Evidence In-Sight:
BEST PRACTICES IN ENGAGING FAMILIES IN CHILD AND YOUTH MENTAL HEALTH

Date: January 2016

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Family engagement

The following Evidence In-Sight report involved a non-systematic search and summary of the research and grey literature. These findings are intended to inform the requesting organization, in a timely fashion, rather than providing an exhaustive search or systematic review. This report reflects the literature and evidence available at the time of writing. As new evidence emerges, knowledge on evidence-informed practices can evolve. It may be useful to re-examine and update the evidence over time and/or as new findings emerge.

Evidence In-Sight primarily presents research findings, along with consultations with experts where feasible and constructive. Since scientific research represents only one type of evidence, we encourage you to combine these findings with the expertise of practitioners and the experiences of children, youth and families to develop the best evidence-informed practices for your setting.

While this report may describe best practices or models of evidence-informed programs, Evidence In-Sight does not include direct recommendations or endorsement of a particular practice or program.

This report was researched and written to address the following questions:

- What are evidence-informed practices for engaging families in child and youth mental health care?
- What does the literature describe as core principles for meaningfully engaging families?
- What are examples of outcomes have been associated with family engagement?

We appreciate your responding to a brief satisfaction survey that the Centre will e-mail to you within two weeks of receiving this report. We would also like to schedule a brief phone call to assess your satisfaction with the information provided and to discuss possible next steps. Please let us know when you would be available to schedule a 15-minute phone conversation.

Thank you for contacting Evidence In-Sight. Please do not hesitate to follow up or contact us at evidenceinsight@cheo.on.ca or by phone at 613-737-2297.
1. Overview of inquiry

As the child and youth mental health sector undergoes significant transition in Ontario, many agencies are seeking to incorporate family engagement practices and processes in their work. In order to support agencies in these activities, the requesting organization is looking for a summary of relevant research conducted to date on evidence-informed practices in engaging family members in child and youth mental health care.

2. Summary of findings

- The child and youth mental health sector is in the midst of a significant paradigm shift towards a more family-centered, inclusive and meaningful system for families accessing care. Family engagement is increasingly understood as the ideal model of service delivery.
- Definitions of family engagement focus on families’ level of participation, collaboration and partnerships with service providers. However, family engagement is not consistently conceptualized in the literature.
- Family engagement is important for several reasons. Families have an intimate knowledge of how the system and its services work, and how they may be improved. Families also have expert knowledge of their child, which is critical in treatment planning and delivery.
- Most outcome studies have focused on the positive impact of family engagement on service use and retention. An emerging thread of research shows that the benefits of family engagement go beyond that, highlighting not only positive outcomes for children, youth and families themselves, but also for the effectiveness of service delivery, organizations and the mental health system as a whole.
- At the level of service delivery, service providers can meaningfully engage families in a number of evidence-informed ways, including viewing families as experts, promoting families’ active participation in care, investing in relationships and therapeutic alliances, addressing barriers to engagement, ensuring culturally-responsive services and tailoring services to fit families’ needs and preferences.
- At the organizational level, family engagement involves integrating families’ perspectives across governance, programming, policy and evaluation activities in agencies. Facilitators of family engagement in this sphere include ensuring commitment from leadership to take up family engagement as a key process, modifying organizational structures and processes to integrate the family voice, building and sustaining relationships with families, providing training opportunities to build capacity in family engagement for staff and leaders, actively supporting families to engage in the organization and evaluating engagement efforts.
- Fostering system-wide family engagement requires ongoing, concerted efforts from multiple stakeholders. At the system level, facilitators of family engagement include partnering with family advocacy (or family-run) organizations, gaining commitment from system leaders to ensure family engagement across organizations, building strategic relationships with families and mobilizing knowledge and information about family engagement across the system.

3. Answer search strategy

- Search terms: family engagement, family involvement, family participation, family-focused, family-centred, policy, governance, advocacy, service delivery, mental health, child, youth.
- Databases searched: Google, Google Scholar, University of Ottawa Library (Scholars portal, PubMed, AMED Allied and Complementary Medicine, Mental Measurements Yearbook, PsycINFO, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) without Revisions)
4. Findings

Family engagement in child and youth mental health care is based on the premise ‘nothing about us without us’ (Chovil, 2009; Heywood, 2009). Dominant service delivery models view service providers as the sole experts on children and youth’s mental health; conversely, family engagement involves understanding families, particularly caregivers1, as co-experts in care, recognizing their unparalleled knowledge of their children’s potential, experiences and lives (Chovil, 2009). To this end, family engagement draws on families’ strengths, insights and expertise to inform and improve direct child and youth mental health services (McKean et al., 2012). It also draws on families’ experiences as recipients of services and calls upon their unique insights on services to inform operations across entire organizations and systems of care (Ferreira, 2011; Friesen, Koroloff, Walker & Briggs, 2011; McKean et al., 2012).

Families have long been denied a voice in their children’s mental health services (Ferreira, 2011; Friesen et al., 2011; Spencer, Blau & Mallery, 2010). Less than three decades ago, caregivers were primarily viewed as contributors to children’s behavioural and emotional problems, leaving them with minimal, if any, roles in being a part of the solution (Ferreira, 2011). In the past twenty-five years, however, families’ empowerment has risen dramatically in the child and youth mental health field as caregivers are gaining a voice and choice in service delivery (Friesen et al., 2011; Spencer et al., 2010). Most recently, the family voice is beginning to influence system-level change as caregivers are articulating insightful perspectives on service infrastructure and policies that affect their children’s lives (Friesen et al., 2011; Ferreira, Hodges, & Slaton, 2013; Spencer et al., 2010). The child and youth mental health system is beginning to shift away from a “service providers-as-experts” approach and towards a more inclusive and meaningful system for children, youth and families. As a result of this ongoing paradigm shift, policy-makers, researchers and practitioners increasingly understand family engagement as an evidence-informed best practice and as an integral component of the ideal model of service delivery (Chovil, 2009; MacKean et al., 2012; Manion & Smith, 2011).

Despite the growing influence of the family voice in child and youth mental health care, there is still room for much learning and growth in family engagement research and practice (Spencer et al., 2010). There appears to be a lack of peer-reviewed research focused on family engagement (Chovil, 2009), not to mention that a common language for and understanding of family engagement has yet to emerge in the literature (Hoagwood, 2005; Staudt, 2007). The implementation and evaluation of family engagement efforts within mental health agencies also lack a consistent and systematic approach (Ferreira, 2011; Hoagwood, 2005; Jivanjee & Robinson, 2007). Importantly, families still often perceive a lack of engagement in services, as many report feeling excluded from decision-making, isolated by lack of information and frustrated from having to repeat their stories multiple times before getting the services they need (Chovil, 2009; Duchnowski & Kutash, 2007; Heywood, 2009).

This report aims to offer a snapshot of family engagement based on grey and peer-reviewed literature by defining family engagement, discussing the evidenced outcomes of family engagement, and providing an overview of family engagement practices in service delivery, as well as at the organizational and system levels.

1 Throughout this report, the terms “caregiver” and “parent” are used interchangeably, as per the research literature.
4.1 Defining the concept of family engagement

A shared definition in practice

The Centre and the Ministry of Children and Youth Services (MCYS, 2013) both define family engagement as an active partnership between families and services providers, which involves listening to what families have to say, engaging in two-way communication and seeing the families as partners and allies in children and youth’s mental health. This definition of family engagement seems to transcend Ontario borders (Chovil, 2009; Heywood, 2009; Spencer et al., 2010), as family advocacy organizations in the U.S. (e.g. National Federation of Families for Children’s Mental Health) endorse definitions of family engagement that emphasize families’ level of participation, collaboration and partnerships with service providers (Funchess, Spencer, & Niarhos, 2014).

Conceptualization in research

While there seems to be a growing consensus on what it means to engage families in practice, the peer-reviewed research on family engagement appears to lag behind in terms of offering a consistent and accurate conceptualization. Different terms have been used to describe family engagement and related activities in the literature, including family involvement, family participation, family-centred care, family-focused care and family-driven care. While these terms are often used interchangeably (e.g. family-driven care and family engagement represent very similar approaches; Chovil, 2009; Spencer et al., 2010), some nuances in conceptualization are worth highlighting. For instance, the terms engagement and involvement are often used synonymously by researchers, yet the former tends to have greater implications:

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).

Similarly, engagement and participation are often used interchangeably in the literature, where family engagement is defined as the extent to which families participate in services and is measured via rates of attendance at appointments or retention in services over time (Staudt, 2007). This is problematic because retention or participation in services alone does not provide a fulsome definition or measure of family engagement (Steib, 2004). A family may very well show up for appointments without feeling empowered to take an active role in their child’s treatment. Successful family engagement creates a powerful, transformational bond between families and services providers (Funchess et al., 2014) which cannot possibly be quantified as the number of appointments attended or missed.

4.2 Why family engagement?

The importance of engaging families in mental health care has been stressed by policy-makers, researchers, practitioners and families themselves for several reasons (Hoagwood, 2005; Ferreira, 2011; Funchess et al., 2014). Families have intimate knowledge of what works and what does not work to support a child with a mental health challenge in mental health care (Chovil, 2009; MacKean et al., 2012). As primary users of the system of care, families have first-hand experience of how services operate, how they help (or fail to help) and how they may be improved (Chovil, 2009; Funchess et al., 2014; MacKean et al., 2012). As well, families have expert knowledge of their particular child’s life (Chovil, 2009) – information that is of paramount importance for any service provider looking to support this...
child through a mental health challenge. Given their unmatched knowledge and perspectives, listening to families is a key to unlocking new ways to improve mental health services.

**Potential outcomes of family engagement**

The positive impact of engaging families has been demonstrated in the published literature (Spencer et al., 2010). Most outcome studies on family engagement have explored service use and retention in services (i.e. attendance at appointments and participation in services over time) as outcomes (Chovil, 2009; Hoagwood, 2005). Although family engagement involves much more than simply having families participate in care, research shows that family engagement is consistently associated with higher retention in services (Ingoldsby, 2010; Staudt, 2007). Since client retention is a significant issue in child and youth mental health services with clear consequences for public wellness, helping to promote retention through family engagement is important (Ingoldsby, 2010; Steib, 2004).

The benefits of family engagement extend beyond an increase in service use. An emerging body of research shows that family engagement is critically important for improving the effectiveness of child and youth mental health care overall, highlighting not only benefits for children, youth and families themselves, but also for service delivery, organizations and the mental health system as a whole (Chovil, 2009; Spencer et al., 2010). It is worth noting that this research is not without gaps. Given the narrow focus on service use and retention-related outcomes, little peer-reviewed research has explored outcomes of real, fundamental significance to family engagement (e.g. quality of partnerships between service providers and families; the nature and extent to which family perspectives are embedded in treatment planning; parental perceptions of continuity and support; etc.) (Hoagwood, 2005). In addition, the absence of a systematic approach to implementation (Ferreira, 2011; Hoagwood, 2005; Jivanjee & Robinson, 2007), along with the lack of clarity around the concept of family engagement (Staudt, 2007), have made it challenging to demonstrate direct links between elements of family engagement and specific outcomes in research (Chovil, 2009; Hoagwood, 2005). Nevertheless, reported benefits of family engagement for children, youth and families are compelling (Hoagwood, 2005), and include:

- improved child and youth psychological adjustment, behavioural functioning and quality of life (Bellin, Osteen, Heffernan, Levy & Snyder-Vogel, 2011; Law et al., 2003a)
- a quicker recovery process for mental health and addiction issues and reduced risk of mortality (Baker-Ericzén, Jenkins & Brookman-Frazee, 2010; CAMH, 2004; MacKean et al., 2012; Robst et al., 2013)
- increased likelihood of medication compliance (CAMH, 2004; MacKean et al., 2012)
- improved child and family management skills and functioning, including improved family interactions and increased stability of the family’s living situation (Hoagwood, 2005; MacKean et al., 2012)
- enhanced psychological well-being among parents and decreased parenting stress (Bellin et al., 2011; Dempsey & Keen, 2008; Law et al., 2003a; MacKean et al., 2012)
- increased caregiver feelings of competence and self-efficacy (Hoagwood, 2005; Davidson, Wiens & Anderson, 2010; Law et al., 2003a; Slaton, Cecil, Lambert, King & Pearson, 2012; Smith, Wohlstetter, Kuzin & De Pedro, 2011)
- reduced rates of relapse (CAMH, 2004; MacKean et al., 2012)
- improved satisfaction with care (Bellin et al., 2011; Davis, Claudius, Palinkas, Wong & Leslie, 2011; Dempsey & Keen, 2008; Koren, Paulson, Yatchmonoff, Gordon & DeChillo, 1997; Law et al., 2003a)
- increased caregiver knowledge about child mental health issues (Hoagwood, 2005)
- improved caregiver adjustment to the child’s mental health issues (Bellin et al., 2011; Law et al., 2003a).
There are also a number of benefits of family engagement at the service, organizational and system levels, including:

- more effective use of resources and improved cost-effectiveness of services (CAMH, 2004; Institute for Patient and Family-Centered Care, 2009; MacKean et al., 2012)
- earlier access to services and improved quality of care (CAMH, 2004; Institute for Patient and Family-Centered Care, 2009; MacKean et al., 2012; Osher, T. W., van Kammen, W. & Zaro, S. M., 2001; Tambuyzer & Van Audenhove, 2013)
- reduced out-of-home treatment placements and shorter lengths of stay in residential care (Affronti & Levison-Johnson, 2009; MacKean et al., 2012)
- reduced reliance on services (CAMH, 2004; MacKean et al., 2012)
- increased satisfaction of staff in their professional career (CAMH, 2004; Institute for Patient and Family-Centered Care, 2009; MacKean et al., 2012; Manion & Smith, 2011).
- improved data collection (both the amount and the quality of data) in program evaluation (Osher et al., 2001)
- increased community awareness of children’s mental health issues (Ferreira, 2011)
- reduced stigmatization of mental illness (Ferreira et al., 2014)
- improved ability to respond to community needs (Ferreira et al., 2014)
- improved service system sustainability (Ferreira et al., 2014)

Beyond its demonstrated benefits, family engagement is a practice with undeniable ethical relevance. Engaging family members in mental health care represents an example of citizen participation, defined as the right to “deliberat[e] on issues affecting one’s own life” (Fischer, 2000, p. 1), which is a fundamental element of democratic tradition (Ferreira et al., 2014). Indeed, having a voice and a role to play in decision-making that directly affects one’s own life is a defendable right (Ferreira et al., 2014).

4.3 Family engagement at all levels of mental health care

Family engagement stresses that families be engaged at all levels of mental health care (Chovil, 2009; MacKean et al., 2012; MCYS, 2013). This includes engaging families from the moment they enter a service provider’s office, as well as in conversations with agency leaders and the Ministry with regard to policy and strategic planning. The following sections discuss evidence-informed ways to engage families in service providers’ individual practice, in organizational activities and decision-making, and finally in system-wide operations.

4.3.1 Engaging families at the service delivery level

Service providers work hard to help families support their children’s mental health. Nevertheless, it is not uncommon for families to feel as though they are shut out of this process (Building Bridges Initiative, 2012; Duchnowski & Kutash, 2007; Heywood, 2009). Family engagement in the context of intervention or support services calls upon service providers’ most empathetic, collaborative and engaging dispositions to build strong partnerships with families and include them as full partners in their child’s mental health treatment (Manion & Smith, 2011). This is a process that is not linear; rather, it requires ongoing, mutually-reinforcing efforts by service providers to build trust, open communication and reciprocity with families.

The literature lacks a formal conceptualization of family engagement as it applies to direct service delivery (Chovil, 2009; Hoagwood, 2005). Nevertheless, a number of elements that can help service providers meaningfully engage families have been identified and discussed in the literature, and are listed below.
Viewing families as experts

In the family-as-expert approach, families are not viewed as a cause of their child’s problem, but are rather collaborators in treatment (Hoagwood et al., 2010; Osher et al., 2001) and a key source of information about the child’s needs and strengths (Chovil, 2009; Manion & Smith, 2011). Family engagement recognizes family members’ expert knowledge on their child and honours this expertise in its many forms (Manion & Smith, 2011).

Viewing families as experts requires using a strength-based approach – that is, focusing on family members’ competencies (rather than only their difficulties or weaknesses) to inform treatment goals, plans and approaches (Gopalan et al., 2010; MacKean et al., 2012). Applying a strength-based lens to treatment can influence the extent to which parents actively engage in services while also increasing their hope and optimism (Gockel, Russell & Harris, 2008; Gopalan et al., 2010; MacKean et al., 2012).

It is also important to recognize the power imbalances inherent in interactions between service providers and families, since service providers are considered experts on the mental health of children, youth and families who access services (Funchess et al., 2014; Gladstone et al., 2014). The ways in which service providers use this power can make all the difference between an engaging and disengaging process (Funchess et al., 2014; Gladstone et al., 2014). Service providers should invite families to share their expert knowledge on the child and other important information (e.g. the child’s strengths, behaviours, sleep patterns) that may influence treatment diagnoses and decisions. This way of working can increase families’ confidence, and also make treatments more effective and meaningful (Manion & Smith, 2011).

Promoting active participation in care

Families care about having a say in their child’s treatment plan (Tambuyzer & Van Audenhove, 2013) and thus are more likely to feel satisfied with services when they are able to participate in service planning (Koren et al., 1997). Promoting families’ active participation in care using collaborative strategies is a crucial tenet of family engagement (Manion & Smith, 2011) and closely aligns with using a strength-based approach, whereby service providers harness families’ expertise and support them as potential agents of change with control over their own lives. Active participation begins with involving families in the development of treatment plans and setting goals with their child’s service provider (Manion & Smith, 2011). Families may also be invited to play the roles of co-therapists or “helpers” for their child (Hoagwood, 2005). For example, caregivers can learn positive parenting techniques to apply at home as a way to bolster treatment outcomes. This approach has shown positive results in studies of children with autism, children with speech difficulties and in the treatment of obesity (Hoagwood, 2005).

Investing in relationships and strengthening the therapeutic alliance

It is well known that the quality of the therapeutic alliance and relationship between service providers and families influences treatment engagement dramatically (Gopalan et al., 2010; Thompson, Bender, Lantry, Flynn, 2007). Research suggests that families are likely to disengage – or entirely withdraw – from services if they feel excluded by service providers, particularly when they perceive a lack of helpfulness or support (Gopalan et al., 2010; Thompson et al., 2007). Conversely, families who experience a personal bond or collaborative relationship with the service provider are much more likely to engage in and benefit from services (Gockel et al. 2008; Saxe, Ellis, Fogler & Navalta, 2012; Thompson et al., 2007). Rapport is built early on in the treatment process by focusing on acknowledging, validating and responding to the families’ expressed needs. Therapeutic alliances are continually strengthened through open communication, positive reinforcement, emphasizing family strengths, and conveying understanding and respect for families’ challenges (Gockel et al. 2008).
**Addressing barriers to engagement**

Working with families to identify and address barriers to treatment engagement is an important part of a family-centered approach (Gopalan et al., 2010; MacKean et al., 2012; Saxe et al., 2012). The first step in engaging families, prior to providing any therapeutic help, is to spend time in the first few sessions or during the initial phone call exploring the family’s concerns, their readiness for change and understanding any barriers they may face in participating in the program or service (Affronti & Levison-Johnson, 2009).

There are a number of practical barriers to family engagement, including transportation issues (e.g. cost of transportation, distance from services), time demands and scheduling conflicts (e.g. appointments during working hours), and a lack of available and affordable child care (Bannon & McKay, 2005; Ingoldsby, 2010; Robst et al., 2013; Tambuyzer & Van Audenhove, 2013). Strategies that address families’ practical barriers as they enter treatment are particularly effective in increasing family participation (Ingoldsby, 2010) and improving engagement (Affronti & Levison-Johnson, 2009; Manion & Smith, 2011). For example, providing bus tickets, snacks or childcare as part of services are simple and relatively low-cost gestures that tend to be warmly appreciated by families (Ingoldsby, 2010; Lietz, 2009; Manion & Smith, 2011).

Addressing psychological barriers to engagement is also critical (Ingoldsby, 2010). Misunderstandings about the nature of services, perceived (or actual) stigma and low motivation to change are examples of psychological factors that can impede treatment success (Gopalan et al., 2010; Ingoldsby, 2010). Techniques used in motivational interviewing can be helpful in increasing families’ readiness for treatment (Ingoldsby, 2010). Stigma can be reduced by using strengths-based therapeutic strategies, implementing outreach initiatives and meeting families in natural settings (e.g. neighbourhoods, homes, parks or spaces that are non-threatening and accommodating) (Cortis, Katz, & Patulny, 2009; Kays-Burden, 2013).

**Tailoring services to fit families’ needs and preferences**

Because families are diverse, it is important to adapt services to fit individual families’ unique needs and preferences. When there is alignment between a family’s preferences for service and the service they actually receive, families tend to have longer and more successful involvement in services (Bannon & McKay, 2005; Miller & Prinz, 2003). Whenever possible, service providers should emphasize family choice, flexibility and options for service delivery (Building Bridges Initiative, 2012; Madsen, 2009). A number of strategies are cited in the literature as helpful in ensuring flexible services, including attending to issues that the family identifies as relevant, accepting how families define these issues and formulating treatment goals jointly so that clients do not perceive them as an imposition (Gladstone et al., 2014). Tailoring services to fit families’ needs and preferences also involves ensuring supports are available across diverse geographic locations, cultures, levels of literacy and languages (Gopalan et al., 2010; Manion & Smith, 2011).

**Ensuring culturally-responsive services**

A family’s worldview and cultural beliefs can affect their engagement (Gopalan et al., 2010; McCabe, 2002). As such, there is a need to develop and test culturally-responsive interventions that engage diverse families with clear guidelines for implementation (Cortis et al., 2009; Ingoldsby, 2010). Culturally-responsive services are inclusive and respectful of differences in lifestyle, cultures, abilities, social norms, etc. (Cortis et al., 2009). Service providers must recognize how their own worldview and biases can influence the ways in which they engage and develop relationships with families. They should be familiar with the cultural background of the families they support and be able to accommodate their diverse needs (Funchess et al., 2014; Robst et al., 2013). While matching the ethno-cultural backgrounds of service
providers and clients is not necessary for treatment success (Cortis et al., 2009; McCabe, 2002), sharing a cultural identity can be beneficial since practitioners may have particular insights into acculturation challenges or speak with clients in their mother tongue. In any case, cultural responsiveness may be enhanced with relationship-building techniques (e.g. showing a genuine interest to learn about families’ cultural practices) and by creating environments that demonstrate inclusiveness of diverse cultural contexts (Cortis et al., 2009; Funchess et al., 2014; Robst et al., 2013).

4.3.2 Engaging families at the organizational level

While service providers play a pivotal role in engaging families one-on-one in their practice, family engagement should occur beyond the service delivery level with deliberate attempts to integrate families’ perspectives across governance, programming, policy and evaluation activities in organizations (Davidson et al., 2010; MacKean et al., 2012; Manion & Smith, 2011). Everyone in the agency, not just service providers, should be accountable in ensuring that family engagement practices are implemented systematically.

The present search found limited research evidence on family engagement at the organizational level. Nevertheless, the literature offers key insights from the field on how family engagement may be implemented within organizations. An overview of the various facilitators of family engagement at the organizational level follows below.

**Ensuring commitment from leadership**

Family engagement at the organizational level requires a shared willingness to alter traditions, share turf and give up some authority (Osher et al., 2001) to progressively make room for power-sharing, collaborative decision-making and greater voice and choice for family members (Bess, Prilleltensky, Perkins & Collins, 2009). It also requires that deficit-oriented perceptions of families (e.g. when families are labeled as “non-compliant” or “resistant”) be challenged and replaced by strengths-based perceptions (Building Bridges Initiative, 2012). These shifts in views and attitudes can be challenging and as such, broad organizational culture changes may be required to support the systematic implementation of family engagement in organizations (Bess et al., 2009; Chovil, 2009; Ferreira, 2011; Funchess et al., 2014; Gladstone et al., 2014; Staudt, 2007).

Such broad cultural change requires serious commitment from leadership (MacKean et al., 2012). Agency leaders need to explicitly reinforce the message that families should be engaged as full partners in decision-making. They must work to infuse a core set of values for family engagement that are reflected in the agency’s vision, mission and goals (Building Bridges Initiative, 2012; Ferreira, 2011; Law et al., 2003b; MacKean et al., 2012). This kind of leadership buy-in is a crucial point of leverage for change as it can inspire a shared vision of family engagement among staff and foster a culture of inclusion within the agency (Ferreira, 2011).

Leaders can ensure family engagement values permeate organizations in a number of ways, starting with embedding them in corporate mandates and policies (Law et al., 2003b; MacKean et al., 2012). The demonstrated benefits and ethical relevance of family engagement should be highlighted as a rationale for its implementation, and be clearly and consistently communicated to staff. Agencies can hire staff with strong beliefs and backgrounds in family engagement or family-centered care (Law et al., 2003b; MacKean et al., 2012), provide opportunities for staff to learn about family engagement practices (e.g. training opportunities), as well as recognize, celebrate and/or reward large and small efforts to engage families (MacKean et al., 2012). Leadership should also play an important role in modeling family engagement practices in their own work (e.g. developing organizational policies jointly with families) and integrating family voice in agency governance (Ferreira, 2011; MacKean et al., 2012).
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Modifying organizational structures and processes

Implementing family engagement at the organizational level requires adapting agency structures and processes to integrate family voice (Ferreira, 2011; MacKean et al., 2012; Manion & Smith, 2011). For example, organizations can make space for experienced family members (i.e. those with lived experience as caregivers and users of the mental health system), within agency governance (Ferreira et al., 2014; Slaton et al., 2012). By embedding family voice at this table, strategic planning decisions (e.g. funding, service priorities, etc.) are more likely to reflect families’ needs (Ferreira et al., 2014). Family representation in governance can be achieved by recruiting family members to sit on governance committees (Ferreira, 2011; Smith et al., 2010) or by creating an advisory committee that informs the decisions of the governing body (Fondrick & Johnson, 2002). Ideally, family representation should be diverse and include a number of family members, as this can offer a rich range of perspectives while also reducing the burden on one family member to represent the range of family voices in a community (Ferreira, 2011; Fondrick & Johnson, 2002). Creating stable, paid positions for family members can also help to formalize family representation in governance and reflect a deeper level of commitment (Ferreira et al., 2014; Fondrick & Johnson, 2002); this not only serves to convey the agency’s appreciation for family members’ contributions (Ferreira et al., 2014) but also helps to solidify their membership as a professional accomplishment (Jivanjee & Robinson, 2007).

Families’ expertise as system users and as caregivers of a child with a mental health challenge can also be used as an asset in direct service provision. For example, experienced caregivers can play the role of ‘peer mentors’ for other families experiencing similar challenges and offer them both emotional and informational support (Affronti & Levison-Johnson, 2009; Building Bridges Initiative, 2012; Chovil, 2009). Models of service delivery that create space for families to use their experience to help others are showing much promise. Families who are matched with a supportive parent mentor with first-hand knowledge of the challenges they are also experiencing report feeling less stigmatized and ashamed of their current context (Building Bridges Initiative, 2012). Additionally, they tend to have a more positive outlook on their circumstances, as well as a better ability to achieve progress in treatment (Affronti & Levison-Johnson, 2009).

Engaging families as agencies develop, implement and evaluate service delivery is essential for ensuring that programs are relevant, culturally appropriate and effective (Funchess et al., 2014; Manion & Smith, 2011). Family input should be sought proactively as programs are conceptualized, as this allows families to inform operations from the beginning, rather than recommend adjustments later on (Supple et al., 2015). Further, family members should be engaged on various occasions (e.g. working groups, conference calls) throughout implementation. This may help families gain a deep understanding of the program and its intended operation, and help them identify potential challenges early on, allowing for more meaningful contributions to problem solving (Supple et al., 2015).

In the context of program evaluation, families may be engaged in tasks such as the development of user-friendly project instruments and surveys, co-facilitating focus groups and interviewing participants (Jivanjee & Robinson, 2007; Supple et al., 2015). In a study of 37 mental health agencies, families’ participation in program evaluation increased both the amount and the quality of data collected; researchers attributed this to families’ cultural competence vis-à-vis the participants being interviewed (Osher et al., 2001). Families can also be skillful knowledge translators and thus help interpret, disseminate and present findings (Jivanjee & Robinson, 2007; Supple et al., 2015). For example, they can offer keen insights into the link between evaluation data and actual services (Osher et al., 2001), lending findings greater real-world relevance and applicability. When called upon to disseminate findings, families may help to improve the tone of messaging and ensure relevance for the general public (Supple et al., 2015). Families may also help to increase the
impact of findings by presenting them from their own perspectives in mainstream conferences, symposia and educational workshops (Jivanjee & Robinson, 2007; Supple et al., 2015).

**Building and sustaining relationships with families**

Building strong, sustainable partnerships between agencies and families is a process that takes time, both because of the complex nature of relationship-building at the organizational level and the high staff turnover rate of many service provider agencies (Ferreira, 2011). At any rate, the approach or process by which relationships are built (i.e. building a level of trust and connectedness with families) is more important than the number of relationships that are developed (Ferreira, 2011).

Without a doubt, successful relationship-building requires that families are engaged in meaningful ways. Tokenism is arguably one of the most significant barriers to fostering trust, mutual appreciation and productive partnerships between service providers and families (Bess et al., 2009). When family engagement efforts limit families’ participation to superficial tasks or roles that offer no real opportunity for worthwhile contributions, families will likely feel devalued and frustrated (Meehan & Glover, 2007). It is crucial to approach family engagement activities not as a series of “tick box” exercises, but rather as an ongoing agency priority with real, long-term value (Meehan & Glover, 2007).

Given the key role of communication in relationship-building, developing strong relationships with families also requires that strength-based and empowering language is used to talk to and about families in agency communications (Bess et al., 2009). Referring to families as ‘patients’ or ‘clients’ is not ideal, since such terms can be disempowering and tend to imply a contractual (rather than authentic and genuine) relationship between families and service providers (Bess et al., 2009). As much as possible, referring to families as ‘our partners’ or simply ‘our families’, and using collaborative terms such as ‘co-learning’ or ‘co-creating’ to frame engagement activities, is preferred, as this kind of language is conducive to the development of long lasting, strength-based relationships with families (Bess et al., 2009).

**Providing training opportunities**

Family engagement training activities are often used as a way to improve the quality of agency-family partnerships (Ferreira, 2011; Friesen et al., 2011; Funchess et al., 2014; Jivanjee & Robinson, 2007; Smith et al., 2011). Training may be used as a capacity-building opportunity for families who want to learn new skills to eventually take on new responsibilities in organizations (e.g. in research or advocacy activities) (Jivanjee & Robinson, 2007; Smith et al., 2011). Agency-wide trainings can also take place for service providers to build capacity in family engagement approaches. Such trainings may focus on the core principles of family engagement, including how to increase strength-based work with families and how to engage them meaningfully in organizations (Dostaler & Cannon, 2011; Ferreira, 2011).

Family engagement trainings for service providers must model engagement, working with families as co-developers to ensure that curricula align with families’ beliefs and experiences (Dostaler & Cannon, 2011). Equally important is families’ participation in co-delivering trainings (Chovil, 2009; Dostaler & Cannon, 2011; Ferreira, 2011). Families may help to humanize training contents by lending them authenticity and real-world relevance. They also help service providers better understand the family perspective (Chovil, 2009; Dostaler & Cannon, 2011), which can bolster learning and skill-building in training activities (Chovil, 2009). Accordingly, in one study, service providers reported that hearing the stories and experiences of families was the most compelling part of a given training session (Ferreira, 2011). Another way to integrate the family voice may be to include written synopses or video vignettes in training materials as means of drawing attention to family insights and perspectives on various topics (Dostaler & Cannon, 2011).
Before investing in any training, it is important for agencies to consider their current level of understanding related to family engagement. Training sessions and implementation efforts need to be aligned with current practices, priorities and staff readiness to ensure success. Any training strategy for service providers should therefore include a tool to assess organizational readiness (Dostaler & Cannon, 2011). Further, service providers will need ongoing organizational support in order to use the new knowledge and skills that they gain from any training program (MacKean et al., 2012). Leadership should continue to explore and evaluate new ways of collaborating with families, including training, as well as other kinds of resources and supervisory supports (Affronti & Levison-Johnson, 2009; Ingoldsby, 2010; Tambuyzer & Van Audenhove, 2013).

Supporting families to engage

Depending on their past experiences, families may need preparation and orientation to the process of family engagement in organizations. If the concept of engagement is new to the family member and there are pre-existing power differentials between service providers and themselves, families may feel uncertain about being asked what they want instead of being told what they will receive (Law et al., 2003b). Families may also feel unsure about taking on roles they are not prepared for, especially if they feel that service providers are not offering them enough support to take part in engagement activities (Law et al., 2003b). It is thus helpful to work with families to understand their level of readiness to engage in services or agency activities, and then promote their readiness by discussing expectations, goals and options for engagement (Cortis et al., 2009).

It is important to recognize that not all families have the desire or capacity to become engaged in leadership activities (Duchnowski & Kutash, 2007; Manion & Smith, 2011). Agencies need to differentiate between families who, for example, need to dedicate energy to more pressing personal needs (e.g., attending to their child’s mental health needs), from those who may be further along their journey in mental health and, thus, find themselves in better positions to become strong trainers, mentors, coaches and leaders (Ferreira, 2011). In any case, families need to decide the extent of their engagement for themselves. As such, agencies should work with families to offer various types of engagement opportunities to accommodate different levels of capacity to engage (Duchnowski & Kutash, 2007). For example, a low-commitment activity could involve asking families for their input and feedback on services with easy-to-complete comment cards in waiting areas of the agency (Law et al., 2003b). Training or coaching opportunities can also be made available to family members who want to become engaged, but lack specific skillsets or want to build capacity in certain areas (e.g., preparing for governance meetings, learning about research and evaluation) (Ferreira, 2011; Jivanjee & Robinson, 2007; Smith et al., 2011).

Osher, Osher and Blau (2006) offer additional strategies to support the engagement of family members in decision-making in child and youth mental health. These include:

- ensuring that meetings occur at times that are realistic for families to attend;
- conducting meetings in culturally and linguistically appropriate environments;
- ensuring that family and youth voices are heard and valued;
- ensuring that families and youth have access to useful, usable, and understandable information and data;
- providing sound professional expertise to help families make decisions; and
- sharing power, authority, resources, and responsibility.
Family engagement

**Evaluating engagement efforts**

Implementing family engagement requires continual reflection, monitoring and evaluation to ensure that services are meeting families’ needs and engagement efforts are working (Law et al., 2003b). Unfortunately, there is an absence of evaluation research in the field of family engagement. At the service delivery-level, engagement efforts have mainly been tested in highly controlled clinical settings (Ingoldsby, 2010), with fewer studies examining engagement in more diverse community-based contexts (Bellin et al., 2011). Family engagement efforts at the organizational- and system-level also need to be evaluated more often and rigorously (Ferreira, 2011). The lack of research on this topic represents both a need and an opportunity for organizations to evaluate their family engagement efforts and advance knowledge. Refer to section 5 for a list of measures that can be used to support evaluation of family engagement initiatives.

**4.3.3 Engaging families at the system level**

Family engagement at the system-level happens when families are being solicited, and most importantly listened to, as advisors of the system of care (Ferreira et al., 2014; Friesen et al., 2011; MacKean et al., 2012). Families have unique perspectives, expertise and knowledge on ‘how things work’ that only system users have. This information is essential for leaders who strive to make the service system more efficient and effective, and ultimately to improve child and youth mental health outcomes (MacKean et al., 2012). Recruiting family members to inform system-wide evaluations or to sit on formal interagency governance or policy boards, for example, are opportunities to draw on this expert knowledge to meaningfully impact system-level agendas (Ferreira et al., 2014).

There are multiple pathways to fostering system-wide family engagement. Without a doubt, it is a process that requires both time (Slaton et al., 2012) and ongoing, coordinated efforts by multiple stakeholders (Friesen et al., 2011). The literature on system-level family engagement in mental health is scant, but nevertheless offers some key insights on factors that may help to drive change in whole service systems. This section provides an overview of some of the facilitators of system-wide family engagement.

**Partnering with family advocacy (or family-run) organizations**

Family advocacy organizations have been instrumental in stimulating changes in practice and policy in the mental health system over the years (Ferreira et al., 2014; Friesen et al., 2011). Family advocacy organizations are run by family members with a child with a serious mental health condition. Among other functions, they advocate for the needs of children, youth and families and for more relevant, family-centered services (Ferreira et al., 2014; Friesen et al., 2011). Family advocacy organizations with broad influence in systems tend to have local representation, as well as connections to state and nationwide networks (Slaton et al., 2012). As a notable example, the [National Federation of Families for Children’s Mental Health](https://www.nffcmh.org) in the U.S. has been an organizing point for local family-run organizations (called ‘chapters’) in several states, while also holding a seat at the national policymaking table. [Parents for Children’s Mental Health](https://www.parentsforehealth.org), a provincial family-run organization, has a similar role in Ontario. These kinds of organizations have been powerful vehicles for the voices of families to influence service infrastructure, as well as local services (Friesen et al., 2011).

A five-year, multi-site investigation on family engagement by Ferreira (2011) found that family-run organizations could successfully partner with agencies to provide useful support in system-wide training, evaluation, budgeting and political advocacy activities. Such partnerships benefit from being very clear and explicit about their goals and nature, with organizational charts outlining the roles and responsibilities of family leaders (Ferreira, 2011). The study also suggests that when aiming to create partnerships that influence high-level, systemic change, there are advantages to partnering with family advocacy organizations as opposed to unaffiliated, single family members. In addition to having political and
financial autonomy, family-run organizations tend to be highly visible and respected partners of systems of care. Moreover, family-run organizations may have a greater influence on policy by unifying the voices of a large number of families and coordinating their efforts (Ferreira, 2011).

Ensuring commitment from system leaders

A commitment from decision-makers is a necessary precursor to systemic change. Governmental authorities and funding organizations are key bases of influence for system-wide family engagement, as they hold the power to issue mandates to service agencies that make the integration of family voice a priority (Bess et al., 2009; Duchnowski & Kutash, 2007; Friesen et al., 2011) and to allocate funding strategically to encourage the adoption of family engagement practices (Friesen et al., 2011). For example, in Ohio, a funding stream named Families and Systems Teams (FAST$) supported activities that focused on empowering the families of children with mental health challenges (Scheer & Gavazzi, 2009). FAST$-funded activities worked, in part, to expand statewide family input in state policy development, in addition to engaging family members in the planning and implementation of services more locally (Scheer & Gavazzi, 2009). In Ontario, MCYS (2013) considers family engagement a key process to support service delivery in child and youth mental health and has made financial commitments to support efforts to build agency capacity in this area.

Similarly, the explicit and active commitment of policy-makers can significantly contribute to the integration of the family voice in the mental health system (Duchnowski & Kutash, 2007; Spencer et al., 2010). For example, the American Academy of Child and Adolescent Psychiatry (AACAP) developed a policy statement mandating that youth and families have a primary role in decision-making in their treatment process, and also at the federal policy and systems levels (Spencer et al., 2010). Similarly, the Substance Abuse Mental Health Services Administration (SAMHSA) asked the National Federation of Families for Children’s Mental Health to develop a definition of family-driven care, which resulted in a policy statement co-created by family leaders and other professionals that is nationally-recognized to this day (Spencer et al., 2010).

Building relationships with families

Systemic family engagement requires that relationships be developed between families and staff, decision-makers and other stakeholders. Family advocacy organizations make concerted efforts to build relationships with agencies (Ferreira, 2011). For example, as a means for strategic outreach, family leaders may make regular calls to agencies to not only problem-solve, plan and strategize on various activities, but also to acknowledge the agency’s family engagement efforts. These small but tireless relationship-building efforts seem critical to foster trust and mutual respect between families and system leaders, ultimately supporting a shift toward system-level family engagement (Ferreira, 2011).

Another widely used strategy to build relationships at the system level is to organize meetings and conferences (Friesen et al., 2011). For example, the Families as Allies conference was an event held in every region of the U.S. in the 1980s that brought together family members, service providers, administrators and other professionals to promote dialogue and encourage partnership-building in the system. This conference resulted in the development of alliances between family-run organizations and agencies in several states (Friesen et al., 2011; McManus & Friesen, 1986). Similarly, the Building on Family Strengths conference held annually in Portland, Oregon brings together family members, youth, researchers, service providers, advocates, policymakers and other stakeholders to share information, both formally and informally, and build relationships with one another (Friesen et al., 2011; Swart, Friesen, Holman & Aue, 2009). In Canada, the Youth and Family Consensus Conference held in Vancouver in May of 2014 brought together youth and families with researchers, policymakers, service providers and educators to share their knowledge of practices that
effectively meet the needs of young people facing mental health or addictions challenges. The conference generated a consensus statement on family engagement that highlights the key role of families in promoting the growth of the child and youth mental health system.

*Mobilizing knowledge across the system*

Getting the word out about family engagement is key to stimulating a shift toward a more inclusive and productive child and youth mental health system (Duchnowski & Kutash, 2007). Frequent communication and information-sharing between families, family advocacy organizations, system leaders and agencies regarding successes and challenges with family engagement is particularly important (Law et al., 2003b; Scheer & Gavazzi, 2009). Families benefit from learning from one another on ways to grow their empowerment and self-efficacy in the system of care (Scheer & Gavazzi, 2009). Agency staff, decision-makers and other stakeholders can also greatly benefit from receiving information on family engagement practices.

One example of knowledge mobilization to support family engagement is to host activities such as “lunch and learn” events and regional training meetings that focus on peer-to-peer learning for families (Scheer & Gavazzi, 2009). Some organizations provide platforms for various types of knowledge exchange activities, including the National Federation of Families for Children’s Mental Health, which provides families with a forum for peer-to-peer support and disseminate resources developed by families (Chovil, 2009; Spencer et al., 2010). In Ontario, Parents for Children’s Mental Health offers workshops for families, educators and agencies to build capacity in family engagement. They also publish resources online that offer advice to those same stakeholders and showcase the family perspective on various issues.

The media can be a powerful ally to get the message out about family-run initiatives and raise attention around specific issues. One family leader describes how she created relationships with various media outlets (newspapers, radio and television) to showcase stories of caregiver experiences in the mental health system (Slaton et al., 2012). She says that this use of the media contributed to reforms in both policy and practice around various issues, including lengthy hospitalization admissions, mental health parity and access to care. It also made her family-run organization more influential and powerful (Slaton et al., 2012).

5. **Next steps and other resources**

Family engagement is an evidence-informed best practice with important benefits for everyone involved. Service providers, decision-makers and other stakeholders have a responsibility - bound by both ethical and strategic relevance - to engage families as full and valued partners in all matters that affect them.

The following tools can be used to implement and evaluate family engagement efforts at various levels. The majority of these tools are profiled in the Centre’s measures database with detailed information on measure structure, administration, psychometrics properties and availability.

*Note: This list reflects the evidence available in November 2015. Other tools may become available at a later time, so keep checking our measures database in coming months.*

- The Measure of Processes of Care (MPOC) assesses parents’ perceptions of the extent to which the health services they receive are family-centred and their satisfaction with staff, agency or community programs and services.
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The National Federation of Families for Children’s Mental Health developed *Indicators of meaningful family involvement: A brief guide for individuals looking to understand how meaningful family involvement is measured* to support organizations in measuring critical elements of family involvement at all levels of the organization.

- The *Youth/Family/Consumer Participation Performance Measure* developed by the National Initiative to Improve Adolescent Health (NIIAH) provides an example of incorporating an ongoing reporting mechanism around youth/family/consumer participation.

- The *Toolkit for Expanding the System of Care Approach*, an initiative of the Substance Abuse and Mental Health Services Administration (SAMHSA), brings together a number of resources (logic model, financial planning tool, community-/state-level rating tools, etc.) that support the adoption of the system of care approach.

- The *Family Engagement Technical Assistance Planning Guide* of the Children’s Bureau and the National Resource Centre for In-home Services provides an assessment tool for the core principles of family engagement at the program, practice and system levels.

- The *Rating Tool for Implementation of the System of Care* by the National Technical Assistance Center for Children’s Mental Health is a tool that can be used by service providers to evaluate the implementation of the System of Care approach within their organization.

The Ontario Centre of Excellence for Child and Youth Mental Health has a number of resources and services available to support agencies with implementation, evaluation, knowledge mobilization, youth engagement and family engagement. For more information, visit:

http://www.excellenceforchildandyouth.ca/what-we-do or check out the Centre’s resource hub at http://www.excellenceforchildandyouth.ca/resource-hub.

For general mental health information, including links to resources for families:

http://www.ementalhealth.ca
Family engagement

References


