Engaging Families in

Child & Youth Mental Health:

A Review of Best, Emerging and

Promising Practices

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April, 2009

"Parents facilitate the interaction between the child and the service system, and as such, represent the 'central dimension' of the system of care." (Tannenbaum, 2001)

"Don't speak about us without us."
(African proverb)

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Acknowledgements

Introduction

The mental health of children and youth in British Columbia is more than the absence of a mental illness...

Mental Health Care is a child's right.

The family is a foundational institution across all cultures. Parents are entrusted with the responsibility for taking care of their children. Because parents are essential to the physical, mental, emotional and spiritual development of their children, it is vital that parents are also involved in their child's mental health. Parent involvement positively influences the outcome of treatment and empowers them to continue to nurture their child's development

The recently released "*A Review of Child and Youth Mental Health Services in BC following implementation of the 2003 Child and Youth Mental Health Plan*" found that in service delivery,

> "family involvement in individual assessment, treatment and evaluation is seen as "hit-and-miss". With regard to their ability to be involved in care planning for their child, 41% of parents or guardians responding to our survey were satisfied or very satisfied, 38% were dissatisfied or very dissatisfied, and 21% were uncertain (Berland, 2008).

The report recommended that

> "there should be a commitment to embed client and family perspectives and resources into the infrastructure both regionally and provincially, with a policy on expectations of family advisory committees at the regional and sub-regional level (Berland, 2008).

The importance of engaging families is being increasingly recognized as a best practice in providing quality services in child and youth mental health. Once regarded as a cause or contributing factor of their child's problems, parents are now viewed as collaborators in resolving their child's problems (Osher, 2001).

Family organizations such as the National Federation of Families for Children's Mental Health in the United States have been a powerful movement in directing the provision of services for families with a child or youth with mental health issues. In the US, child & youth mental health is undergoing a transformation and is moving towards a 'system of care" which includes family involvement (Tannen, 1996).

The FORCE Society for Kids' Mental Health has taken on a leadership role in furthering family engagement in child and youth mental health in British Columbia. As a first step in this process, the FORCE Society undertook a review of the literature regarding family engagement. This report provides a summary of the review.

The aim of this report is threefold:

(1) To explore key themes emerging from the current literature on the concept of family engagement in child and youth mental health (CYMH).

(2) To identify evidence based and promising strategies that promotes meaningful engagement of families in CYMH.

(3) To identify examples of policies and practices that enhances family engagement at all levels in CYMH.

It is based upon a review of literature from peer-reviewed scientific journals, technical reports, presentations, policy papers, planning documents from Canadian and international child and youth mental health agencies that are available through the internet. The search also extended to the child welfare, education and youth justice fields, but to a lesser degree. The short timescale for the review means an exhaustive search was not conducted, and therefore this report captures only a snapshot of the material that is available. Although not all of the strategies reviewed are evidence-based per se, they reflect priorities, trends and interests and show promise for promoting beneficial outcomes. The research in this area is limited and family engagement practices are only beginning to emerge as an area of research and evaluation.

The information contained in this report is intended to serve as a reference guide and inform policies and practices in family engagement in child and youth mental health. It outlines current knowledge and understanding regarding family engagement in child and youth mental health. The objective is to provide a guide to assist in the evaluation and selection of practices that support family engagement.

In light of the vast amount of literature that was found, this review incorporates only a subset of the available resources. To help facilitate knowledge transfer, a bibliography of resources is also available. The majority of these resources is available via the internet and thus is easily accessible. To obtain this bibliography, please contact the FORCE Society for Kids' Mental Health.

Definition of Family Engagement

For the purposes of this report, family engagement is defined as

> "Any role or activity that enables families to have direct and meaningful input into and influence on systems, policies, programs, or practices affecting services for children and families" (New York State Council on Children and Families, 2008).

Although there are a variety of terms used in the literature on family involvement, we have chosen to use the term "family engagement". As Steib (2004) noted,

> "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".

Engagement involves a commitment to working with families and to unite together. Engagement is reflected in the <u>partnership</u> between the CYMH system and families. Partnership does not mean that parents and professionals assume each other's roles, but rather that they respect each other's roles and contributions. While professionals bring clinical knowledge and expertise to this relationship, parents offer the most intimate knowledge of their children and often special skills (Allen & Petr, 1996).

Smith (2002), defined engagement as

> "the act of doing something for your child, your self, or your family that determines or derives from a care plan or supports the delivery of services and supports."

Engagement means both engaging families **in** services (e.g., ensuring access and overcoming barriers to seeking services to involvement in assessment, treatment and care planning) and engaging collaboratively **with** families to ensure quality mental health services for children and youth.

Engagement goes beyond direct services to include the "participation of families and youth with the intention of improving or enhancing service planning and delivery of treatment, services, family supports, or care." (Holden & Santiago, 2001)

Elements of Family Engagement

The diagram below illustrates the multiple elements that make up family engagement.
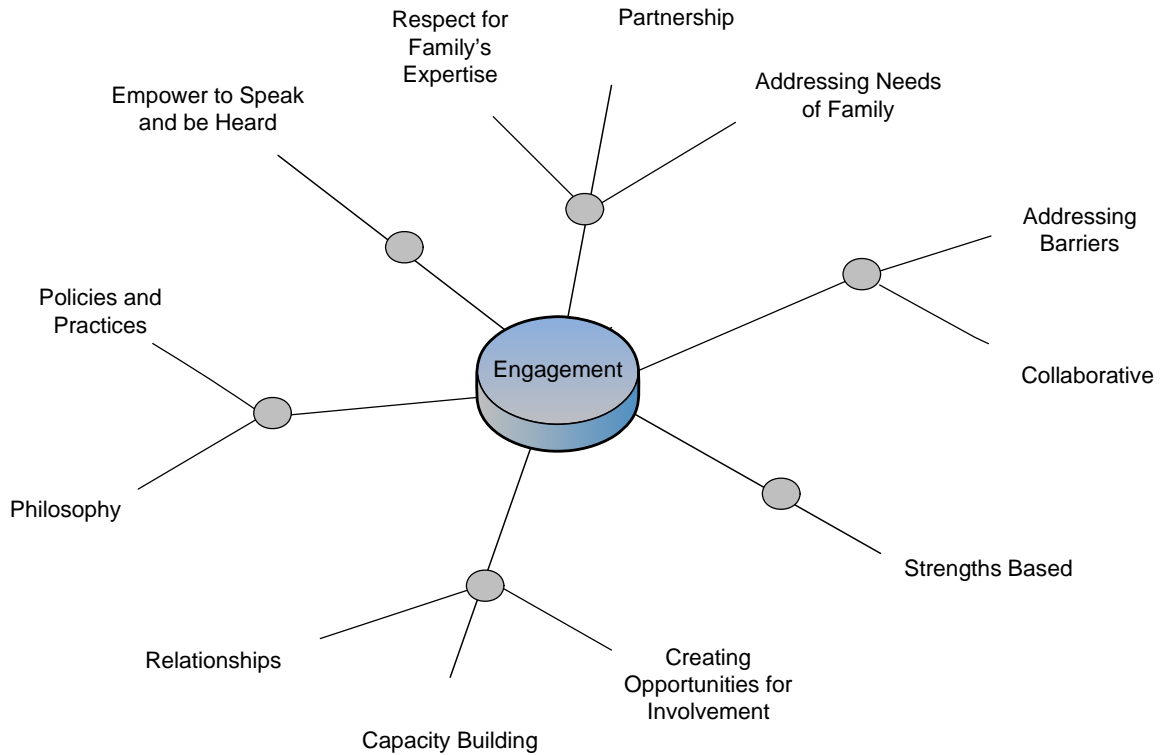
As this report will demonstrate, "family engagement" is not a simple construct, but rather is made up of key elements that work together to ensure ongoing involvement of families as partners in children's mental health. Mental health is best achieved when there is input and involvement by families of children and youth dealing with mental health challenges.

Definition of Family

Family is a complex concept to define. The following definition has been adopted for the purpose of this report:

"Families are big, small, extended, nuclear, blended, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, fostering, adoption, marriage, or from a desire for mutual support. Together, our families create our neighborhoods and communities."[1] (Pediatric Care Online, 2008).

Even though our concept of "family" has changed over time, some have rightfully argued that the importance of family to the welfare of individuals remains the same.

> Family forms are many and varied, beyond the boundaries of those defined through partner and 'blood' relationships. Whilst family forms and definitions change, the importance of family for the experience of both interdependence and individual support and wellbeing remains.
>
> (Cabinet Office: Social Exclusion Task Force, 2008)

Traditional Service Delivery and Family Engagement Model of Care

The system of care for child and youth mental health has evolved over time, with the increase in understanding about child and youth mental health, effective treatments and supports, and the essential ingredients needed to deliver quality services.

Traditionally the service model has been one in which mental health professionals take on the role of expert who assess the child and decide the best course of action. Parents might play a role in providing information about the child but have not been consistently consulted and included meaningfully in treatment and service planning. The focus tends to be on the child, although parents may be referred to parenting classes or family therapy if the professional feels it would be helpful to child. The emerging paradigms of recovery, empowerment, early intervention, and building family and community capacity have begun to change the way that families are helped.

The chart below outlines some of the differences between the traditional (professional as expert) model of care and a family model of care (family as full partner).

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[1] Based on definition used by the Young Children's Continuum of the New Mexico State Legislature.

Traditional Model of Care	Family Model of Care
Focus is on the child. Narrow focus on the individual client as the recipient of care and the resource for change	"Family" is the client and a resource for change. Child's needs are considered within an ecological framework of which family is central in the life of the child.
Professionals are trained and expected to "fix" the problems in the child. Professionals placed in the role of being an "expert" with the knowledge and skills to provide interventions and "treat" the child Professional directed - in charge of care	Families are experts on their child Family firmly in control of the service delivery process, with the professional serving as an agent
Concentration on pathology or deficits Possible that the family may be viewed as the source of the problems, as an obstacle to the child's growth, or as irrelevant to the intervention process	Strengths, capabilities, resiliency and skill building of families are emphasized Families are viewed as critical partners in the child/youth's recovery
No supports automatically provided to the family	Families supported in their caregiver role and in dealing with the impact that the illness had on their family
Families may or may not be involved in mental health treatment planning and services provided. May avoid or minimize involvement with the family, according to the professional's goals	Professionals are friendly and respectful to families and focus on developing a positive collaborative working relationship Family engagement is a key part of the process
Treatment needs of the child and family are assessed by the expert and goals are established according to the "problems" presented	Relying upon family choice or decision making Family is the director and consumer of the service delivery process
Limitation of client choice and responsibility Professional decides how existing services can be used to meet the client's needs	Families are empowered. Choice through informed decision-making and self-responsibility are supported
Families are passive recipients of services professionals decide should be given to the family	Families are active participants in all aspects of services and involved in decisions about care.
Evaluation of services/programs and monitoring of quality are based upon the needs and function of the agency; outcomes are based on reduction or symptoms or cost savings.	Families assist in evaluation of service; outcomes are measured through enhancement of family management and quality of life. Families decide what their needs are and goals are established in accordance with the outcomes they see as important.
Policy, practices and procedures are set by professional committees and advisors	Families involved as partners in decision making at all levels of the system

Family Engagement Concepts

As Spragins (2007) noted in her review of family-centered practices, there are multiple terms and overlap in the terms referring to the active role families play in the child and youth mental health and welfare care. The most commonly used terms found in this review are: family engagement, family involvement, family empowerment, family-centered, family focused, and family-driven.

Family engagement has most often been discussed with reference to initial engagement of families in service.

> "Engagement has been defined as a process that begins with a child being identified as experiencing mental health difficulties and ending with a child receiving mental health care. More specifically, engagement in care is described as beginning with the recognition of a child mental health problem by parents, teachers, or other adults within a child's context. (McKay, 2004 p. 906)

Engagement has been thought of as a process by which a family comes to understand their child is in need of mental health care (Trunzo 2006). The initial part of engagement is when a parent makes the decision to seek services, makes the call for obtaining an intake or assessment, and attends the scheduled appointment (Holm & Hansen, 2004).

Getting a child into a first appointment is not enough. Engagement goes beyond the initial encounter with services -- it is a process that continues throughout the delivery of services.

> "At different stages of treatment, when new themes emerge or different interaction patterns are targeted for change, new barriers to retention can emerge in different family members. Keeping the family members engaged at these points in the therapy process requires the same thought and skill required early in treatment." (Coatsworth, Santisteban, Mcbride, & Szapocznik, 2001)

> "Engagement is the basic task of mental health care but can never be taken for granted and must always be worked for"
>
> (Adapted from Ayre, 2007)

To complicate matters, *family engagement* has also been used to refer to a broader involvement within the system.

> "Engagement is the act of doing something for your child, your self, or your family, that determines or derives from a care plan or supports the delivery of services and supports. Engagement is also participation of families and youth in governance, management or evaluation activities with the intention of improving or enhancing service planning and delivery of treatment, services, supports, or care for children in the community as a whole. Families may engage in different ways and intensity as their child's and family's needs change or as opportunities to become engaged in their child's care or in the system vary." (Osher, Xu & Allen, 2006)

Family Involvement

The term *family involvement* is generally used to encompass involvement at all levels of the child and youth mental health system.

> "Any role or activity that enables participating families to have direct and meaningful input into and influence on systems, policies, programs, or practices affecting services or community life for children and families". (New York State Council on Children and Families, 2008)

Wood (2004) defines *family involvement* as "respecting families as experts on their children, enlisting them as partners in the care of their children, supporting them in their caregiver role, and involving them as partners in decision making at all levels of the system".

Family involvement means that families have the opportunity to be involved in every aspect of mental health care. They are empowered to speak and be heard with respect to their family's needs and to actively participate in the designing and shaping of their child's mental health care, and to have voice and choice in when and how services are to be delivered. *Family involvement* also includes opportunities for families to influence systems change with their ideas, concerns, and strategies in pursuit of a common goal: to improve the quality of life for

> When you ask families, 'were you involved in the development of your child's plan?' they respond with, 'they asked me to sign it.' When you ask further, 'were you involved in its development, and were you assigned equal decision making power regarding the services and supports your family needed?' they responded, NO!"
>
> (Wood, 2004)

children and families. *Family involvement* can help to ensure that policies and service design reflect families' needs and preferences. Ultimately this will create more effective mental health care.

Family involvement has also been conceptualized as "a guiding set of values and principles around which community mental health can be organized." (McBride, Ostrogorsky & Hurt, 2004)

Family Empowerment

The term "empowerment" is widely used in mental health. Empowerment is seen as building confidence, insight and understanding, and developing personal skills and having a voice in decisions that affect the individual.

Family empowerment has been conceptualized as "a process by which the families access knowledge, skills and resources that enable them to gain positive control of their own lives as well as improve the quality of their life-styles" (Singh, 1995, p. 13). Heflinger, Northrup, Sonnichsen, & Bickman (1997) conceptualized empowerment as "enabling parents to become collaborators in their children's mental health treatment".

Generally *family empowerment* focuses on promoting resources, competence and self-efficacy of families; having or taking more control over all aspects of their life, including mental health care.

> It appears that for many professionals collaboration means involvement in treatment — mandatory family therapy — and learning how to parent or being present at a meeting to receive information.
>
> (Borden and Fine, 1996)

Family-Focused

The term *family-focused* has been used to refer to plans, services and evaluation processes that focus on the whole family and not just on the child. In contrast to child-focused approaches which address needs of the child, *family-focused* approaches also work to address the needs of the family. The child and family are considered the client, rather than just the child alone. Both family and child strengths are addressed (SAMSHA 2004).

However, the concept of *family-focused* has been criticized in that it limits the extent to which families determine how their needs can be met.

> In a *family-focused approach*, families are seen as capable of making choices from options that the professionals deem important. Professionals provide advice and encouragement to families on the basis of their choices, and interventions focus on monitoring family use of professionally valued services. (Dunst et al., 2002, cited in Spragins, 2007)

In addition, evaluation of services may still be based on professional and agency determined criteria. Osher and Osher (2006) noted that practices in many communities still revolve around the needs, expertise, and resources of professionals and agencies.

Family-Centered

A *family-centered* care philosophy starts from the premise that families have a critical role to play in supporting people with mental health and/or substance use concerns and in promoting their wellness (Community Research, Planning and Evaluation Team Community Support and Research Unit, 2004).

The term *family-centered* is both a philosophy and practice for working with families.

> "Family-centered service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses upon the strengths and capabilities of these families." (Allen & Petr 1996, p. 68).

Family-centered care extends support beyond the young client and focuses on meeting the needs of both clients and families. The approach emphasizes relationships, and the needs to build on the strengths and interconnectedness of families.

One principle of family-centered care is that interventions which strengthen the family will help all members of the family (Wells & Fuller, 2000).

> Family-centered treatment is not simply a new technique that can be learned by frontline clinicians. Family-centered treatment involves the program's philosophy, organization, financing, staffing, and many other policies and procedures.
>
> (Ooms & Snyder, 2007)

"In a *family centered* approach, families are considered to be fully capable of making informed choices and acting on them. The professionals view themselves as family agents and help families strengthen existing skills or acquire new ones. Interventions emphasize capacity building and resource and support mobilization by families" (Dunst, Boyd, Trivette, & Hamby, 2002).

> Adopting a family-centered care philosophy requires a shift in organizational practices and in the attitudes and behaviours of individual providers from a model in which professionals are seen as the only people in possession of expert knowledge to a model that is based on *knowledge exchange* and *partnership.*
>
> (Community Research, Planning and Evaluation Team Community Support and Research Unit, 2004)

Family -Driven

Of all the terms, *family-driven* seems to be the most encompassing, with families being the primary decision-maker and driver of services.

"*Family-driven* services exist when the beliefs, opinions, and preferences of every child, youth and their family/caregiver are a deciding determinant in service planning on the individual level; are a significant determinant in

program development and implementation at the agency level; and are integral to legislation and appropriation at the policy level. Children, youth and their families/caregivers make the decisions about their own care and participate in developing and implementing strategies for mental health system improvement" (United Advocates for Children in California, 2008).

Traditional children's mental health services have been described as "provider-driven" in that professionals and agencies were viewed as the key force in solving problems.

"Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

- choosing supports, services, and providers;

- setting goals;

- designing and implementing programs;

- monitoring outcomes;

- participating in funding decisions; and

- determining the effectiveness of all efforts to promote the mental health and well being of children and youth."

By involving family and youth **at all levels** a system of care assures itself that the culture of the system will be impacted by the perspectives and the cultures of the families and youth in the community.

(Penn & Savage, 2004)

(Federation of Families for Children's Mental Health, 2008)

Friesen & Pullman (2002) noted that in the United States

"The full participation of family members in planning, implementing, and evaluating services for their children with mental health needs is increasingly accepted as an essential aspect of planning and providing mental health services to children and families. The Surgeon General's report on mental health acknowledged family members as "essential partners" (U.S. Department of Health and Human Services, 1999), both at the individual child and family level, and as key participants in system-level planning and evaluation."

Benefits of Family Engagement in Child and Youth Mental Health

Family engagement not only benefits families as their needs are more effectively met, but can also help to improve the system of care. Families are being regarded as essential allies in the provision of services. They bring knowledge about their child that is invaluable to the

assessment and treatment process and about how the system is experienced. The Federation of Families for Children's Mental Health (2001) has pointed out that, "families provide meaningful, culturally relevant information, from a perspective that <u>no one else has.</u>"

The involvement of families is related to successful treatment outcomes (Kutash & Rivera, 1995; Pfeifer & Strzelecki, 1990). There is some evidence that family involvement in planning, implementing and evaluating services may be a more critical factor in the effectiveness of services for children and youth than the particular type of intervention provided.

Koren, Paulson, Yatchmonoff, Gordon, & DeChillo (1997) found that families are more likely to feel their child's needs were met when they are able to participate in service planning. Curtis & Singh (1996) and Thompson, Lobb, Elling, Herman, Jurkidwewicz, & Helluza (1997) found that families who participated in their child's care felt they have control over the child's treatment.

The evidence base for family engagement with respect to outcomes is sparse. Hoagwood (2005) noted that

> "too few experimental studies exist to conclude decisively that family-based services improve youth clinical outcomes. However, those studies that have been rigorously examined demonstrate unequivocal improvements in other types of outcomes, such as retention in services, knowledge about mental health issues, self-efficacy, and improved family interactions – all outcomes that are essential ingredients of quality care",

Another limitation is that outcome indicators have typically defined by professionals and academics and may not reflect important outcomes defined by families. Hoagwood and Burton (2006) offered some examples of outcomes not typically assessed in child and youth mental health services. These include:

- Degree or levels of family participation in treatment planning
- Degree to which family expectations were met
- Family empowerment
- Working alliances
- Family satisfaction
- Family stress

Family engagement has been researched fairly extensively with respect to service use. McKay, Hibbert, Hoagwood, Rodriguez, Murray, & Fernandez, (2004) reviewed empirical support for introducing engagement interventions into child clinical settings. There is strong evidence that intensive engagement interventions implemented during initial contacts with youth and their families, either on the telephone or during a first interview, can boost service use substantially. Bannon & MacKay (2005) found when there was a match between the parent's preference service offered to children and what the child actually received was significantly associated with longer lengths of involvement in child mental health care.

The Virginia Commission on Youth (2003) noted that following benefits of family engagement in service delivery improvements:

- promotes positive changes in the way children are served. There is increased focus on the family's role in treatment and recovery itself; services are likely to be provided in settings outside of the clinic (such as home, school, etc.); family engagement results in greater cultural sensitivity.
- enhances the process of delivering services and their outcomes and facilitates service coordination. (NCTSN 2008)
- promotes an increased focus on families
- family participation improves the process of delivering services and their outcomes (Knitzer, Steinberg, & Fleisch, 1993).

Additional benefits noted by Gathers (2002) with respect to family engagement in the health care system include:

- help in raising public awareness
- Family members bring important skills and perspectives to training programs for administrators and direct care providers
- Families advocate for improved pediatric/adult medical care
- Families bring an important perspective to system design

Increase in Accountability as a Result of Family Engagement in Care Plans

Family members who play a strong, active role in planning discussions may specifically promote coordination among service providers, and, even in the absence of purposive efforts in this regard, their very presence may provide a measure of accountability that leads to improved coordination.

To some extent, the findings may also reflect the effects of better information because increased participation may afford family members the opportunity to observe coordination efforts that would otherwise go unnoticed. Regardless of the functional reason, the findings support efforts to increase family participation as an important part of the service coordination process.

(Koren, Paulson, Yatchmonoff, Gordon, & DeChillo, 1997)

Barriers (and Supports) to Family Engagement

Barriers have been discussed and researched with respect to accessing or the initial engagement with services. Barriers that impact on family engagement at the policy and planning levels have also been examined.

Family engagement can be hindered by attitudes, procedures or policies, and the lack of training opportunities for families or professionals.

Spencer and Gehring (2008) identified the following barriers as seen from the perspective of parents:

- We can be scared. Make sure the environment is safe and comfortable for families and youth to speak frankly with honesty without incriminating themselves.

- We can be misinformed. Make sure families have a "roadmap" with all the information they need to understand what is being discussed – be accurate and factual not judgmental.

- We can be isolated. Open up multiple lines of communication with families and connect them to other families.

- We can be confused. Watch the vocabulary – avoid acronyms and technical jargon.

Collins and Collins (1990) discuss how professional attitudes and perceptions of parents can be a barrier to family engagement.

> What parents describe as the parent-blaming attitudes of professionals may be better understood as a reflection of the cultural tendency to blame mothers. The traditional orientation of mental health professionals is toward pathology and the weaknesses or inadequacies of parents, usually mothers. (p.1)

Duchnowski & Kutash (2007) reviewed barriers to parent involvement in the school system when a child had special educational needs. Barriers identified included:

- Parents feel overwhelmed and isolated by lack of information

- Parents feel intimidated by unequal power

- Parents feel blamed and disrespected by school personnel

- Parents have experienced poor school customer service

Professionals have at times contended that "some families don't want to be involved". Anecdotally, they report that some parents "expect" to drop off their child and have the clinician "fix" them. A report by the Cabinet Office Social Inclusion Task Force (2008) encouraged professionals to understand the family's own perspective.

> Family members' perspectives may redefine the problem of resistance as one bound up with feelings of defeat, complexity of life and anticipated disappointment. However these narratives are difficult to achieve particularly if conflict has been the defining quality of all previous engagement with professionals. (p.7)

Another barrier to professionals and families working together that has been identified is lack of experience and training mental health professionals have in working with families (Kaas, Lee, & Peitzman, 2003).

Not to be forgotten is that many professionals working with children, youth and families, outside of mental health specific fields, often do not see that mental health of children, youth and families is 'part' of their job.

Challenges outlined in a national policy brief by the National Child Traumatic Stress Network (2008) include:

- Staff attitudes and misconceptions about families' mental health service needs. This can be a barrier to creating a "family engagement culture" where families may feel "welcomed, respected, supported or heard by agency staff."

- Stigma is another barrier to seeking help or involvement with services.

- Lack of finances or other resources. Families dealing with low income, major life stresses and single parenthood may find it difficult to be fully involved. Having to take time off work; not having transportation or child care are impediments to attending meetings.

Kruzich, Jivanjee, Robinson, Friesen (2003) reported the following barriers were identified by families as impeding involvement in their child's care:

- Distance from service providers
- Caregiver's work schedule
- Cost of transportation
- Lack of access to transportation
- Child care arrangements
- Cost of child care
- Lack of communication between staff from different programs or agencies
- Lack of open communication
- Lack of opportunity or encouragement to participate in the child's treatment
- Inflexible visiting and meeting schedules
- Lack of clarity about whom to contact with questions and concerns
- Negative staff attitudes about the family
- Restrictive policies
- Lack of consideration for cultural values

The Family Involvement Learning Collaborative (2008) offers a number of "flip chart notes" which include barriers families face when seeking helping for an adolescent with a substance abuse problem. These barriers were identified by administration and staff.

Barriers identified included:

- Transportation
- Staff resources
- Hopelessness
- Lack of trust:
- Cultural competence

The following were identified by families as supports to their participation:

- Provision of a contact person
- Notification of caregiver when something was wrong or if there were health or other concerns about the child
- Flexible scheduling of meetings
- Information about rights and grievance procedures
- Comfortable and private space for meetings
- Prompt return of phone calls
- Inclusion of caregiver's comments in the child's records
- Support for transitions into or out of services or programs
- Communication with all relevant family members
- Help with transportation costs
- Help with telephone costs
- Assistance with child care costs
- Caregiver treated with dignity and respect
- Caregiver made to feel that his or her participation was important
- Caregiver made to feel welcome
- All family members encouraged to participate
- Responsiveness to the family's cultural values

(Kruzich, et al., 2003)

- Lack of time: family and staff time management

Koroloff, Hunter, & Gordon (1995) conducted an analysis of family involvement in policy making. The following barriers to involvement in policy development were identified by parents:

- Lack of time and energy
- Family Crises
- Disruption in Home Life (when one parent is away to attend meetings etc.)
- Available Child Care
- Blame or Stigma
- Vulnerability
- Meeting Times and Location
- Reimbursement for Expenses
- Representation (Tokenism)
- Lack of Appreciation for Cultural Differences
- Language Barriers
- Professionals' attitudes to family member participation
- Professional subculture
- Slow Process of Change
- Lack of Available Services

Role of Families in Child and Youth Mental Health

Although family engagement is most often connected to direct service provision, it extends throughout the system. Families can (and need to) be involved in multiple roles and levels within systems. Ways in which families can become engaged include:

- Involvement in case planning/treatment
- Families as service users
- Involvement in service delivery (in-service or contracted support services)
- Decision-making within service delivery
- Involvement in service evaluation; monitoring service planning; and strategic planning.
- Advocacy for families
- Involvement in policy and advisors to government funded services

Evolving roles of families

- Cause
- Patient
- Credible informant about their child
- Partner in treatment planning
- Service evaluator and research partner
- Policy maker

(From: Duchnowski & Kutash, 2007)

McCammon, Spencer, & Friesen (2001) identified similar roles for families but added:

- Family members as context (i.e., they are a critical part of the child's life); and
- Educators and trainers of professionals, students, and other family members.

Family Engagement Across All Levels of Mental Health Services

In the table below, are examples how families can be engaged across the three main levels of mental health care.

Individual Service	Service Delivery	Policy
• Engaged in the assessment of their child's and family's needs • Actively supported in their role of parent • Are informed about the process, treatment options and outcomes • Meaningfully involved to support their child during treatment	• Parent support staff positions • Participation in quality improvement processes • Evaluate services in terms of process and outcomes • Co-trainers in the education, training, and professional development of mental health professionals • Involved in the recruitment of staff and development of professional competencies • Development of educational resources for families	• Active involvement in the reviewing and writing of policy • Participate in task forces, work groups, or councils that inform the field of issues and trends • Engage in family-based evidence gathering around best practices

Family Engagement at the Individual Service Level

Initial Engagement Strategies

Establishing a relationship between the service provider and the family as early as possible in the service pathway has been shown to increase attendance at initial appointments (Staudt, 2003). Staudt also suggests that

> "Building on this early relationship throughout the family's participation in services, by attending to the family's concerns and needs and engaging family members as equal partners in the help seeking process, helps ensure sustained engagement in services."

There is evidence for a variety of strategies and methods professionals can use to help increase the likelihood of families engaging in services – both initially and over the course of service. Strategies that have been evaluated include:

- Making contact with the family prior to the first appointment: Evidence suggests that contact through phone calls, letters, actual visits, or requests to complete forms prior to the first can increase attendance at the first meeting (Deane, 1991; Kourany, Garber, & Tornusciolo 1990; MacLean, Greenough, Jorgenson, & Couldwell, 1989).

- Using reminder letters: Parrish, Charlop & Fenton (1986) found that reminder letters that indicated a consequence for missing an appointment or a reward for keeping it increased attendance at initial appointments. An example of a consequence is placing the family on a waiting list if more than three appointments are missed. An example of a reward is placing the family's name in a monthly prize lottery for each kept appointment.

Additional methods for increasing family engagement include:

- Comprehensive Referral Pursuit and Maintenance Approach (CRPMA): CRPMA was developed by Szykula (1984) to increase treatment retention. Both the referral source and the therapist meet with the client at the first appointment. The belief is that when the referral source is someone already familiar to the family, their comfort level will increase. The approach is flexible and meetings can take place in the family's home and at times that are convenient for families. The approach also helps families locate needed resources (e.g., housing, transportation).

- Use of Paraprofessionals: Paraprofessionals who assist families in accessing and using mental health services .has been shown to increase attendance at first appointments (Staudt, 2003). There is some suggestion that the use of paraprofessionals to meet family needs such as information about services, respite, transportation, can increase attendance at first appointments and decrease drop out rates.

- Combined Engagement Intervention: A combined engagement intervention consists of both an initial contact (by telephone) and a first interview that is focused on family engagement can increase initial and ongoing use of services (McKay, Stoewe, McCadam, & Gonzales, 1998)

- Engage the Whole Family and Address Family Concerns Not Directly Related to Parent-child Interactions: Including family concerns such as the stigma of seeking help, work concerns, marital difficulties, and financial worries can increase both attendance at first appointments and continuation with treatment sessions.

- Strategic Structural Systems Engagement (SSSE): The focus of this approach is on establishing an alliance with all family members. Information is sought on the family members' interests and values. The approach is flexible and meetings can take place in the family home. This approach has been shown to increase attendance at first appointments of Hispanic families with adolescent drug abusers (Santisteban, Szapocznik, Perez-Vidal, Murray, Kurtines, & LaPerriere 1996; Szapocznik, Perez-Vidal, Brickman, Foote, Santisteban, Hervis, & Kurtines, 1988). SSSE focuses on establishing an alliance with the other family members. The service provider also inquires about family members' values and interests, and calls significant others to gather more information about the family. Home visits to the family are made if necessary.

- Enhanced Family Treatment is another approach that has been found to increase retention. In this approach, the therapist works to address parental concerns that go beyond the difficulties that led the family to seek help (Staudt, 2003).

- Train Staff to Show Consistent Respect for Families: Training of professionals is associated with higher participation rates in parenting programs. Training includes specific communication, encouragement, and disciplinary techniques to staff and may increase retention of families in services (Dumka et al, 1997).

(Safe Start Demonstration Project, 2005)

Ongoing Engagement With Families

There are a variety of models that are currently used to increase family engagement. Engaging families in treatment and service requires a shift from conceptualizing the family as the source of (or significant contributor to) the child's problem or not necessary to resolving the child's problem to viewing them as partners in care. Both the professional and family are acknowledged for the expertise they bring -- the parents bring knowledge of their child and family, and culture and the professional brings knowledge of mental health challenges and treatment.

Meaningful family engagement requires families and professionals be empowered to work in partnership. The climate needed is one of collaboration, respect and trust. Together as a team, they identify how to best support the needs of the child and family (Winters & Pumariga, 2007).

The United Advocates for Children of California (2008) have endorsed the above beliefs and extend their model to:

- Children, youth and their families/caregivers are the primary decision makers with respect to care planning. These decisions are based on a partnership with their provider(s).

- Care plans are tied to the family's beliefs, opinions and preferences.

- Families are respected and valued throughout the process

- Stigma including shame, guilt and blame are acknowledged and families are supported so that the stigma is not perpetuated.

- Families are given easily understood information on mental health disorders, the process for obtaining help and services, assessments and care, legal rights and protections.

- Services and supports build on the strengths of the child and family.

- Children, youth and their families/caregivers are offered clear, easy to understand information that is necessary for them to be full and meaningfully involved in service planning.

- All communication with the family is clear and honest.

Family Involvement in Team Decision Making

Brinkerhoff and Vincent (1987) provide an example of family engagement in team planning. The researchers compared the participation in team meetings by two groups of families of children with disabilities. The experimental group participated in a developmental assessment of their child, (b) recorded their family profile, and (c) met with a school or community liaison assigned to their family. The families in the control group were given no specific instructions or activities prior to meeting with the team. The results showed that the parents in the experimental group presented their goals and concerns before professionals presented theirs, suggested more goals, and made more decisions than the parents in the control group. The authors conclude that parents who are invited to participate in preparatory activities prior to the actual meeting are more likely to contribute more fully at a team meetings.

Families as Service Providers

Family members of children with mental health challenges have been providing services to families through self-help groups as well as often serving as de facto case managers (Ignelzi & Dague, 1995). In the past, (and to some extent today), these services were provided for without any funding.

As parents gain a stronger role in the provision of mental health care, agencies and organizations are increasingly funding parents to provide support to families. These paid positions go by a variety of job titles. For example, parents are employed as "System of Care Facilitators" through initiatives in Illinois and Rhode Island. Families reported increased knowledge regarding their children's disabilities, how to care for them and obtain services as a result of working with a Family Resource Developer (Osher, DeFur, Spencer, & Toth-Denis, 1999). Elliott, Koroloff, Koren & Friesen (1999) provide a description of the "Family Associate" position and the benefits it had for providing outreach to low-income families.

"The world of being a parent of a child with serious emotional or behavioral issues is challenging, frightening and very lonely. Your child is often viewed as a 'bad kid' or you are seen as a less than adequate parent. Meeting and talking with other parents who are experiencing similar issues can bring some comfort and strength that no other connection can bring.... It is an opportunity to share ideas and resources along with just 'letting your hair down' with one another. It can bring a restoration and renewal that allows you to continue walking tall to help your child and your family."

Elizabeth Vickery, Mother
(Webber, 2005)

An example of a family member staff position is the "Family Advocate":

> "A family advocate has personal experience in dealing with a child that has an emotional, behavioral, and/or mental health challenge. *The family advocate has walked the walk, learned from the experience of the journey, and is willing to help other parents or caregivers benefit from their experiences." (Webber, 2005)*

Family Advocates

- Provide emotional and informational support – parent run support groups and one-on-one parent support

- Identify unmet needs and create ways to meet those needs. Parents are linked to other parents and community based and professional resources

- Provide education opportunities that help parents understand mental health, services available, related issues and laws

- Advocate for individual families and for fair and responsive policies that affect all families; sit on policymaking, planning and oversight boards

- Support Professionals in Service Delivery - partner with the professional in a way that allows the professional to focus on their area of expertise while the Family Advocate provides social and other supportive services

Wells and Reiss (2002) published a training manual entitled "Making It Work: When Families That Represent a Service Population Become Employees. The training centers around helping leaders and family members interested in developing family member staff positions.

Family Engagement and Professional Training

Family Members as Co-Trainers

The expertise that families have with respect to their needs and experiences in child and youth mental care is invaluable to training professionals. Family trainers provide an "insiders" viewpoint. Understanding family's experience enables professionals to strengthen their skills and approach to better meet the needs of families.

McCammon, Spencer & Friesen (2001) noted that "family members are increasingly being used as trainers, educators and consultants within mental health programs (cited in Spragins 2007 p.14). Parents have also been active as educators on university campuses (Osher, deFur, Nava, Spencer, & Toth-Dennis, 1999). Werrbach, Jenson, & Bubar (2002) described a curriculum program (for paid parent staff and professionals) delivered co-jointly by parents and professionals.

Service Provider Training in Family Engagement

An example of Family Engagement Training for Providers is McKay's (2004) "Evidence-informed engagement training for CATS providers". The training consists of an eight hour intensive workshop. The focus is on helping service providers understand child, family, community and system level barriers and develop a set of strategies to overcome these barriers. Training is divided into two parts: 1) first contact engagement skills and; 2) initial interview engagement skills. Providers learn ways to discuss "difficult to talk about" barriers with caregivers (e.g. stigma, mistrust of professionals, fear of being blamed) and engage in proactive problem solving around concrete obstacles to care. Training elements include:

- A review of evidence based engagement interventions
- Identifying and practicing telephone engagement skills
- Helping providers examine their perceptions of barriers
- Practice skills related to the initial face-to-face interview with a family

- Supporting professionals' abilities to develop collaborative working relationships with families
- Helping professionals identify an immediate and practical concern of the family that can be addressed in the first meeting.
- Facilitation of skills related to the development of a shared commitment, language and understanding with the family.

Empowering Families to Become Active Partners

The Parent Empowerment Program (PEP) for Professional Parent Advisors (Jensen & Hoagwood, 2008) is an example of training for parents. This training targets family advisors/advocates who work directly with parents. The program is co-led by an experienced parent advocate and mental health professional to model collaboration. The goals of the training are to enhance family advisors' knowledge of evidence-based practices and their skills in working with parents, and to "improve parent activation and youth mental health".

Family Engagement at the Policy Level

The Federation of Families for Children's Mental Health plays an active role in the development of both national and state policy through its national office and state branches. State mental health services also recruit and train parents to assist in policy development. The example below describes the process used in Florida to engage families in policy reviews and development.

> Policymakers' image of their client is disproportionately focused on individuals, with families relegated to the periphery of policy development, implementation, and evaluation.
>
> (Moen and Schorr, 1987)

"The Children's Mental Health central office asked the district Children's Mental Health Specialists and the SEDNET Project Managers to recruit two parents per district who expressed interest in working with us at the district and state levels on planning and policy issues. Thirty parents were recruited and, with the help of the Florida Mental Health Institute and the Family Network on Disabilities, Children's Mental Health staff provided two days of training for the parents, including strategies for effective collaboration with professionals and advocacy for their children. Training was also provided for the district Children's Mental Health Specialists on strategies for recruiting, retaining and effectively collaborating with parents. This training focused on practical tools for partnering with families and assisting them to become task force members, reviewers of grants and policies, advocates for system of care issues and resources, and mentors for other families" (Florida Florida Department of Children and Families, 1996).

Family Oriented Research in Child and Youth Mental Health

In the past, family-oriented research has been focused on parental contributions to the child's emotional problems, or on developing and testing interventions aimed at changing the parents' or family functioning (Friesen, Yatchmenoff & Gordon (1998).

Within the past two decades, there has been shift to knowledge and evidence-based practices with respect to increasing family engagement; the benefits it has for families. Families are also beginning to be meaningfully involved in the design and collection of data. (families as researchers).

Family Engagement in Evaluation and Continuous Quality Improvement

Family involvement in evaluation of services and programs ranges from being in the role of participant (e.g., satisfaction surveys or focus groups) to fully incorporating perspectives and interests of families into all aspects of the research.

Building a Science on Family Involvement and Activation

- Nothing about us without us: ongoing and continuous collaboration
- New measurement approaches targeting family-relevant outcomes, not child symptoms
- Draw upon social-organization and behavioral literatures
- Examine mediators and moderators
- Recognize the journey, turning points, individual preferences and choice

(Hoagwood, 2008)

Spragins (2007) found that researchers and evaluators are increasingly recognizing that family participation in children's mental health research and evaluation can lead to improvements in the relevance and quality of research. In the US, family members are engaged as advisors to and members of site review teams for large-scale evaluations, and as evaluation planners and data collectors on evaluation teams. Family members publish research reports and as act as peer reviewers in federal grant processes. Agencies such as the Center for Mental Health Services actively encourage grantees to include family members in research and evaluation.

Family involvement is becoming mandatory in evaluations by organizations providing mental health services. For example, the Comprehensive Community Mental Health Services for Children, Youth and their Families Program specifically indicates the need for family involvement in evaluation (SAMSHA, 2009).

The program requires applicants to "describe how family partnerships will occur and be demonstrated in planning, implementing, and evaluating the project."

Applicants must also "explain how family members and youth will be incorporated into evaluation activities. These activities may include providing feedback on the design and objectives of the evaluation, conducting interviews, analyzing data, and interpreting and

reporting results." The National Evaluation requires that a "family representative on evaluation or case review team" be listed as one of the persons to be interviewed during the System-of-Care Assessment site visits (Federation of Families for Children's Mental Health, 2006b).

Opportunities to involve families have not come without resistance from professionals unused to working in partnership with families. Slaton (2004) outlines some of the concerns raised by researchers and ways to address these issues.

A challenge in the field is that family engagement has been operationalized in many ways – not surprisingly, given its complexity. Staudt (2007) offers some preliminary ideas on the definition and conceptualization of family engagement and future research that helps to fill in our knowledge gaps.

Some limitations of the current evidence based noted by Friesen & Pullmann (2002) include:

(1) Participation has been operationalized as caregiver compliance, receipt of services, number of contacts with the child, or retention of parenting functions such as providing pocket money or cooking meals;

(2) When measures do include caregiver participation in planning services, they tend to focus on professional behaviors and activities designed to invite family participation;

(3) several existing measures do not directly ask the caregivers about their levels of participation, but instead gather information from clinical staff or case records, and;

(4) Some existing participation measures are difficult to administer (lengthy or require case record reviews).

In spite of the challenges, there is an ever increasing number of published research with respect to family engagement. Examples of research topics include:

1. Families' experience engaging in child and youth mental health care (e.g., through focus groups or interviews)

2. The effectiveness of interventions designed increase family engagement as a means to decreasing no-show rates and dropping out of treatment There is a strong evidence base that indicates a significant percentage of families do not come for initial appointments or discontinue with services (Watt, 2007).

3. Research that incorporates family involvement in all phases of design and implementation of the study. An example is Worthington, Hernandez, Friedman, & Uzzell (2001) investigation of successful treatment outcomes and services that promote them for children and families.

4. Environmental scan of family participation in evaluation reported by Osher, van Kammen, and Zaro (2001).

5. Family-Driven Research – designed & conducted by family members who are the researchers. For example, Smith (2002) provides a description of the "Bear Team", a family-driven research project.

Development of Family Engagement Standards for Service

The following standards were developed in Idaho to provide direction and guidance to the Children and Family Services (CFS) programs regarding the importance of Family Involvement in all levels of the Children's Mental Health Program. These standards are intended to achieve statewide consistency in the development and application of the CMH program and shall be implemented in the context of all applicable laws, rules and policies.

The standards include:

- Families of children with serious emotional disturbance shall be full partners in all aspects of planning, developing, implementing, and evaluating the children's mental health system of care for children with SED.

- Each family receiving mental health services for their child/youth from the CFS CMH program shall have the opportunity to provide input regarding those services through an anonymous satisfaction survey

- The Department shall be responsible to assist and support families to be able to participate to the fullest extent possible in the planning for their own child's care.

- Families requested to participate in meetings or activities related to the development or implementation of the system of care can be provided a stipend/honorarium for their contribution and reimbursed for the costs associated with their involvement.

- The Department will provide reimbursement to parents on the ICCMH and on the councils established by ICCMH.

- The Comprehensive CMH Assessment, the service/treatment plan, and treatment services shall, whenever possible, be a collaborative effort between the family and the CMH Clinician and based on Systems of Care core values and the principles of Family-Centered Practice.

  - Everyone desires respect;
  - Everyone needs to be heard;
  - Everyone has strengths;

- Judgments can wait;
- Partners share power; and
- Partnership is a process.

- Families shall be encouraged to include the involvement of other individuals based on their own "voice and choice" during assessment, planning, delivery, and evaluation of the services they and their child are provided.

- It is the responsibility of the Department to empower families by providing them with the necessary information and options to make informed decisions regarding treatment services. (Idaho Child Welfare Research & Training Centre, 2005)

Family Engagement Policy

Child and youth mental health policy in the US is gradually changing to reflect the importance of family engagement. For the most part, policies are not generally available through the Internet. The policy developed by Oregon Department of Human Services Addictions and Mental Health Division is presented here as an example of policy that incorporates family involvement.

In 2006, the Oregon Department of Human Services Addictions & Mental Health Division implemented a policy on family involvement. The policy is aimed at supporting meaningful family involvement and family leadership at the child, state and local levels. Excerpts from the policy include:

- Support participation in state level advisory councils, planning groups and workgroups
- Engage family leaders in the provision of technical assistance and training to state and local providers:
- Develop capacity for family run psycho-educational groups, materials, and support services at the local level.

Summary

Family engagement transforms mental health care from a set of professionally driven services into a partnership whereby families and professionals work together to create positive outcomes for children, youth, and their families. Family engagement refers to meaningful involvement of families in the delivery of mental health care – from direct services to policy development.

The topic of family engagement is receiving substantial interest in child and youth mental health and addictions; youth justice and child welfare. The Federation of Families for Children's Mental Health has been a leader in reforming mental health care in the United States. The National

Federation's chapters and other family run organizations have provided family members of children with mental health needs with support, information, and educational opportunities to facilitate and support family involvement at all levels, and across all systems.

There is more than sufficient evidence that demonstrates the necessity to engage with families in child and youth mental health as families, children and youth are intrinsically woven together, as are their mental health needs.

Family engagement is gaining increasing interest and support in British Columbia. A number of practices reviewed during the process of this literature review are currently implicated in some BC communities. For the past ten years, the FORCE Society for Kids' Mental Health has been partnering with government and nonprofit agencies to identify needs of families and effective practices with respect to family engagement, evidence-based treatments, and continuous quality improvement in services. Family engagement in BC includes:

- The FORCE Society is represented on child and youth mental health committees (provincial and community-based).

- The FORCE Society involvement in critical incident reviews.

- Support and Resource Coordinators are employed in some communities to provide information and resources to families. The coordinators are co-located within CYMH offices. In addition to working with families, they participate in clinical team meetings and act as a resource for clinicians.

- Parent-Professional development and co-facilitation of educational events for families.

- Parent Peer Worker at the Kelty Resource Centre (Family Resource Centre) at Children's Hospital who provides support and resources to families.

- Conference on Engaging with Families for Child and Youth Mental Health (October, 2008) for families and professionals.

- Families' involvement in the development of quality indicators for child and youth mental health and Continuous Quality Improvement.

- At the policy level, seed funding has been provided to develop a Family Council for Child & Youth Mental Health. The Council will be co-chaired by a parent and a youth and will include a membership of foster parents, grandparents, siblings, multi-cultural parents and youth, Aboriginal parents and youth, and others. The intent of this council is to provide input and identify opportunities for family engagement in child and youth mental health across the many systems serving children, youth and families.

The work in British Columbia towards furthering family engagement is ground-breaking in Canada. While there has been progress, there is still much we can do together.

If it is ABOUT families, it must be WITH families... child and youth mental health is about families.

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