers.

KEY INGREDIENTS OF A FAMILY ENGAGEMENT TRAINING PROGRAM

Based on all information gathered throughout Phase 1, several key ingredients of a family engagement training program emerged. This report outlines both topics for content in the final report and considerations for planning. These components have been summarized below.

WHY IS FAMILY ENGAGEMENT IMPORTANT?

In any training program, it is important to outline exactly *why* the training is important. "The Importance of Family Engagement" could be a component included in a training program for front-line service providers. This section would be grounded in the literature and could outline how the involvement of families can be related to successful treatment outcomes (Hoagwood, 2005), and could include studies that demonstrate that engagement interventions implemented during first contact with youth and families boosts service

use (McKay et al., 2004). When there is a match between the family's preference for service and service they actually receive, families have longer involvement in service (Bannon & MacKay, 2005).

This section in a family engagement training program should also include evidence from the family's perspective on why family engagement is important. Throughout the literature review, key informant interviews and the e-mail survey, families expressed that they felt more engaged and supported when considered a part of the decisions, were treated with respect, and felt involved in their child's care. This would be an opportunity for family members to participate as co-trainers to provide a family perspective and help the literature to come to life.

PRINCIPLES OF FAMILY ENGAGEMENT – USING A FAMILY CENTRED MODEL

Family engagement is a multifaceted construct, made up of key elements and principles that work together to promote ongoing partnerships between families and service providers. Over time, there has been a transition in understanding and practice from a traditional service model (professional-as-expert model) to a family model of care (family-as-full-partner model) in mental health. True family engagement that is meaningful to the family and considers the family the expert on their child/youth is part of a family centred model of care.

A family engagement training strategy would not be complete without a discussion about the traditional model of care, as compared with family centred models. When families were asked through the e-mail survey or key informant interviews for examples of actions or events that have *hindered* engagement, they clearly cited examples that fell into the traditional model, while examples of things that facilitated engagement most often fit into the family centred model. Though most service providers and organizations may consider themselves family centred, it is possible that they continue to practice many aspects of the traditional model.

The table below outlines differences between the two models.

Traditional model of care vs. Family centred model of care

Traditional	Family Centred
Focus is on the child as the recipient of care and resource for change.	Whole family is the client and resource for change. Child's needs are considered within an ecological framework where family is central in the life of the child/youth.
Professionals are trained to fix the problems in the child and placed in the role of being an expert. Professionals direct care.	Families are the experts on their child/youth. Families are in control of the service delivery process with professionals serving as an agent.
Concentration on pathology or deficits. Families often viewed as the source of problems or an obstacle to the child's growth, or as irrelevant to the intervention process.	Families' strengths, capabilities, resiliency and skill building are emphasized. Families are viewed as partners in the child/youth's recovery.
No supports automatically provided to the family.	Families are supported in their caregiver role and in dealing with the impact that mental health issues has had on their family.
Families may or may not be involved in treatment planning and services provided. Involvement with families may be avoided or minimized according to professional's goals.	Professionals maintain friendly and respectful working relationships focused on collaboration.
Treatment needs of the child and family are assessed by the expert and goals are established according to "problems" presented.	Treatment needs are determined based on family choice and decision making. The family is the director and consumer of the service delivery process.
Families are passive recipients of services that professionals decide should be given to the family.	Families are active in all aspects in service and involved in decisions of care.
Evaluations of services or programs are often not conducted. When completed, evaluation of services/programs and monitoring of quality are based on the needs and function of the agency. Outcomes are based on re-education of symptoms or cost savings.	Families assist in the development and evaluation of service. Outcomes are measured through enhanced of family management and quality of life. Families determine what their needs are, and goals are established in accordance with outcomes they determine important.
Policies, practices and procedures are set by professional committees and advisors.	Families are involved as partners in decision making at all levels of the system.

Adapted from Chovil, N. (April, 2009). Engaging families in child and youth mental health: A review of best, emerging and promising practices. The F.O.R.C.E. Society for Kids' Mental Health.

A report by the Centres for Addiction and Mental Health (CAMH) (2004) summarized key principles of family centred care:

- Families and clients are treated with dignity and respect
- Open communication with families and clients
- Building on strengths of clients and families and fostering partnerships with them
- Collaboration with clients and families in making treatment, programming, and programming decisions (including designing, monitoring, and evaluating services)
- Viewing clients and family members as individuals, as well as members of both families and their community
- Regarding families as a key source of information about relatives' and their own needs
- Tailoring services to fit the family's' needs and preferences, including appropriate services for culture and traditions
- Recognizing that views on illness and substance use may vary within and between families

These principles of care should found the basis for any training program for front-line service providers working with families.

Don't assume you know better than the person living with the child, and don't judge the caregiver who is also needing to be supported so that they can better support their child. Take the time and listen so that you can support better."
- Parent

ROLE AND PRACTICE STANDARDS

When considering practice standards that improve the quality of family involvement in community mental health settings, Lakeman (2008) argues for the importance of clearly articulating guidelines that can improve family participation and has outlined practice standards in the areas of:

- Family/carer rights and responsibilities in sharing and exchanging information
- Principles
- Quality assurance standards of the mental health service
- Community treatment

Other examples of standards of engagement can be found in policy, such as in the Children and Family Service programs in Idaho. These standards outline practices that aim to achieve statewide consistency in all programs and outline roles for the department of Children and Family Services, agencies/organizations, service providers, and service providers (Idaho Child Welfare Research and Training Centre, 2005).

List of "Do's" and "Don'ts" for Front-line Service Providers

After reviewing information from Phase 1, a summary of "Do's" and "Don'ts" for front-line service providers has been developed. The language used reflects the language of families with children who use child and youth mental health services.

Do's and Don'ts for front-line service providers from the voice of families

Do	Don't
Have understanding and compassion. We need you to understand the stress that we may be dealing with, or the uncertainty that we are faced with.	Blame our child's difficulties on our lack of parenting skills or make assumptions about home situations based on stigma or prejudice.
Recognize that we as families are "experts" in our child's care. No one knows our children as well as we do.	Assume that because you have education and training in mental health that you know best for our child.
Ask families how things are going at home, or how things have been going over the past few weeks. We may be able to share some important additional context that is important to our child's care that they might not otherwise share.	Shut us out of the process. Sometimes we need to be able to add information to what our child is telling you.
Act as an advocate for us. Often, we don't know where to turn, or even what services are available. We need your help to navigate the system, and to find the proper supports for our child.	Tell us that "our organization doesn't offer that" and turn us away, or stop looking for solutions.
Have and promote hope for our child.	Dwell on the worst case scenario, or make it seem unlikely that our child will be able to contribute to their community.
Recognize that you as a service provider and we, as a family, may have very different ideas culturally about mental health and treatment. We need to work together to find options that fit with the worldview of our family.	Offer culturally incompatible opportunities or treatment and wonder why we aren't engaged.
Follow through on what you say you are going to do. We depend on you keeping your appointments, making those phone calls or following through on those next steps.	Change appointments, neglect to call us when you say you are going to or neglect to call other agencies/professionals when those were part of our next steps. We are quickly turned off when we feel neglected or ignored.
Be patient.	Push to meet a preconceived timeline of therapy.

Do	Don't
Look at our work together as an equal partnership. Listen to our needs, goals and desires, and work to achieve them together.	Make decisions without us, or assume you know what's best. Don't discount our experiences and the benefits they can offer.
Recognize the uniqueness of each child, and each family.	Assume that we need the same things as other families. We may have different beliefs, family circumstances or challenges.
Treat our children and families with dignity and respect, and use language that respects us as individuals.	Use language that hurts, is not clear, or is disrespectful to my strengths, beliefs, and experiences. Use our names.
Use language that we can understand.	Use acronyms or technical language that can be confusing to us.
Think about how you would feel if it were someone talking to you or your child.	Treat me in ways you would not like to be treated or have your own child treated.
Celebrate successes with us.	Base successes on societal norms. Allow children their own success based on their own capacity
Acknowledge efforts of the present.	Base decisions, judgments and opinions solely on behaviours.
Include strategies to strengthen the whole child/family.	Be stuck in only utilizing clinical therapy and what outcomes are suggested through academic evidence.
Listen, hear and understand.	Assume you have heard it all before.
Be prepared to use more than one situation to form opinions.	Base judgments on one setting/appointment.
Remain calm and anchored.	Allow emotion to anger you.

ORGANIZATIONAL COMMITMENT AND READINESS

Though the concept of family engagement through a family centered model is generally accepted as "best practice", often organizations do not have a culture to support a family centred model or to effectively train and promote family engagement by service providers. This could be due to an organization's principles and practices being rooted in a traditional model of care, lack of funding and/or resources to implement change, or differences in understanding what family engagement truly means. Organizations that value family engagement through family centred care incorporate these values into strategic planning, facilities design, human resource policies and fiscal planning (CAMH, 2004) They can be hindered by lack of program leadership, conflict between philosophy and practices and inadequate dynamics at the system level (Kelleher, 2010). Organizations must also be ready and willing to work with other agencies and professionals to meet the family's needs, as opposed to only offering support through their own staff. Service providers in organizations who are asked to change to family centred models often experience role confusion and a sense of lost control (Graham, 2009).

In order to better understand an organization's readiness to change prior to undertaking a parent training centered in a family centred model of care, organizations should complete an organizational assessment to better understand current state and its ability to incorporate innovations. A tool to assess readiness to change/engage parents should be included in a training strategy for service providers. The tool can be based upon other organizational readiness to change tools or examples of readiness to change rubrics from education.

Examples of organizational readiness tools:

- The SFUD Parent Engagement and Partnership Plan offers an example of a rubric that demonstrates a continuum of "what does a parent-engaging/parent-partnering school look like?". A similar model could be developed for family engagement in child and youth mental health.
- Austin and Classen (2008) developed a tool to assess organizational readiness for implementation of evidence-based practice that asks organizations to rate their status on several questions in categories of organizational capacity, organizational culture/climate, staff capacity and an implementation plan. A similar report card for family engagement could be developed for agencies/organizations.

INVOLVING FAMILIES IN THE DESIGN, DELIVERY AND EVALUATION OF TRAINING

Feedback from families was clear. They feel that the most engaging service providers understand the unique challenges that families face when dealing with a child/youth that uses child and youth mental health services. Families suggested this sense of compassion and understanding to be one of the most important aspects to be included in a family engagement training strategy. Families also recommended that often, the most helpful people they had encountered were individuals (either family members or service providers) who had lived experience in the mental health system with their own children and youth. For this reason, family members should be included in all aspects of the development, delivery and evaluation of any training curriculum and program. Opportunities exist to include examples of family experiences either through in person delivery, written synopsis or video vignettes. Ideally, family engagement training could be provided by a team that included a family member and a service provider.

OVERVIEW OF BARRIERS AND FACILITATORS OF FAMILY ENGAGEMENT

A training curriculum would not be complete without an in-depth discussion of barriers and facilitators of family engagement, including:

Who Defines "Meaningful" – Understanding of Differences in Perceptions

A theme that emerged through all data collection methods is the differences in perceptions that can arise between family members and front-line service providers. As mentioned previously, families can have very different perceptions of what family engagement means. Service providers must be aware of these potential differences and be sure to communicate clearly with families to ensure everyone is on the same page. Baker-Ericzen et al., (2010) found that clinicians and parents might agree on the number, types and importance of parent and family factors in child and youth mental health services, but saw things differently when asked what factors were most important. Clinicians described parent resistance to treatment as contributing to lack of involvement. Clinicians saw this reluctance to participate as denial or a defense mechanism. Parents emphasized positive expectations of treatment and feelings of being supported to their involvement or lack of involvement in treatment. Parents were less likely to be involved if they felt clinicians don't listen, or if they feel that they are being blamed.

> "We never say that a client is in the wrong place…we might not currently have the type of service they are looking for, but we put our heads together to create one, or hook them up with one" – Service provider

One benefit of including families in Phase 2 of training development will be to examine the term "meaningful", so that service providers can have a better understanding of both family's perceptions of meaningful engagement and the differences in understanding that can arise.

Diverse Backgrounds of Service Providers and Settings

Mental health service providers in community settings are comprised of individuals with diverse professional backgrounds who work in varied service settings. Mental health services are often provided in diverse agencies often viewed outside of the mental health

care setting, such as schools, the justice system and child welfare. In fact, when families responded as key informants, or in the e-mail survey, they mentioned mental health professionals in all settings and job descriptions.

Training for front-line service providers must take into account this wide range of pre-existing knowledge, experience and background. A training program must be flexible enough to adapt to various organizations, regions and backgrounds of front-line service providers. Including a range of providers and families in the development of the training strategy will ensure that the program is adaptive to a wide range of needs.

Lack of Perceived “Fit” Between Training and Real Life

Often, training is less effective than it could be due to difficulty in applying knowledge and skills to real-life settings that are often complex. Risz et al., (2010) found that after training, participants found it especially helpful to have contact with clients early on since face-to-face work was perceived as beneficial.

Developing a training program that includes families or “clients” as trainers will be advantageous in helping to apply theory to practice, as families will help to provide first-hand experience and feedback on interactive activities within training. Families will provide the real-life experiences necessary for knowledge transfer.

Lack of Perceived “Fit” Between Intervention and Real Life

Just as service providers need to see a fit between training and real life, family members need to be able to see a fit between treatment and real life. The nature of the intervention being implemented can also impact on the ability of providers to engage families through family centred care (Graham et al., 2009). In some cases there can be a contradiction between ecological emphasis of family centred practice and the child-centred emphasis of some evidence-informed and evidence-based practices (EIP/EBP). As well, Hoagwood et al., (2001) suggest that in many cases EBP that have proven effective for one age group can be ineffective, or even harmful, for populations of a different age group.

Weisz et al., (2005) suggest that for each intervention that works, researchers and front-line staff need to know as much as possible about the range of youth, family and community characteristics within which benefits are realized. Front-line staff need to understand person and condition factors that moderate intervention effects, and with whom to apply prevention and intervention programs. If families do not see a fit with their situation, values or culture, EIP/EBP may become unsuitable. Since both families and the providers of interventions carry norms, beliefs and values derived from their respective cultures, effective interventions may also require compatible norms, beliefs and values or an ability to work with differences.

> "Not all parents are in a place to advocate for themselves, and if that social worker can help them to navigate the system, to find the right doctor, or school program, that's key" - Parent

A family engagement training program will need to address the issue of perceived fit of treatment with a client-centered approach, and the family's goals and desires.

Practical Barriers

When families are asked why they drop out of services they frequently cite practical obstacles such as time demands and scheduling conflicts, high costs, lack of transportation and child care, crowded waiting rooms, and lengthy intake procedures (Ingoldsby, 2010). Effective training in the realm of parent involvement respects the lifestyle, commitment and comfort level of families. The literature review, key informant interviews and the e-mail survey provide examples of practical barriers that families face, and that front-line service providers can learn to anticipate and problem solve around, including:

- Lack of transportation
- Lack of finances
- Scheduling difficulties due to work or other obligations
- Child care
- Inaccessible location for services
- Crowded waiting rooms
- Long waits in waiting rooms

- Long intake procedures
- Scheduling appointments without first consulting with families
- Information packages that were hard to read or understand
- Information/documents not translated into family's home language
- Lack of information on the Internet

During Phase 2 of the training strategy development, it will be important to address these practical barriers and use the participatory approach to add to both the list of barriers and potential solutions.

Cultural Competency

In today's society professional mental health care providers are increasingly required to interact with families whose race, culture, origin, living circumstances and family make-up is different than their own (Alegria, Atkins, Farmer, Slaton, & Stelk, 2010). Working with culturally diverse families in training, or supporting family driven organizations requires close attention by support providers to one's cultural biases. The development of a cultural humility and reflecting on practice in attempting to address biases provides a starting point for support providers working with families.

The development of the training strategy in Phase 2 should address the context and needs of delivering services to diverse communities, rather than viewing cultural issues as peripheral (Ayon & Aisenberg, 2010). Front-line service providers will need to reflect on their own cultural biases, and learn to engage families from their own vantage point.

The Importance of Relationships – A sense of collaboration

The relationship between the family and front-line service provider may be the single most important aspect that impacts on family engagement. Dixon et al. (2001) outline factors that have been found to contribute to a sense of collaboration:

- Listening to families concerns, needs and questions
- Soliciting input and feedback from the family since they have knowledge of the client and can shed light on strengths, interests and competencies

- Acknowledging strengths, expertise and contributions of family members
- Exploring family's expectations of the intervention and the client
- Facilitating the resolution of family conflict by responding thoughtfully to family distress
- Acknowledging and dealing with feelings of loss
- Working with families to develop a crisis plan
- Helping to improve communication between family members
- Providing education and training for the family
- Encouraging family to expand their support network
- Being flexible in meeting the needs of family
- Providing resources to facilitate involvement (e.g. child care)
- Providing family with back-up support
- Developing strategies for resolving problems related to confidentiality

The front-line service provider-family relationship will be an important component of the family engagement training strategy. Families will be able to provide more concrete suggestions for activities or actions that help to promote strong relationships and improve therapeutic alliance.

Stigma/Values

One of the key themes identified by parents as a problem or challenge through key informant interviews and the e-mail survey was stigma. Mental illness has been identified as one of the most stigmatized attributes a person can have in modern society (Heflinger & Hinshaw, 2010) and is a key barrier to mental health service's access and utilization. A growing body of literature suggests that those who serve in mental health professions may hold many of the same stigmatizing attitudes toward mental illness, as does the general public, including the communication of shame and low expectations to youth and their families.

Ways in which professional and institutional stigma are conveyed include:

- Referring to children/youth by their diagnosis instead of using people-first language
- Focusing on deficit models of client symptomology and family dysfunction instead of consumer assets and family strengths
- Holding planning meetings without youth/family present or keeping them in passive roles
- Focusing on mental illness instead of the whole child
- Having facilities for treatment that are physically difficult to access

Stigma is an issue that can be explored in depth through a front-line service provider training program. It will be important to have opportunities for reflection and sharing, and families can share specific examples of times when they felt stigmatized.

> MANY YEARS AGO YORKTOWN FAMILY SERVICES INITIATIED A PARENTS-BASED PROGRAM THAT HAD GOOD ATTENDANCE, EXCEPT FOR PARENTS FROM THE SOMALI COMMUNITY. THROUGH INVESTIGATION, THEY LEARNED THAT THERE IS NO WORD IN SOMALI FOR "THERAPY". WHAT YORKDALE WAS OFFERING IN PROGRAMMING, AND THEIR OUTREACH EFFORTS, DID NOT MEET THE NEEDS OF THE SOMALI COMMUNITY. TO ENCOURAGE ENGAGEMENT, THEY BEGAN DOOR-TO-DOOR SOLICITING, BUILT RELIGIOUS PRACTICES INTO PROGRAMMING AND SPENT TIME LEARNING THE NEEDS OF THIS UNDER-ENGAGED POPULATION. YEARS LATER, THEY HAVE EMPOWERED ANOTHER COMMUNITY TO TAKE ON A SIMILAR PROGRAM AND THEIR OWN PROGRAM DESIGNED TO MEET THE NEEDS OF THE SOMALI POPULATION IS THRIVING.

Architectural Design

The physical structure of buildings can impact on the experience of families and outcomes experienced by patients. Family centred principles, processes and approaches can be expressed through the environment with warm, inviting colours, welcoming signage, areas for children to play, comfortable seating and private meeting rooms. Planning for the design of facilities should be anchored in the vision, mission, values and philosophy, and can be completed in conjunction with families. Planning groups should consist of service providers, families, children and youth.

The Institute for Patient and Family Centred Care is an organization that aims to advance the understanding and practice of patient and family centred care in partnership with patients, families and health-care professionals. This website has examples of firms and projects where architectural design has been incorporated into family centred care philosophy.

STRENGTHS, WEAKNESSES, OPPORTUNITIES, THREATS (SWOT) ANALYSIS

A SWOT analysis is a strategic planning method used to evaluate the strengths, weaknesses, opportunities and threats of a project. A SWOT analysis was conducted on family engagement training opportunities for front-line service providers in child and youth mental health. After reviewing the literature, conducting the environmental scan, and talking to key informants, the following themes emerged as strengths, weaknesses, opportunities and threats.

SWOT Analysis – Family engagement training for front-line service providers in child and youth mental health

Strengths	**Weaknesses**
• Family centered systems of care and family engagement are valued as important within child and youth mental health • Strong parent community with many opportunities to link to parent-operated groups for feedback and guidance • Many champions and experts in the field, many in mental health as well as other fields. There is relevant research taking place in Ontario related to family engagement • Recognition by the government that family engagement in child and youth mental health is important • Willingness of other sectors (e.g. education) to work with community mental health for children and youth	• Often parents are not being involved by service providers. This can depend on the region or agency as there is inconsistency of service provision across Ontario • Evidence-based practices on which many interventions are based have not been tested in unique communities • Service provided to families may not be culturally sensitive • Language used within organizations can depersonalize the client and their family • Wide range in both availability and implementation of training opportunities • Several organizations/experts may be unknowingly working on similar projects regarding family engagement
Opportunities	**Threats**
• To partner with strong parent agencies to establish criteria for family engagement • To tap into existing training program/resources in Canada, United States, internationally • To offer reverse training opportunities (e.g. Have parents from different backgrounds provide cultural training for service providers) • Develop communities of practice related to family engagement • Develop a database of parent resource, referral agencies, support programs, services available for children etc. for access by families • Develop partnerships between trainers/training bodies to share costs and ideas • Promote research and evaluation in community settings • Use technology to reach a broader audience and new staff	• Challenges with definitions (within mental health and other sectors) can make it difficult to have meaningful discussions about family engagement • Difficulty in evaluating and replicating services in community settings due to funding or personnel constraints • Conflicting interests of agencies, competing for funding • Lack of funding for implementation of training or evaluation • Life circumstances of families – often have difficulties in their own lives (and may require intervention) • Variance in type of programming across Ontario • Importance of developing training that is culturally sensitive • Privacy issues

PROMISING MODELS

INVOLVING FAMILIES ACROSS MENTAL HEALTH CARE

Families can be involved in the child and youth mental health system as more than passive recipients of services. In fact, meaningful engagement requires that families can have more active roles in their child's care.

There are three main categories of involvement for families:

Families as recipients of services	Family led supports/programs: Families as co-therapists	Engagement through the process of involvement
Programs are typically led by professionals and improve the ability to deal with behaviours through improved problem solving and reduced stress.	"Families helping families" such as family driven support groups and mutual support programs are associated with reduced subjective burden and distress. *See document for "Tips for Developing Sustainable Family-Run Organization"*	Factors that impact on family involvement in care (eg. therapeutic alliance, empowerment, expectations of families and choice.

While all three types of engagement of families is important, this paper focuses mainly on engagement through the process of involvement and what factors should be covered when training service providers to be better at engaging families.

The following table outlines various ways that families can be engaged across the mental health care system. This list could be revised and other opportunities added through discussions with families, service providers and the steering committee in Phase 2.

Individual	Service/Program Level	Policy
• Collaborate and contribute to goal setting • Recognized as an expert in the role of parent/family member and supported in that role • Informed of treatment options and outcomes in a way that is meaningful, and consulted and collaborated with in determining treatment plans, goals and outcomes • Meaningfully involved to support their child through treatment • Consulted before decisions are made with respect to treatment • Engaged in the assessment of their child and family's needs • Recipients of workshops and/or training • Create an environment for open and honest communication, free from judgment • Consider parent/family support network part of the treatment circle	• Involved as parent-support staff • Involved in the design of programs • Involved in quality improvement processes • Involved in the design and implementation of evaluations • Co-trainers in education and training of mental health professionals • Trainers in education and training of family operated groups • Developers of resources (educational, advocacy, or otherwise) for families • Involved in the recruitment of staff • Consulted either individually or through a family advisory regarding language of agency communications	• Participate in task forces, work groups or councils that affect policy • Review and writing of policy • Actively involved in gathering evidence about best practices • Actively involved in the governance of child and youth community mental health settings • Involved in all levels of family advocate organizations • Included as members on the Board of Directors .

Family Check Up Model

One way to engage families is to train family members to be service providers. This helps not only to involve family directly in service provision, but other families can benefit from their experience having navigated similar situations and circumstances in the mental health system.

The Family Check Up (FCU) model is a family centred intervention to enhance positive adjustment of youth and prevent future problem behaviour (Stormshak et al., 2010). This model has been used mainly in public educational settings. It requires training of both service providers and parents who act as

consultants. Parent-training programs are challenging to implement on a large scale due to low enrolment and lack of individualized focus. The authors began systemic research to design a family centred intervention that could be implemented in settings that include diverse youth and families, such as in public schools.

The FCU model was designed to engage and motivate parents to improve parenting practices. Within this model, family resource centres are staffed with service providers and trained part-time parent consultants who provide services to families within the school context. Parent consultants serve as a bridge between school and home and also organize and offer special seminars on topics of interest, such as homework completion and home-to-school planning. There are also opportunities within this model to match parent consultants and families on such dimensions as ethnicity. In the FCU model consultants were trained through a series of workshops including week-long initial training and several follow-up training workshops. Supervision was provided weekly by a doctoral level practitioner.

Logic Model for Family Engagement

The Harvard Family Research Project (2009) has developed a process and template for developing a logic model for family engagement to be implemented throughout school districts. The logic model contains instruction for developing:

- Goals
- Inputs
- Activities
- Outputs
- Performance Measures

Though intended for use in school districts, the logic model template could be adapted for use by community mental health organizations, and offers a method to categorize and visualize family engagement goals, activities and outcomes.

Canadian Mental Health Association (CHMA) – Knowledge Resource Base

The CMHA has proposed a model of knowledge resource base that demonstrates the various areas where knowledge and attitudes must support inclusion. This visual guide is one of several developed by CMHA to help understand the multifaceted nature of consumer engagement. These models are helpful for conceptualizing factors at play, and requests could be made to adapt the models for family engagement purposes.

Copied from “Back to Basics: Enhancing our Capacity to Promote Consumer Participation and Inclusion: Discussion Guide on Recovery”. (CMHA) Retrieved June 21, 2011 from http://www.cmha.ca/data/2/rec_docs/692_Discussion%20Guide%20on%20Recovery.pdf.

HIGHLIGHTS OF EXISTING TRAINING

There were several examples of training that were uncovered through the environmental scan. Highlights to demonstrate both the depth and range of opportunities are presented below. These opportunities are also captured in the Addendum.

IN ONTARIO:

Canadian Mental Health Association (CMHA) – Back to Basics: Enhancing our Capacity to Promote Consumer Participation and Inclusion

The CMHA website houses a number of tools and resources, including:

- Discussion Guide on Recovery
- Workshop outline on best practices for promoting inclusion
- Guidelines for analysis (for reviewing current barriers and opportunities of consumer involvement)
- Tips for Good Practice

Though these resources are not developed for children and youth, they provide a model for the types of resources that could be beneficial in a front-line service provider training.

SickKids – Palliative Care Program

In this program that worked with service providers and clinicians who were working with families using palliative care, the training group included family members. The trainers used a variety of methods, and included role playing and case studies.

Sick Kids – Family Advisory Committee

On this committee, parents and former patients worked with doctors, nurses, and residents. Most of the training was conducted by parents or former patients and aimed to provide first-hand practical experience for what helpful information might look like for parents.

IN EDUCATION:

Alberta Education

An opportunity exists to develop a website that houses all resources related to family engagement. The Government of Alberta has developed a link on their website dedicated solely to family engagement and that also acts to link users to other helpful resources or websites. The website also offers definitions and contact information for parents.

IN THE UNITED STATES:

Comprehensive Community Mental Health Services for Children and their Families Program (CMHI) – Technical Assistance Partnership for Child and Family Mental Health

Regular meetings, teleconferences, workshops and conferences are held through communities of practice (COPs) that aim to address issues and share ideas. Communities of practice include: Family Involvement (including a Fatherhood Involvement group), Systems of Care, and Cultural and Linguistic Competence. Similar COPs could be developed around family engagement in Ontario.

National Alliance on Mental Illness (NAMI)

NAMI provides a 10-week course currently offered in 22 states that presents the view of family and consumer experience with serious mental illness to staff at public agencies. The course emphasizes the involvement of consumers and family members in provider-staff training.

IN THE UNITED KINGDOM:

Children's Workforce Development Council

Train the trainer courses are aimed at providing practitioners with skills to work with families. This is a certification process not limited to mental health, and offers four levels of "work-with-parents" training.

SETTING THE STAGE TO IMPLEMENT EVIDENCE-INFORMED TRAINING IN COMMUNITY-BASED ORGANIZATIONS

Prior to implementing family engagement training in community-based organizations, it will be important to consider how the training will impact the whole organization. The following factors should be considered:

Readiness to Change

As mentioned previously, it will be imperative to understand an organization's current state with respect to family engagement, and their readiness to change. Program managers will be required to look at their organization's current state and the local community, to better prepare for the implementation of family engagement training and programming.

Armstrong et al., (2000) outlined the stages of family involvement in community mental health and policy development:

1. Family exclusion – family members and family advocacy organizations, if they exist, are ignored or patronized.
2. Family advocacy – as parents begin to feel supported their voices start to be heard as organized advocacy efforts are developed at provincial/state and local levels.
3. Statewide federation of programs – formation of statewide federation of local parent programs create a stronger presence and power base. Specific goals and lobbying activities are developed.
4. Family inclusion – individual parents are formally invited to be at the table as representatives of larger family groups.
5. Family impact – family voices become sufficiently loud enough to impact on policy and service provision.

At a senior administrative level, readiness to change will need to be assessed.

Supervision

In order for innovations to stick, regular follow up and supervision are required (Long, 2008). Strategic and innovative efforts will be required to provide ongoing training and refreshers to front-line service providers. In some cases, the front-line service provider will be the expert. For this reason, technologies such as interactive CD training programs, video-download, web-based supervision, blogs or the use of communities of practice could prove to be effective in combination with traditional strategies.

Quality assurance

For successful implementation of an innovation, it is important to ensure that all parts of the innovation are implemented correctly (Waller, 2009). Addington (2009) outlines tools that can be developed or modified for use in all areas of mental health:

- Fidelity Scales - are measures that assess the extent to which delivery of an intervention adheres to the protocol or program module originally developed.
- Clinical practice guidelines – are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.
- Performance measures – is the use of statistical evidence to determine progress towards specific defined organizational objectives.
- Standards and benchmarks – can be set once performance measures have been identified. These are numerical thresholds for performance and can be established by individuals or groups using arbitrary decisions, consensus or statistically derived thresholds.

Phase 2 of the training strategy development will require the identification of appropriate quality assurance measures for both organizations and individuals. These tools can be developed with feedback from and in collaboration with families and can be part of the training toolkit.

Ongoing Evaluation

There are a range of opportunities for family engagement, from being a participant in focus groups or survey completion, to fully collaborating into all aspects of the evaluation design and implementation (Chovil, 2009). Any training strategy promoting family engagement naturally fits with the use of a participatory approach to evaluation. Participatory evaluation involves active collaboration between key stakeholder groups in designing, implementing and interpreting the evaluation (Green & McAllister, 1998). Evaluations should share the program value system and contain the following features:

- Collaboration among all stakeholders with all parties contributing equally to the development of the evaluation
- Family centred and driven approach
- Strengths-based orientation and focused on building on the program's strengths and continuous program improvement
- Comprehensiveness and flexibility to account for the multifaceted nature and ongoing changes in program goals and services

Challenges to participatory evaluation can include control and power, methodogical inadequacies, time and cost, and objectivity of the evaluator (Green & McAllister, 1998). Nonetheless, building participatory approaches toward the training program, and within all areas of a program, can provide benefits for the organization and will inform the Centre on strengths and areas of need.

As with all programs within the mental health system, prior to implementing family engagement training, it will be important to determine the evaluation strategy to better understand the impacts of the new program and how to improve services to support families.

Funding

Program managers will need to consider costs of family engagement training in annual budgets, as funding should be provided on an ongoing basis for both training and evaluation. The following costs should be considered:

- Initial training for front-line service providers – will one staff member become an expert in a train-the-trainer model, or will all staff receive the training?
- Follow up supervision
- Training for new staff
- Funding for family members who also become train-the-trainer experts – including costs associated with travel, resources, etc.
- Ongoing evaluation

Little literature exists that documents the costs associated with training, but feedback from both the e-mail survey and key informant interviews indicated that funding for training and follow up is imperative. Costs may be reduced by having regional experts who can travel to agencies to provide training, having a bank of online resources or using online meeting capabilities that save on travel.

Sustainability

Prior to implementing any new program or innovation, sustainability must be considered. Langford (2007) suggests that often, sustainability is not discussed early enough in program design or implementation, failing to create explicit expectations with clear responsibilities for sustainability, and has developed a tool intended to help leaders address the challenges of sustainability. Though this tool was developed for use with youth programs receiving grants, it could be modified for use within child and youth community mental health settings. The tool is organized by eight elements of sustainability and raters are asked to rate their capacity on a scale of 1 to 5 in the eight areas, including:

1) Vision

2) Results orientation

3) Strategic financing orientation

4) Broad-based community support

5) Key champions

6) Adaptability to changing conditions

7) Strong internal systems

8) Sustainability plan

Sustainability will need to be considered with respect to the roll out of the training strategy provincewide, and also within individual organizations. Sustainability will be a key issue to be addressed in Phase 2 of the training strategy development.

SUMMARY - KEY COMPONENTS OF A FAMILY ENGAGEMENT TRAINING PROGRAM

Phase 1 of the training strategy development involved gathering information from a large number of sources. As a result, there are several components recommended to be part of the training program. The next section provides suggestions for the methods, and ideas for modules/content.

> "Parents should be trained and they should be the ones offering training, not so much the psychologists and youth workers. If there are parents out there, they should be trained to do it. They will have a better impact". - Parent

Who conducts the training?

Families who provided feedback for Phase 1 of the training strategy development overwhelmingly suggested that training should be provided by a team, and should include families as co-trainers. One of the major challenges for families becoming engaged is that they feel that front-line service providers and/or clinicians do not understand them. Therefore, training offers an opportunity for sharing families' stories during training to provide context for what families face. Training should be provided by a team consisting of two or more front-line service providers, family members and clinicians.

Method

Further investigation with front-line workers will be required, but it appears that workshop format with interaction, and use of media (e.g. video narrative, etc.) are effective and engaging methods for training. Key informants also recommended that having segments or modules online for refreshers, or for individuals who are unable to access training, would be helpful.

Modules could be developed on the following content:

- Importance of family engagement (including relevant literature)
- Mental health literacy – Key definitions
- Organizational culture
  - Readiness checklists
  - Self-awareness checklists
- Principles of Family centred models
- Barriers and facilitators of family engagement
- Stigma
- Diversity and cultural competence
- Making your organization engaging
  - Physical/Verbal/Design
- Relationships – Partnerships
- Engaging families in all levels of the mental health system
  - Therapy
  - Programming
  - Accessing resources
  - Advocacy
  - Governance
- Key messages
- Sustainability
- Evaluation

RECOMMENDATIONS AND NEXT STEPS

The following recommendations and next steps briefly summarize key points in the current paper. Additional recommendations can be found in the literature review, and should be brought forward through discussions with the steering committee and family participants in Phase 2.

- Phase 2 of training program development will need to finalize common definitions and terminology to be used consistently in order to support the meaningful involvement and the empowerment of families. The mental health literacy should become part of the training curriculum. The preferred definitions and consistent language must be shared with families, within agencies, across agencies and across the service sector.

- The training curriculum should be developed and based around a family centred model. Principles of a family centered model will be a main component of training curriculum.

- Training should be participatory and include family in all aspects of development, delivery and evaluation. When possible, training should be provided by teams including family members and service providers or clinicians.

- Efforts should be made to ensure that front-line service providers and family members are represented from all areas of Ontario. Training should be adaptable to individual communities and agency contexts.

- A variety of modes should be used to ensure training is interactive, and to keep attention levels of adult learners high. Opportunities exist to use video narratives, activities and technology incorporated into a training program.

- A community of practice should be developed related to family engagement.

- Creative methods can be used to assist with follow up supervision and fidelity monitoring. Fidelity tools can be accessed online. Teleconference or community of practice meetings can assist with collaboration and problem solving.

- At the organizational level, community mental health agencies will be required to assess their current practices and policies prior to attempting to increase family engagement/involvement. Leadership will recognize the multifaceted nature of family involvement and must be ready to lead the implementation to make required changes for support. Tools to assist with the assessment of readiness to change will need to be developed.

- The development of practice standards will indicate clear expectations of staff regardless of tenure, and can assist in embedding client-centred practice within the culture of services. Practices with respect to confidentiality and sharing of information will also need to be discussed.

- Several barriers exist to family engagement, including differences in perceptions, diverse backgrounds of service providers and settings, lack of perceived fit between training and real life, lack of perceived fit between intervention and real life, practical barriers, cultural competency, stigma/values and architectural design. In Phase 2, family members will be able to provide more insight on these and additional barriers, as well as identify potential solutions. Barriers and facilitators should be part of the curriculum in Phase 2.

- It will be important to continue to build an inventory of what training is being used in community agencies that is purported to improve family engagement/involvement. This information may be of assistance in disseminating best practices, but will also help to determine the most frequently under-evaluated interventions and identify priorities for research.

- Opportunities exist to tap into existing training that has been developed, or to modify existing training. When possible, resources and documents that have already been developed can be modified for use for family engagement training.

Adequate and ongoing funding will need to be allocated to ensure the sustainability of family engagement training in the province and within individual agencies.

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APPENDIX A – HEADINGS IN ENVIRONMENTAL SCAN

Training Opportunities

- Location (Country)
- Agency/Organization
- Name of trainer/organization
- Method of delivery/Type of training
- Description
- Intended audience
- Language
- Theoretical model (if available)
- Cost
- Contact information
- Website
- Related documents or links

Organizations/Experts

- Location (Country)
- Agency
- Name of organization/group
- Description
- Intended audience
- Language
- Theoretical model
- Contact information
- Website
- Related documents or links
- Comments

APPENDIX B – SUMMARY OF QUESTIONS ON E-MAIL SURVEY

Introduction

We are working with the Ontario Centre of Excellence for Child and Youth Mental Health in developing training for meaningful family engagement and family centred care. We are trying to better understand what factors make services and support more helpful for families accessing Child and Youth Mental Health Services. Please take a few moments to tell us what has made a difference both positively and negatively with your experiences (for example: what was helpful in allowing you to be a meaningful part of the process, made your experiences more welcoming, and was helpful to your family as a whole, etc).

What are some examples of things your local community mental health agency, school, or other support has done to make you feel welcome and involved in your child's care, planning treatment, exchange of information, etc?

1,	
2.	
3.	

What are some examples of things your local community mental health agency or school, or other support has done that makes you feel unwelcome and uninvolved in your child's support, care, planning treatment, exchange of information etc?

1,	
2.	
3.	

If you needed information about local mental health resources/services, which of the following would you most likely refer to? (check all that apply)

	An online mental health resource directory
	Printed resource materials
	Someone at your child's school
	Your primary care physician
	City/County services or crisis line
	Law enforcement
	Clergy/spiritual leader
	Family or friend
	Local library
	e-Mental health
	Community mental health agency
	Other (please explain)

What barriers exist that prevent or delay access to mental health services (select all that apply)

	Lack of finances (money for services, insurance, etc)
	My own lack of knowledge about what I should do (symptoms, where to go, etc).
	Lack of knowledge by service providers or others providing support (about symptoms, where to go, etc.)
	Negative perception of mental illness by service providers
	Negative perception of mental illness by the public
	Lack of transportation
	Lack of service providers
	Lack of access to providers (when services are offered, waiting lists)
	Not qualifying for services/eligibility
	Cultural barriers
	Other (please explain)

Do you currently have access to the following services?:

Service	Yes	No	Unknown
Inpatient			
Crisis			
Same Day			
Residential			
Psychiatric services (medicine management)			
Outpatient			
Support groups			
Alcohol and other drug abuse			
Respite			
Access to a Navigator/Peer Support Worker			
Psycho educational Assessment			
Other (list)			

Would access to the following services provide you with better engagement/involvement in your child's care?

Service	Yes	No	Unknown
Inpatient			
Crisis			
Same Day			
Residential			
Psychiatric services (medicine management)			
Outpatient			
Support groups			
Alcohol and other drug abuse support services			
Respite			
Access to a Navigator/Peer Support Worker			
Psycho educational Assessment			
Other (list)			

What would you like to receive additional education or training on? (select all at that apply)

	Recognizing and understanding mental health illnesses
	Talking with your child about mental health illnesses
	Knowing where to get help when faced with mental health illnesses
	Knowing the rights of my child and being able to make informed treatment choices
	Other (please explain)

In what format would you be interested in receiving information about mental health illnesses (select all that apply)?

	Webinars/Online training
	Workshops at school
	Workshops within the community
	Newsletters
	Video/DVD
	Participatory workshops
	Other (please explain)

When would be a good time for you to attend a workshop or presentation?

	In the evenings
	During the day
	On the weekends
	Other (please explain)

In your opinion, who should deliver training to families?

☐ Mental health professionals/clinicians

☐ Front-line service providers

☐ Family members with lived experience using the mental health system

☐ A combination of all of the above

☐ Other (please explain)

What are areas where you feel you your service provider(s) would benefit from additional training

	Recognizing and understanding mental health illnesses
	Talking with your child/family about mental health illnesses
	Knowing where to direct people to get help when faced with mental health illnesses
	Knowledge about cultural issues/cultural differences and how to provide culturally appropriate services
	Understanding the rights of children and youth and learning tools and approaches to help them (and their families) make informed treatment choices
	Other (please explain)

Thinking about family engagement and your experience with the CYMH system, if you could give one piece of advice to a front-line CYMH service provider what would it be?

Can you please tell us in which region town/city you currently live (this information will not be shared but will be used to understand differences by region)?

Do you have any other comments you would like to share?

Thank you for taking time to answer some questions related to parent involvement in mental health! We appreciate your time!

APPENDIX C – E-MAIL SURVEY: HIGHLIGHTS OF FEEDBACK

A link to the feedback form was distributed to members of the steering committee for distribution through their own networks. Potential recipients had five days to provide input. The following pages summarize the feedback from 40 family members of children and youth using mental health services.

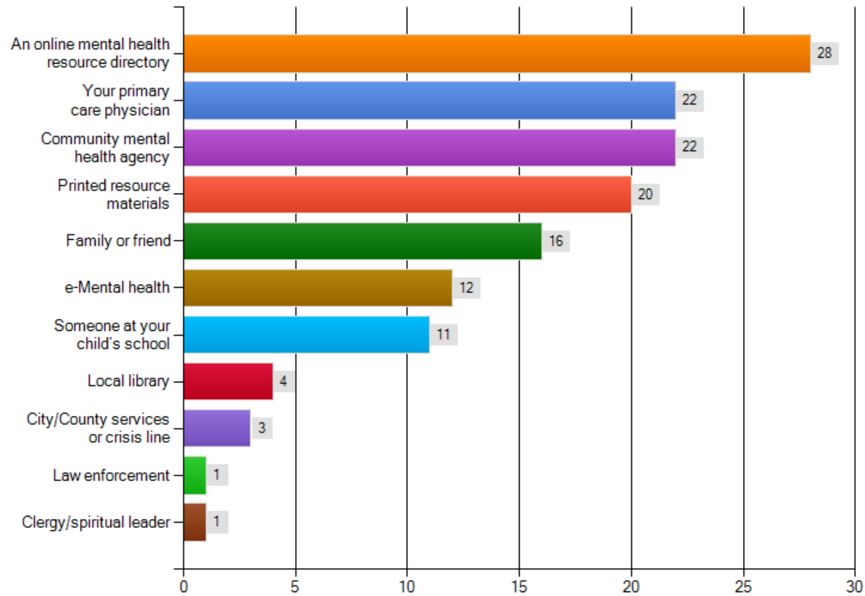
Q1. What are some examples of things your local community mental health agency, school or other support has done to make you feel welcome and involved in your child's care, planning, treatment, exchange of information, etc.

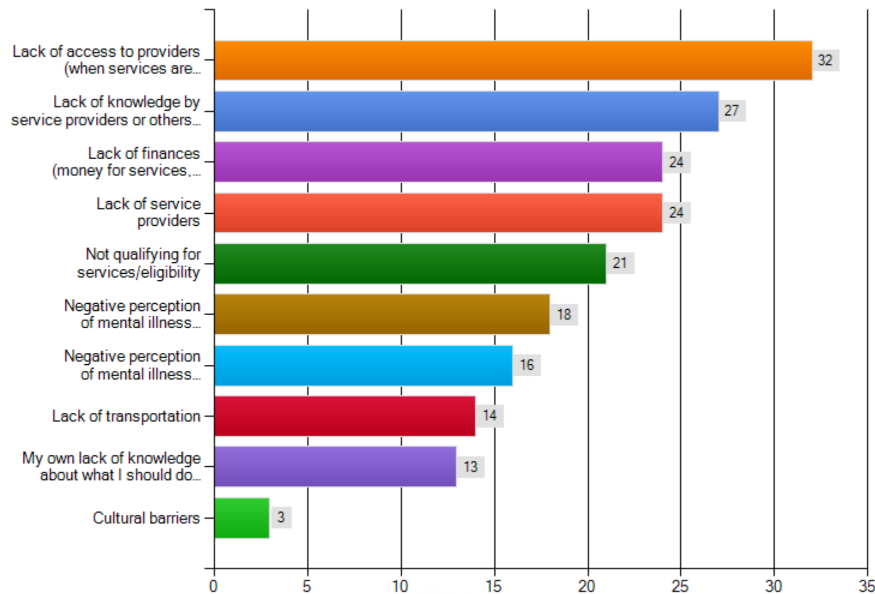
Families articulated a number of factors or actions that made them feel welcome, such as:

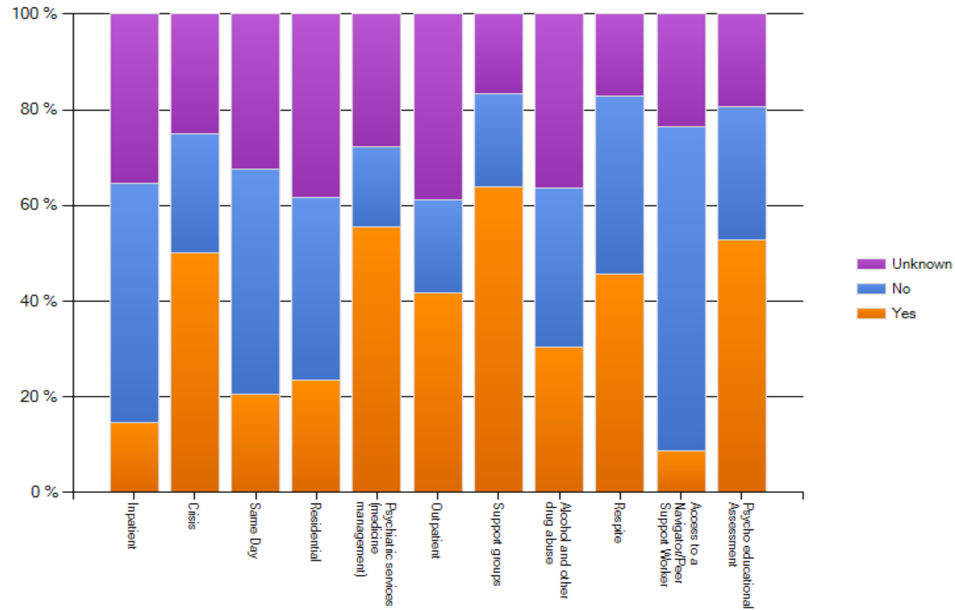
- Including families in meetings, and scheduling meetings when families were able to attend
- Asking families what their goals were and working with families to achieve those goals
- Providing creative solutions to issues that arose as opposed to sticking with what the service provider knew from past work
- Advocating for parents or children and youth in meetings with other agencies
- Being an expert in existing services or opportunities so as to be able to refer families
- When service providers were not experts in an area, they were willing to look outside the box or link the families with individuals/supports that were experts in the area
- Responding to what parents and caregivers were saying or telling them
- Providing parenting workshops and opportunities, but not assuming that the parents were "bad parents"
- Allowing and encouraging opportunities for families to get involved in task forces, advocacy committees, boards of directors, etc.
- Being dependable, promptly returning phone calls or following through on what they said they would
- Quick turn around on first appointment (e.g. under two weeks)
- Providing a forum for parents and youth to encourage feedback on services
- Not being judgmental, treating the family like an "expert"

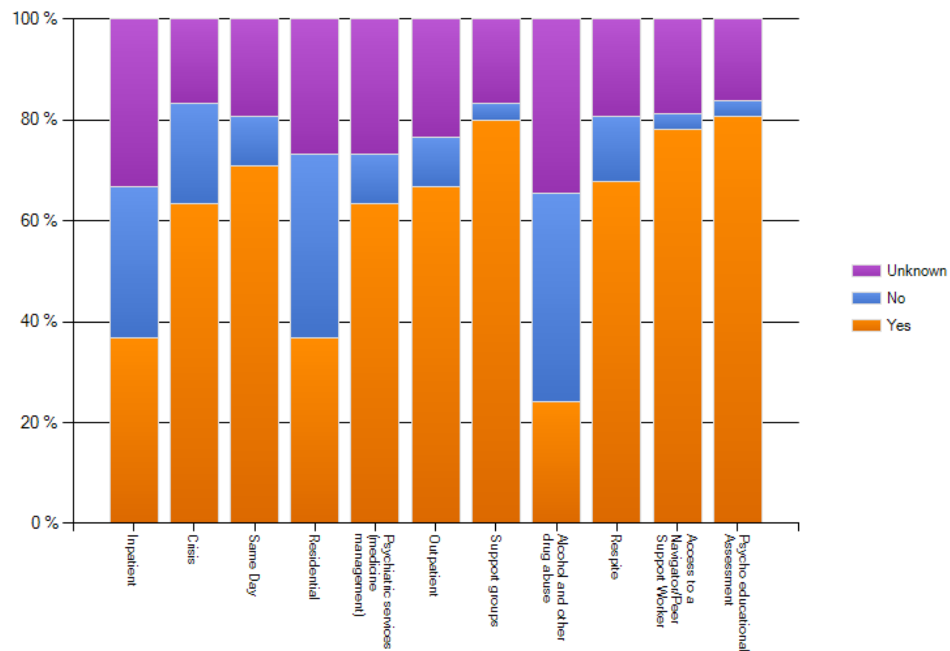
Q2. What are some examples of things your local community mental health agency or school, or other support has done that makes you feel unwelcome and uninvolved in your child's support, care, planning treatment, exchange of information etc?

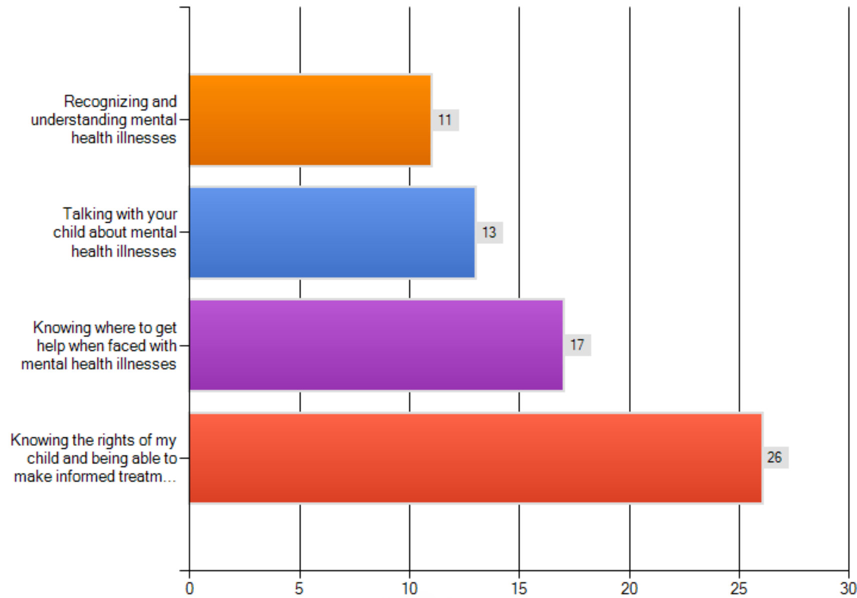
- No collaboration, they just tell me how it will be
- Services are not coordinated with other agencies
- Set meetings without asking about our schedule
- Assume they understand the situation when they have not asked for details
- Don't tell us what the treatment plan is
- Make medical decisions without consulting parents
- Make program changes, and implement them, without consulting with us first
- Have their own agenda and don't ask about mine
- Harassment or bullying
- No single point of access for services
- Blamed me for the issues, insinuated that I was not a good parent
- Have little knowledge about the disorders
- Not knowing what services or supports are available, both within schools, and within the community
- Ignore my requests
- Refusal to provide referrals
- Find reasons to exclude my child from services (or education)
- Make decisions about our child's school timetable without telling us
- Long waiting lists for services
- Do not help through periods of transition (e.g. between schools or into adult services)
- Asking me to "settle my child down" in the waiting room
- Cut services
- Don't return phone calls, show up late
- Lack of consistency with help from the same person, or feeling like you have to start over with every agency
- Use punitive measures as discipline with my child
- Not being forthcoming with information, being secretive, or having to "pry" out information
- Threaten me
- Not being educated on mental illness (especially in schools)
- Language used in treatment, and in annual reports
- Confidentiality issues prevent collaborative approaches.

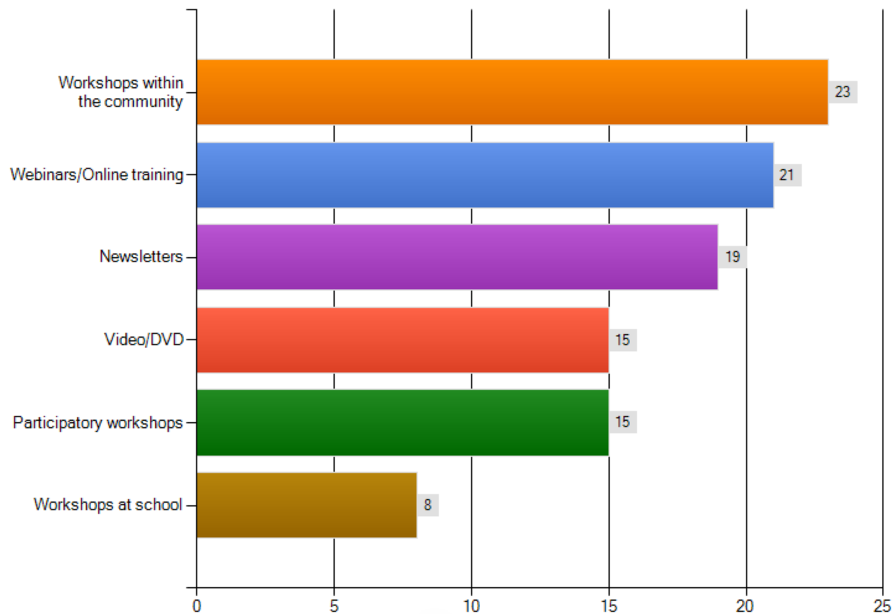

If you needed information about local mental health resources/services, which of the following would you most likely refer to? (check all that apply)
An online mental health resource directory
28
Your primary care physician
22
Community mental health agency
22
Printed resource materials
20
Family or friend
16
e-Mental health
12
Someone at your child's school
11
Local library
4
City/County services or crisis line
3
Law enforcement
1
Clergy/spiritual leader
1
0
5
10
15
20
25
30

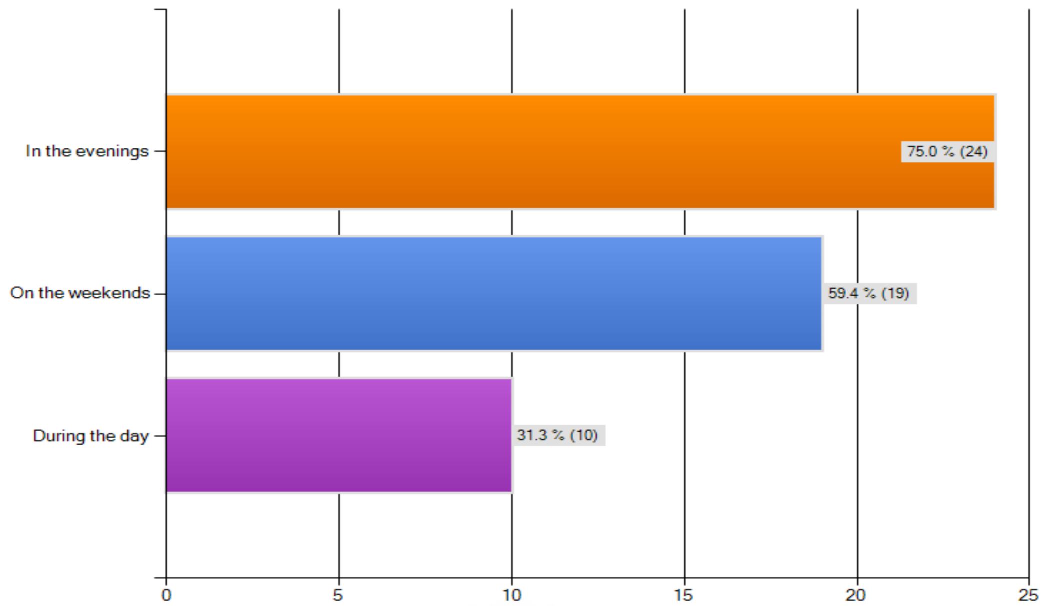

What barriers exist that may prevent or delay access to mental health services (select all that apply)
Lack of access to providers (when services are...
32
Lack of knowledge by service providers or others...
27
Lack of finances (money for services,...
24
Lack of service providers
24
Not qualifying for services/eligibility
21
Negative perception of mental illness...
18
Negative perception of mental illness...
16
Lack of transportation
14
My own lack of knowledge about what I should do...
13
Cultural barriers
3
0
5
10
15
20
25
30
35

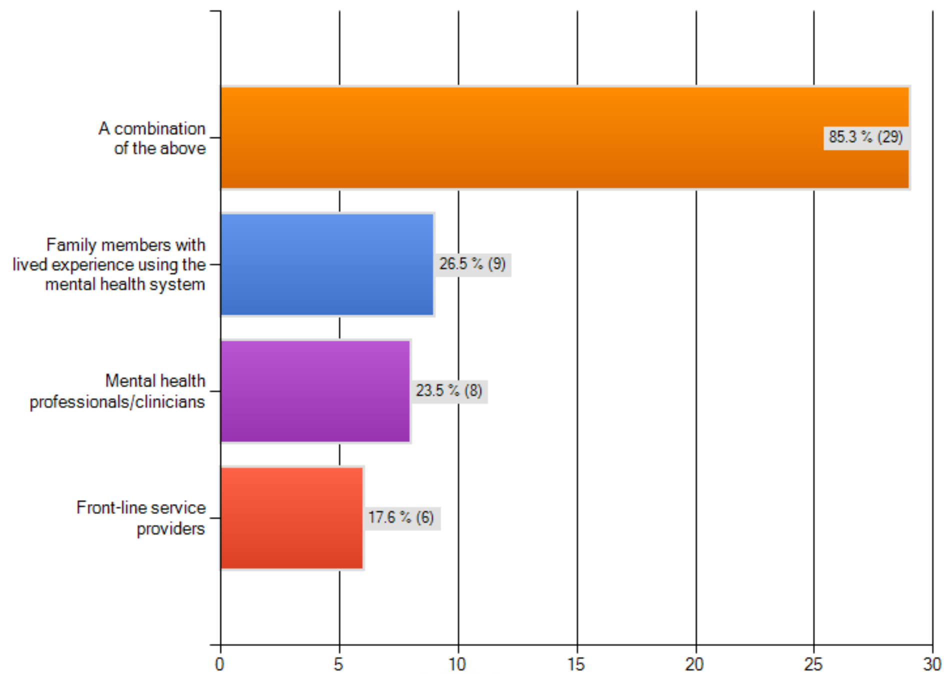

Do you currently have access to the following services? :
100 %
80 %
60 %
40 %
20 %
0 %
Unknown
No
Yes
Inpatient
Crisis
Same Day
Residential
Psychiatric services (medicine management)
Outpatient
Support groups
Alcohol and other drug abuse
Respite
Access to a Navigator/Peer Support Worker
Psycho educational Assessment

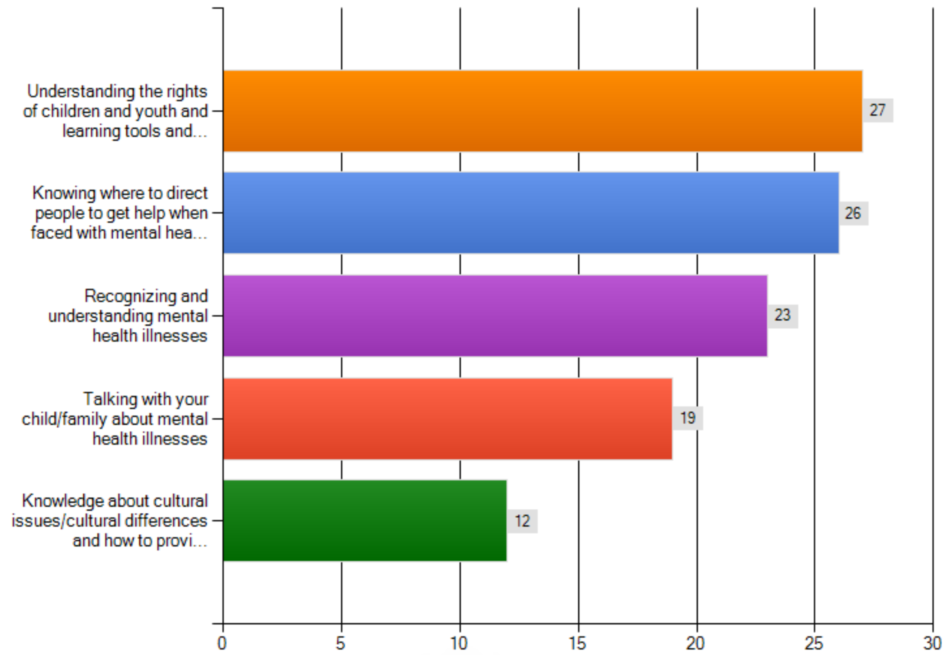

Would access to the following services provide you with better engagement/involvement in your child's care?
100 %
80 %
60 %
40 %
20 %
0 %
Unknown
No
Yes
Inpatient
Crisis
Same Day
Residential
Psychiatric services (medicine management)
Outpatient
Support groups
Alcohol and other drug abuse
Respite
Access to a Navigator/Peer Support Worker
Psycho educational Assessment


What are areas you would like to receive additional education or training on? (select all at that apply)
Recognizing and understanding mental health illnesses
11
Talking with your child about mental health illnesses
13
Knowing where to get help when faced with mental health illnesses
17
Knowing the rights of my child and being able to make informed treatm...
26
0
5
10
15
20
25
30


In what format would you be interested in receiving information about mental health illnesses (select all that apply)?
Workshops within the community
23
Webinars/Online training
21
Newsletters
19
Video/DVD
15
Participatory workshops
15
Workshops at school
8
0
5
10
15
20
25


When would be a good time for you to attend a workshop or presentation?
In the evenings
75.0 % (24)
On the weekends
59.4 % (19)
During the day
31.3 % (10)
0
5
10
15
20
25


In your opinion, who should deliver training to families?
A combination of the above
85.3 % (29)
Family members with lived experience using the mental health system
26.5 % (9)
Mental health professionals/clinicians
23.5 % (8)
Front-line service providers
17.6 % (6)
0
5
10
15
20
25
30


What are areas where you feel you your service provider(s) would benefit from additional training?
Understanding the rights of children and youth and learning tools and...
27
Knowing where to direct people to get help when faced with mental hea...
26
Recognizing and understanding mental health illnesses
23
Talking with your child/family about mental health illnesses
19
Knowledge about cultural issues/cultural differences and how to provi...
12
0
5
10
15
20
25
30

Thinking about family engagement and your experience with the CYMH system, if you could give one piece of advice to a front-line CYMH service provider what would it be?

Selected quotes:

- Stop talking down to us…drop the shame and blame. We are doing the best that we can do in the worst of situations.
- A child with mental health issues affects the health of the entire family. The issues are not confined just to the child.
- Be compassionate
- Be patient
- Never belittle the parent for bringing the child in for help, especially in front of the child. Both the child and parent need help and support.
- Don't assume you know better than the person living with the child and don't judge the caregiver who is also needing to be supported so that they can better support their child. Take the time and listen so that you can support better.
- Shorten waiting lists!
- You have no idea the issues we face and you need to respect us and treat us as equal partners.
- Don’t make any assumptions
- Empower and use strength-based approaches and applications. Help people who ask for help.
- To treat those walking through the front door with the same dignity and respect and level of care that a doctor or nurse treats a patient in their offices or at the hospital who have come in with a broken bone. Also to understand that parents are the experts on their child and should be treated as such.
- Families are the expert in their children and their experiences should be considered and valued.
- Children and their families need assistance in dealing with the mental health issue from all aspects. They are living with this daily and encountering many obstacles that they are unable or unaware of how to handle. ie education, treatments options
- Don't judge me - help me with my child who has an invisible disability.....