QUALITY STANDARD FOR FAMILY ENGAGEMENT

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INTRODUCTION

Consistently delivering a seamless experience and strong outcomes — the care kids need, when they need it, how they need it — is key to helping children and youth in Ontario grow up with good mental health. The 2016 Annual Report of the Ontario Auditor General highlighted a range of opportunities to improve the child and youth mental health system.[1] Woven through the recommendations was a clear reminder that we must focus on the experience and needs of children, youth and families. And there is no one better to tell us what they need than children, youth and families themselves.

Evidence shows that meaningfully engaging youth and families in the child and youth mental health sector can have significant positive impacts on service experience and outcomes. With a voice and an active role in treatment planning and service delivery, Ontario's children, youth and families have their lived experience and context incorporated into their care. This leads to improved outcomes,[2] better relationships with healthcare professionals delivering care, a stronger sense that needs are being met through services delivered[3] and greater satisfaction with care.[3,4,5,6,7] When youth and families are engaged in their own care, they experience improved psychological well-being, behavioural functioning and quality of life,[4,7] and services overall are more cost-effective.[8, 9 10] Families experience less stress,[4, 6, 7,10] improved family interactions[10, 11] and more confidence in their ability to support their children and youth through mental health challenges.[7,11,12, 13]

Family engagement and youth engagement are essential drivers of excellence across all aspects of the system.[14] Collectively, we are most efficient and effective when we work not just for children, youth and families, but with them, every step of the way.

About the Ontario Centre of Excellence for Child and Youth Mental Health

The Ontario Centre of Excellence for Child and Youth Mental Health (the Centre) works to channel the momentum for change in child and youth mental health into practical initiatives that will improve service access, experience and outcomes in every community. Together with our partners, we will set the standard for child and youth mental health services and stand up for an evidence-informed system that makes a real-life difference for people across Ontario.

What are quality standards?

Pursuing excellence demands that we define it. Together with youth, families, clinicians and researchers, the Ontario Centre of Excellence for Child and Youth Mental Health (the Centre) develops quality standards that support consistent and effective child and youth mental health services across Ontario.

Quality standards are essential to a system that is accountable and constantly improving. They are also central to ensuring that Ontario children, youth and families access and receive consistent high-quality mental health services wherever they are within the province.

Quality standards consist of several quality statements, or principles, that describe what high quality looks like, based on evidence.[15] None of the statements stand alone. Rather, the statements work together to make up a cohesive quality standard. Evidence comes from many sources: the research literature, the experiences of youth and families and the perspectives of service providers. We recognize that much of this evidence and perspective comes from a Western-oriented worldview.

Quality standards include best practices that describe how high-quality services can happen.[15] They also include indicators to show progress or the impact of these practices. Tools and resources are provided to guide implementation, evaluation and ongoing improvements in applying the quality standards.

Quality standards complement accreditation standards and clinical practice guidelines from professional bodies. Together, these standards and guidelines provide the way to have the best mental health outcomes for everyone involved in the child and youth mental health system.

For more information on quality standards for child and youth mental health, contact cymhstandards@cheo.on.ca.

This standard, like many quality standards, was developed in a context and from an evidence base that largely reflects a Western worldview. We recognize the importance of continually engaging with diverse voices and ever-broadening our sources of knowledge as we support the implementation of this standard and refine it over time.

About this quality standard

What is family engagement?

We define *family engagement* as an ongoing process that includes families as active decision-makers and partners at the organizational and system levels. A *family* is a circle of care and support that offers enduring commitment to care for one another, and is made up of individuals related biologically, emotionally, culturally or legally. This includes those who the person receiving care identifies as significant to their well-being.

Partners in family engagement at the system level include (but are not limited to) youth, other families, service providers, child and youth mental health leaders, cross sectoral representatives from other areas (such as education, justice, social services, etc.), communities, community organizations and many others. This quality standard describes critical aspects of engagement at the organizational and system levels, and goes hand-in-hand with the quality standard on youth engagement in child and youth mental health system planning.

Family engagement:

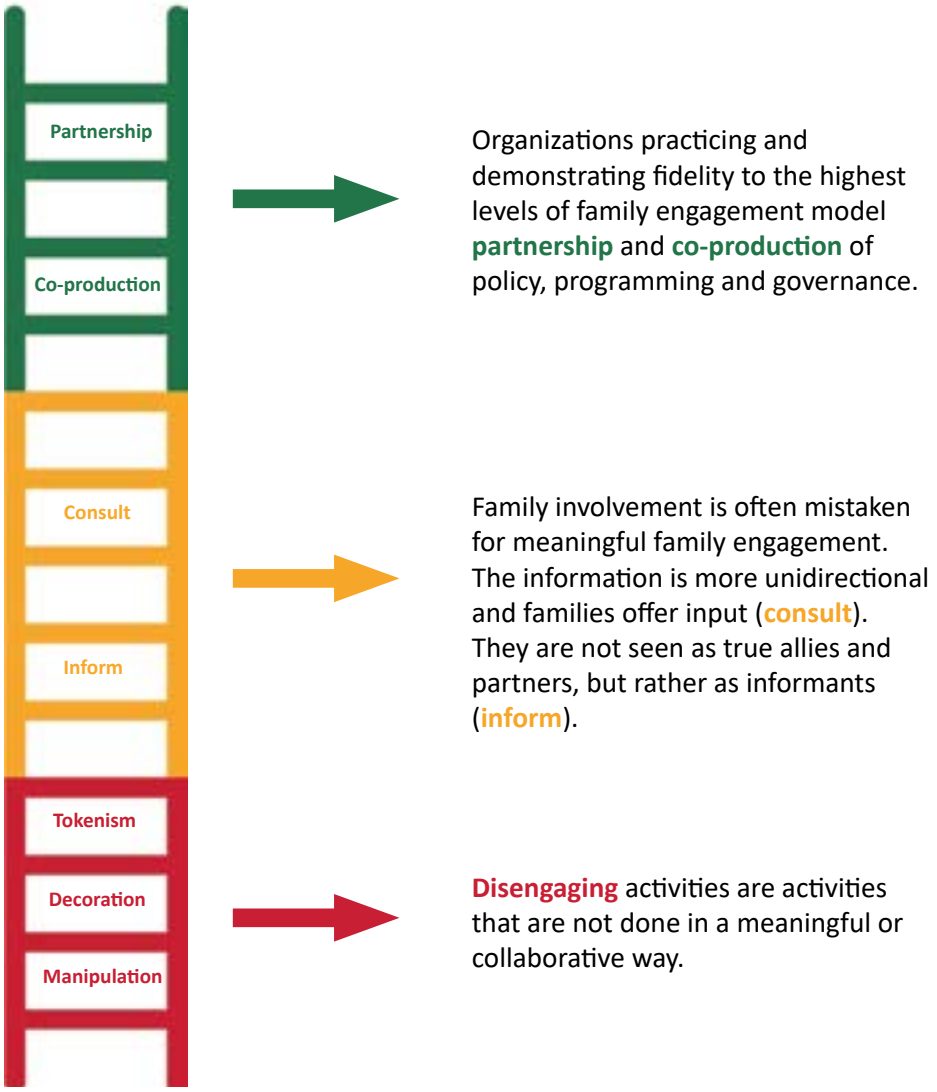
an ongoing process that includes families as active decision-makers and partners at the organizational and system levels.

There is a continuum of family engagement practices, a concept that is visually represented in an adapted version of Hart's Ladder[16] (see Figure 1). The continuum ranges from negative engagement such as manipulation, decoration and tokenism, to the highest forms of engagement, co-production and partnership. These are more fully described in the Centre's resources on family engagement.[17]

Why do we need this quality standard?

The community-based child and youth mental health sector's ability and dedication to engage families in Ontario has grown over the past several years.

Figure 1



This figure illustrates the contiuum of family engagement, from highest to lowest levels of engagement. Adapted from Hart's Ladder of Youth Participation.[16]

Many agencies have been implementing a wide range of family engagement processes within their organizations and across their communities, including with support from the Centre and Parents for Children's Mental Health (PCMH). These include the development and delivery of training sessions, implementation supports, and various tools and resources.

There has been progress in advancing family engagement across the province, but there is still work to do to ensure that children, youth and families receive the best care and outcomes no matter where in the province they seek care. With the increase in family engagement initiatives, there are some inconsistencies with how family engagement is understood and practiced in the child and youth mental health sector.

Establishing a quality standard ensures consistent practices or processes for family engagement. It formalizes family engagement practices and expectations for the system and validates the lived experience of families who engage in system level efforts. A quality standard on family engagement also serves to provide a baseline of measurement across the province where one does not exist and challenges us as a sector to continue to improve.

What is the scope of this standard?

Family engagement can occur along a continuum and across three levels.[18] Family engagement at the level of personal care and health decisions is focused on the relationship between families and healthcare professionals and improving health outcomes for children, youth or families. Engagement within an organization is focused on improving programs and services or improving organizational policies and governance.

Engagement at the system level is focused on improvements beyond a single organization. The quality statements in this standard describe family engagement at the system level (that is, beyond the delivery of care or improving programs) and at the highest level of the continuum (co-production and partnership).

This quality standard is relevant to efforts that improve services involving many organizations in a community and efforts that improve the transition or coordination of services across different agencies or sectors.

How was this standard developed?

The Centre co-developed this family engagement quality standard with an advisory group (see Appendix A) following a validated process (see Appendix B).[15] We reviewed the literature for existing standards or guidelines on family engagement at the system level. We then identified the key areas depicting family engagement at the high end of the continuum and drafted quality statements. We consulted a diverse group of stakeholders across Ontario through surveys and focus groups to gather feedback and revise the quality statements.

We will be piloting this standard to assess implementation needs and develop resources to support implementation. We are also developing indicators so that system level initiatives can evaluate their efforts when implementing this standard.

This quality standard describes family engagement at the system level, with the highest forms of engagement.

What do we mean by "system level"?

Ontario's child and youth mental healthcare system is made up of the many people and organizations that deliver mental health services to children and youth across the province and the networks and pathways that connect them.

The system also includes the governments and other institutions that provide the resources and structures that enable this care.

Family engagement at the system level is focused on improvements affecting these networks, pathways, resources and structures rather than individual organizations.

QUALITY STATEMENTS

The quality standard for family engagement in child and youth mental health system planning is comprised of eight quality statements.

None of these statements stands alone.

These statements intersect and work together to form high quality family engagement. Those implementing the standard will need to pay active attention to all areas to ensure strong and sustainable family engagement practices.

Each statement will be explained in greater detail in the following pages, including what it means for families, for agencies and for system decision-makers. Read on to learn more about the background and rationale of each statement area and the best practices identified through existing literature and stakeholder consultation.

CO-DEVELOPMENT

Families jointly develop all activities and processes involved in system planning and improvements.

COMMITMENT

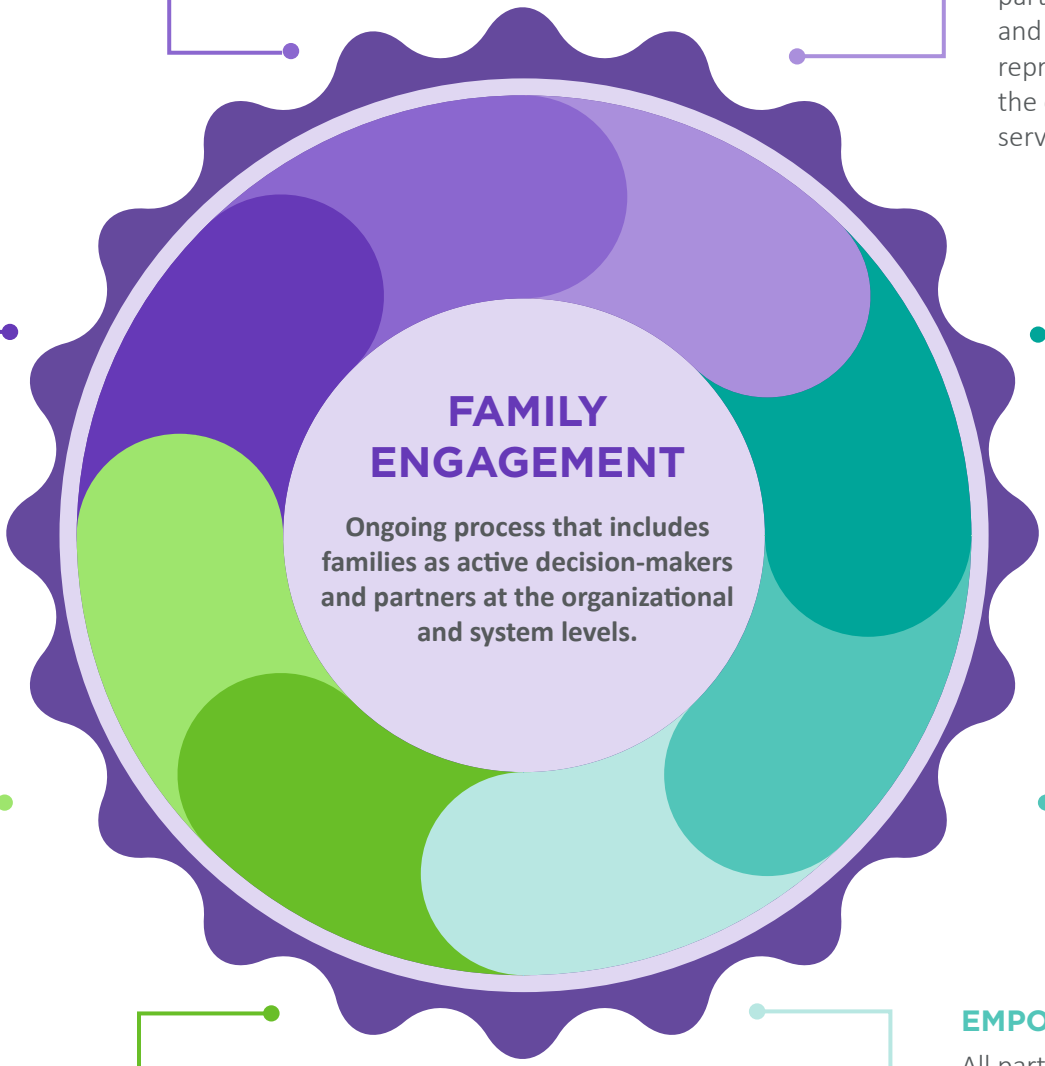
All partners are committed to family engagement and those in system leadership roles are accountable for embedding this commitment in system planning and improvement efforts.

COMMUNICATION

Communication between all partners is timely, transparent, respectful and accessible.

DIVERSITY & INCLUSION

Family engagement practices are inclusive; the diversity of partners is valued, and engagement is representative of the communities served.



RESEARCH & EVALUATION

Families and partners jointly research, evaluate and make ongoing quality improvements in all aspects of system planning.

PARTNERSHIP

Families are essential partners, collaborating in all decision-making processes.

ONGOING LEARNING

All partners, including families, have a shared understanding of the philosophy and practice of family engagement and have accessible, ongoing learning opportunities.

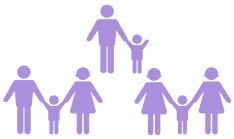
EMPOWERMENT

All partners share trusting, respectful relationships that enable family experience, expertise and perspectives to be clearly reflected in system planning and improvement efforts.

CO-DEVELOPMENT

Families jointly develop all activities and processes involved in system planning and improvements.

What this means for...



Families

Partners value and rely on your experience and expertise and you have opportunities to co-develop organizational projects and system priorities with other partners.

Agencies

You regard families as experts and provide opportunities for them to partner actively. You ensure that the co-development approach is woven into all organizational work, including family engagement processes.

System decision-makers

You model co-development, partnering with families in the shared development of policies, system level priorities and funding and research decisions.

Background and rationale

The practice of meaningful family engagement is built on the premise of families as partners at all levels of mental health service delivery. This is akin to the notion of "nothing about us without us." For meaningful engagement to happen, it is necessary to create an environment in which families can work side by side with partners to improve programs and services.[19] The process of *co-development* enables families and partners to reflect on their experiences, define a common purpose, share in decision making, work together to identify improvement priorities, implement changes and jointly reflect on achievements with a collective sense of accountability.[20]

Family members can and should be engaged in co-developing, implementing and evaluating improvements of specific mental health programs and services.[21] At the organizational level, families can help determine whether existing programs meet their needs and identify improvements. At the system level, families can help define and offer advice on how to address policy changes, propose the introduction of new policies, provide input on funding decisions and implement

new standards.[21,22, 23] Importantly, the level of engagement in the process of co-development may look and feel different depending on the setting and other factors.[21] It is essential to work with families to match the right approach to the right situation at the right time.

It is necessary to create an environment in which families can work side by side with partners to improve programs and services.

Best practices

- Families and partners work together at all stages (including design, implementation and evaluation) of any process or project. Partners ensure it is clear to families how they can partner throughout the process.
- Families have a mechanism for identifying system level issues and priorities and addressing them in *collaboration* with partners.

Definitions

co-development: process of working collaboratively on a shared purpose; joint decision making; a commitment to action and collective accountability among all stakeholders.[24]

COMMITMENT

All partners are committed to family engagement and those in system leadership roles are accountable for embedding this commitment in system planning and improvement efforts.

What this means for...

Families

Your perspectives are equally valued and consistently embedded at the organizational and system levels.

Agencies

Family engagement principles are built into organizational policies, processes and activities. Leaders exemplify their commitment in strategy and resource allocation.

System decision-makers

You treat family engagement as essential, not optional. You plan and allocate funds in a way that ensures family voice is integrated into the mental health system.

Background and rationale

Family engagement requires that partners at the highest levels of decision making work collaboratively with families. Leaders and their organizations must express and exemplify their *commitment* to family engagement.[10] This includes allocating adequate *resources* to embed family perspectives at the individual, organizational and system levels.[25] Leaders should model family engagement practices in their own work — for example, by jointly developing organizational policies with families — and ensure they are reflected in their organization's vision, mission and goals.[26, 27]

This buy-in is crucial to bring about change. It can inspire a shared vision of family engagement among staff which helps to foster a culture of engagement within organizations.[28] System decision-makers, including policy-makers, play an important role in ensuring family voice is among those shaping the mental health system.[29] They must demonstrate explicit and active commitment to family

engagement.[30] Government bodies and funding organizations have a particular influence on system-wide family engagement as they have the authority to issue mandates and allocate funding towards family engagement initiatives.[31]

Commitment to family engagement includes allocating adequate resources to embed family perspectives at the organizational and system levels.

Best practice

- Organizations and system level partners demonstrate commitment by ensuring targeted resources are available and provided to support and sustain family engagement practices.

Definitions

commitment: willingness to persist in a course of action; a sense of obligation to stay the course; the state or quality of being dedicated to a cause, activity, etc.[32]

COMMUNICATION

Communication between all partners is timely, transparent, respectful and accessible.

What this means for...

Families

Partners listen to what you say and communicate with you often. You receive information in a format, style and language that is accessible and easy for you to understand.

Agencies

You practice active listening and communicate frequently in language that is clear, easy to understand and accessible to everyone. You can communicate in many different formats and styles and you ensure that communication is never unidirectional.

System decision-makers

You communicate regularly and consistently. You make sure that complex information is presented in a way that everyone can understand. You follow best practices for communication in all you do, and you have mechanisms in place to ensure two-way or multi-way communication.

Background and rationale

Communication is a key ingredient in building and maintaining strong relationships and collaborative partnerships among families, agencies and system decision-makers.[33] It is about more than the words used to convey a message — it is also about speaking mannerisms, tone and body language. Likewise, communication is not merely about providing information; rather it is a two-way process that requires all parties to be effective listeners.[34]

Effective communication allows everyone involved to express their feelings and voice their opinions without fear of being ridiculed or attacked (verbally or otherwise).[35] *Active listening* skills are critical for developing rapport, respect and trust.[34] Rapport is also built between partners by acknowledging, validating and responding to each other's needs.[36]

Using a *strengths-based approach* and empowering language is important to develop strong relationships with families.[31] Families prefer to be called "partners" or simply "families". Using collaborative terms such as co-learning and co-creating also helps grow trusting relationships and strengths-based partnerships.[31] For successful *collaboration*, partners should also work together to develop shared language, free of jargon.[37]

Regardless of the method, communication in organizational and system processes should start early on and occur consistently throughout the engagement process. Regular communication between families, agencies and system decision-makers may help effect a cultural change towards more a more *inclusive* and productive child and youth mental health system.[38, 39]

Using empowering language is important to develop strong, trusting relationships and strengths-based partnerships with families.

Best practice

- Multiple *accessible* methods are used to communicate with families and among all partners.

Definitions

communication: the exchange of thoughts, messages or information between people or among a group of people, using spoken languages, body language, tone of voice and gestures. Effective communication occurs when there is a shared understanding; in other words, the message that is received and understood is the same message that was sent.[35]

DIVERSITY AND INCLUSION

Family engagement practices are inclusive; the diversity of partners is valued, and engagement is representative of the communities served.

What this means for...

Families

Your family structure and ethno-racial, cultural and social identities are respected and embraced. Engagement activities and environments are inclusive, safe and adapted, where required, to meet your needs.

Agencies

You understand the ethno-racial and cultural backgrounds of the families you work with and strive to meet their diverse needs. You make focused efforts to build relationships with families from marginalized communities and ensure engagement practices are culturally appropriate.

System decision-makers

You make a concerted effort to engage diverse families in creating policies and ensure their contributions are valued and recognized. This is particularly important when working with marginalized and underrepresented populations.

It is important to ensure inclusive and safe environments in which families feel that their diverse identities are respected and valued.

Background and rationale

Mental health care providers often work with families who represent a range of ethno-racial and cultural identities, living circumstances and family structures.[40] To be successful, *diversity* initiatives should use an anti-oppressive approach to practice, support staff to understand and recognize diversity and strive for *equity*.[41] Partners also need to be aware of their own history, experiences and worldviews, and recognize how these might influence the way they engage and develop relationships with families.[33]

Service providers should be familiar with a family's background in order to best support and respond to their diverse and unique needs and preferences with *culturally-appropriate practices*.[42, 43, 44] While speaking a common language or sharing some cultural traditions might help when supporting families, a shared cultural identity between service providers and service users is not critical for

ensuring high quality services.[45] It is, however, important to ensure *inclusive* and safe environments in which families feel that their identities are respected and valued.[33]

Governing bodies that inform child and youth mental health service design, policies and strategies should engage diverse families who are representative of the communities served. This can ensure a rich array of perspectives and reduces the burden on any one family member to represent the range of voices in a community.[47]

Best practices

- Families and partners reflect the diversity of the communities served.
- All partners adopt an *anti-oppressive practice* (AOP) lens and actively use this approach to ensure diverse and inclusive processes.

equity:

fairness; creating equal access and opportunities; achieved by removing barriers that prevent access to mental health care or engagement opportunities, particularly barriers related to gender, race, sexual orientation, income, education and many other identities.

Definitions

anti-oppressive practice: approach that encourages diversity, prioritizes the needs and strengths of marginalized groups and works to transform structures that create inequalities.[47]

culture: shared experiences of people, including their language, values, customs, beliefs, worldviews, ways of knowing, and ways of communicating. Culturally significant factors encompass, but are not limited to race/ethnicity, religion, social class, language, disability, sexual orientation, age and gender.[48]

culturally-appropriate practices: practices that are responsive to the cultural concerns of racial and ethnic minority groups, including their language, histories, traditions, beliefs and values.[49]

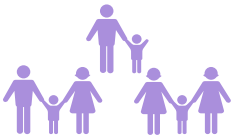
diversity: a broad term that refers to the variety of differences among people, often within the context of culture, education, organizations or workplaces.[50]

inclusion: striving for equity and maintaining a culture where difference within the collective is embraced, respected, accepted and valued;[51] the process of improving the ability, opportunity, and dignity of participation for those disadvantaged on the basis of their identity.[50]

EMPOWERMENT

All partners share trusting, respectful relationships that enable family experience, expertise and perspectives to be clearly reflected in system planning and improvement efforts.

What this means for...



Families

Partners in the child and youth mental health system value and rely upon your experience, expertise and perspective. They help you to identify your strengths and build your capacity to influence processes and services at the organization and system-level.

Agencies

You take a strengths-based approach, valuing families' lived experiences as expertise and empowering them to use that expertise to inform and co-develop services and processes within your organization.

System decision-makers

You model empowerment in family engagement processes, identifying existing strengths in partners and helping them to build their capacity to further influence system-level services and processes.

Background and rationale

Family engagement is an *evidence-informed* practice recognized by service providers, policy-makers and researchers alike as an integral part of the child and youth mental health sector.[10] Family voice impacts system-level change as families share their perspectives on service infrastructure and policies that affect their children's lives.[52, 53] As such, families must feel confident to openly express their insights, needs and concerns without fear of undue negative consequences.[21] This requires agencies, system decision-makers and other partners to recognize, respect and value families' strengths, capacities and lived experiences as expertise.[54]

A *strengths-based approach* values trust, respect, intention and optimism by emphasizing personal relationships, inviting meaningful participation, acknowledging contributions, providing support and ongoing *learning opportunities* and concentrating on solutions.[55] Adopting a strengths-based

approach helps empower families by focusing on their existing strengths and helping them to build on their best qualities.[56] This includes reinforcing qualities that enable families to take on leadership roles and participate meaningfully in *decision-making* processes. As a result, families are better able to share their unique insights to inform practices within organizations and across the system more broadly.[28,57]

Families must feel confident to express their insights, needs and concerns and see their perspectives used to inform practices within organizations and across the system more broadly.

Best practice

- Family perspective and expertise is embedded in system planning efforts.

Definitions

empowerment: the process of enhancing the capacities or abilities of individuals to influence or make informed choices and to transform those choices into desired actions and outcomes.[58]

strengths-based approach: an attitude and way of working that focuses more on individuals' internal strengths and resourcefulness and less on weaknesses, failures and shortcomings; putting the spotlight on opportunities, hope and solutions, enabling a positive mindset that helps those involved to build on their best qualities and develop reasonable expectations of self and others.[56]

ONGOING LEARNING

All partners, including families, have a shared understanding of the philosophy and practice of family engagement and have accessible, ongoing learning opportunities.

What this means for...

Families

You are provided with accessible learning opportunities (during times and in places and ways that make sense for you) to acquire tools, knowledge and skills to be able to engage and partner more effectively at the agency or system level. You can also count on your partners to continually improve their own engagement knowledge and skills through ongoing learning opportunities.

Agencies

Your organization supports ongoing learning opportunities for both staff and the families with whom you partner. You work to continually build families' knowledge and skills through modalities that make sense for them.

System decision-makers

You make sure all partners, including families, know what skills and knowledge are needed to engage at the system level and you work towards building the necessary preparation into system-level processes.

Background and rationale

The practice of family engagement requires ongoing *learning opportunities* to increase the knowledge and skills of families, organizational staff and system-level decision-makers alike. Depending on previous experience, all partners may require preparation and orientation to the philosophy and practices of family engagement.

Training and coaching opportunities should be made available to family members who want to become engaged, yet lack specific skillsets, or want to improve in certain areas, like preparing for governance meetings or learning about research and evaluation.[59] Capacity building for partners can focus on emphasizing strengths-based work with families and exploring ways to engage families.[60]

In addition to being provided on an ongoing basis, learning and training opportunities should model engagement.[59] For example, those providing learning opportunities might co-develop content with families to ensure that their perspectives, knowledge and lived experiences are reflected.[59] It is also helpful to work with families to understand and support their readiness to engage, by discussing expectations, goals and options for engagement.[44]

Not all families have the desire or capacity to become engaged in leadership activities. Partners need to be mindful of this and have open conversations with families about their interests.[28] For example, family members currently attending to their child's mental health needs may need to dedicate more energy to those pressing personal needs while those further along in their journey in mental health may be better positioned to become strong trainers, mentors, coaches and leaders.[29] In any case, families need to decide for themselves their appropriate level of engagement.

Depending on previous experience, all partners may require preparation and orientation to the philosophy and practices of family engagement. All partners should be provided ongoing training and learning opportunities.

Best practices

- All partners are well-prepared to participate in all activities and processes, including decision making. Namely, they are aware of, and knowledgeable about, family engagement policies and practices and other relevant topics.

- Families inform the environment, format and content of learning opportunities to ensure that such opportunities best facilitate their ongoing growth and learning.

Definitions

learning opportunities: coaching, training or other learning events supporting the pursuit of knowledge and skills to achieve a goal; building on strengths among individuals, organizations and communities.[62]

PARTNERSHIP

Families are essential partners, collaborating in all decision-making processes.

What this means for...

Families

You are a partner in decision-making processes and you are given opportunities to build successful relationships with other partners. Your expertise is valued, and you are aware of how your expertise is reflected in final decisions.

Agencies

You value families as partners and work to build successful relationships, avoiding tokenism and offering a range of engagement options in decision making processes. You are *transparent*, ensuring families understand how decisions are being made and how their expertise is being integrated.

System decision-makers

You collaborate with families when developing policies that impact them. You value their expertise and make sure their perspective is included in decision making processes. You are transparent, ensuring families understand how decisions are being made and how their expertise is being integrated.

Background and rationale

Family engagement is rooted in authentic, collaborative and respectful relationships among families, service providers, policy-makers and other partners.[31,62] This represents a clear departure from traditional stigmatizing paradigms blaming families for the mental health problems of their children or excluding them from organizational and system-level decision making. Building successful relationships with families also requires meaningful engagement without *tokenism*, which is one of the most significant *barriers* to fostering trust, mutual appreciation and productive *partnerships* with families.[31] As such, it is important to engage families in ways that are empowering and in roles that offer a range of opportunities for worthwhile contributions.[63]

The *evidence-informed* practice of family engagement demonstrates that families have valuable skills, lived experiences, knowledge and expertise to contribute to system planning, program development, implementation and *evaluation* of child and youth mental health services.[64] Accordingly, families must be empowered as essential partners in *decision making* at all stages of a project or process. Leaders need to share power and give up some authority, so families can have a louder voice than traditional dynamics have allowed.[31,62]

Organizational and system leaders need to share power and give up some authority, so families can have a louder voice than traditional dynamics have allowed.

Best practices

- Families and partners build and maintain mutually beneficial trust-based relationships that acknowledge power and position. This relationship is evident in all interactions.
- Families are actively engaged in decision-making roles.
- All partners work together to establish clear expectations about what family partnership looks like at all levels of decision making.

Definitions

collaboration: an interactive process among individuals and organizations with diverse expertise and resources, joining together to devise and execute plans for common goals as well as to generate solutions for complex problems.[65]

decision making: process of collecting information, establishing selection criteria, developing possible alternatives or options and evaluating the most appropriate option based on selection criteria.[66]

partnership: collaborative relationship between two or more people. People or organizations in a partnership collaborate to advance their mutual interests. A partnership involves sharing individual skills and resources, while working together towards a common goal.[67]

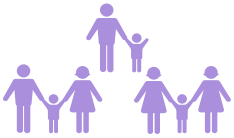
tokenism: the practice of making only a symbolic effort; trivial engagement of underrepresented groups.[16]

transparency: an open flow of information, and clarity about decisions.

RESEARCH AND EVALUATION

Families and partners jointly research, evaluate and make ongoing quality improvements in all aspects of system planning.

What this means for...



Families

You are a partner in developing and carrying out program, organizational and/or system-level research and evaluation activities.

Agencies

You work side by side with families to develop and carry out research and evaluation activities at both the program, organizational and/or system level, including ongoing evaluation and improvement of family engagement practices.

System decision-makers

You regularly and frequently engage families, working jointly to develop and carry out system-level research, evaluation and improvement efforts.

Background and rationale

Family engagement requires ongoing reflection, monitoring, *research* and *evaluation* to ensure that services are meeting families' needs and engagement efforts are working.[27] Engaging families at all stages of research and evaluation processes helps ensure that the process and outcomes are relevant, meaningful and user-friendly for all involved.[61]

In program evaluation, families may participate in the development of user-friendly surveys and other research instruments, co-facilitate focus groups and interview participants.[68] Families can also help interpret, disseminate and present findings.[61] They can offer qualitative insights into the link between evaluation data and services and help improve the tone of messaging to give the findings more real-world relevance and application, especially for the general public.[21,62] Families can also help increase the impact of findings by presenting them from their own perspectives in conferences, symposia and educational workshops.[61]

While engagement efforts have been studied in clinical settings like hospitals, where the environment is highly controlled,[69] few research studies have looked at engagement in more diverse community-based settings.[62] This lack of research in the field of family engagement presents an opportunity for organizations to evaluate their own family engagement efforts and add to the body of knowledge for family engagement. Family engagement efforts at the agency-level and the system-level also need to be researched and evaluated more often and more consistently.[28]

Engaging families at all stages of research and evaluation processes helps ensure that the process and outcomes are relevant, meaningful and user-friendly for all involved.

Best practices

- Families are co-developers and co-evaluators of research and evaluation processes (e.g. design, implementation, analysis, dissemination and mobilization).
- Families actively contribute to ongoing improvements to engagement activities or processes.

Definitions

evaluation: systematic collection and analysis of information to understand whether a project, service or process is doing what it was intended to do and how well (or not) it is doing so.[70]

quality improvement: systematic approach to making changes that lead to better patient [client] outcomes and stronger health system performance. This approach involves the application of Quality Improvement (QI) science, which provides a robust structure, tools and processes to assess and accelerate efforts for the testing, implementation and spread of QI practices.[21]

research: process of creating new knowledge or the use of existing knowledge in a new and creative way to generate new concepts, methodologies and understandings. This includes synthesis and analysis of previous research to the extent that it leads to new and creative outcomes.[71]

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APPENDICES

Appendix A: Family engagement advisory group

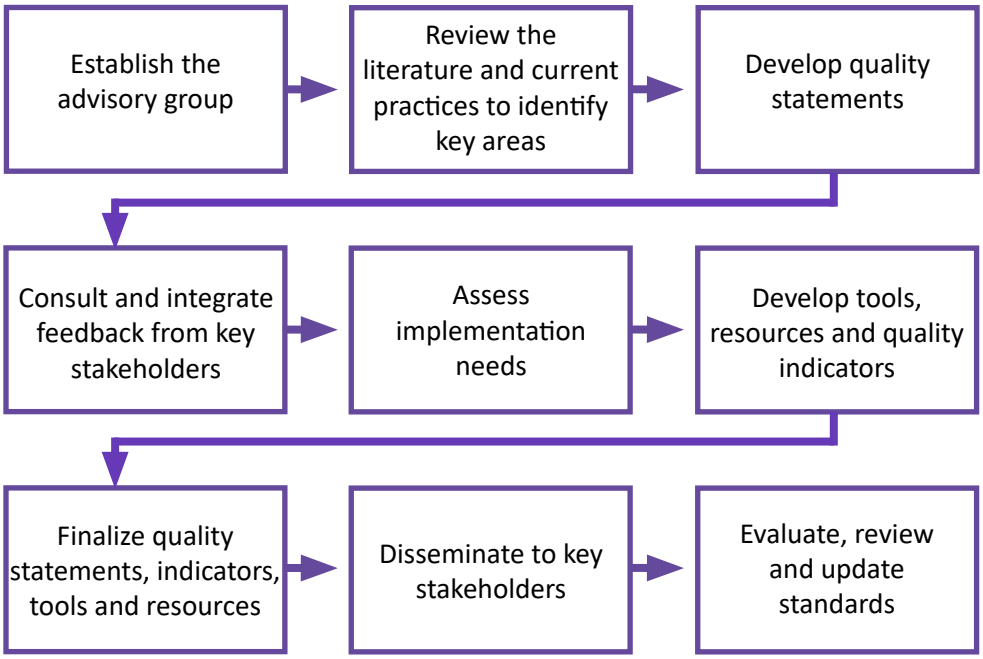
- Carrie Bullard, Community Engagement Lead
  Central Access Project, St. Joseph's Healthcare Hamilton
- Louise Murray-Leung, Family Engagement Lead,
  Lynwood Charlton Centre
- Mamta Chail-Teves, Executive Director,
  Wellkin Child & Youth Mental Wellness
- Natalie Markoff, Family member
- Sarah Cannon, Executive Director,
  Parents for Children's Mental Health
- Vicki Cochrane, Family member
- Vicki Mowat, former Senior Director of Planning and Research,
  Kinark Child and Family Services

Centre staff acknowledgements

- Brooke Eboule, Communications Specialist
- Cameron Jette, Youth Advisor
- Chrissi Galanakis, Senior Data Analyst
- Evangeline Danseco, Performance Measurement Coach
- Huma Muhammadi, Research Assistant
- Jana Kokourek, Manager, Engagement and standards
- Julie Breau, Quality Improvement Specialist
- Kamill Santafe, Youth Advisor
- Kristina Rohde, Quality Improvement Specialist
- Marta Krygier-Bartz, Research Assistant
- MaryAnn Notarianni, Director, Special Projects and Operations
- Shruti Patel, Program Associate
- Tracey MacLaurin, Project Coordinator

Appendix B: Standard development process

To develop this quality standard, the Centre adapted the process from Health Quality Ontario's quality standards process and methods guide.[15] The major steps are outlined below.



Appendix C: Glossary

accessible: activities (including communication and processes), products (such as devices) and environments that are designed to be easy to understand, use, participate or access, especially for people who face barriers

active listening: paying close attention to a conversational partner's words, repeating back key ideas and phrases from time to time to confirm one's understanding of what the person has said. Demonstrates respect for — though not necessarily agreement with — the other person's feelings and views.

anti-oppressive practice (aop): approach that encourages diversity, prioritizes the needs and strengths of marginalized groups and works to transform structures that create inequalities.

barrier: a circumstance or obstacle that separates people from other people, places or things. Barriers come in many forms — including attitudes, policies and programs, as well as physical, social, communication or transportation obstacles — and may even be unintentional.

co-development: process of working collaboratively on a shared purpose; joint decision making; a commitment to action and collective accountability among all stakeholders.

collaboration: an interactive process among individuals and organizations with diverse expertise and resources, joining together to devise and execute plans for common goals as well as to generate solutions for complex problems.

commitment: willingness to persist in a course of action, often owing to a sense of obligation to stay the course; the state or quality of being dedicated to a cause, activity, etc.

communication: the exchange of thoughts, messages or information between people or among a group of people, using spoken languages, body language, tone of voice and gestures. Effective communication occurs when there is a shared understanding; in other words, the message that is received and understood is the same message that was sent.

culture: shared experiences of people, including their language, values, customs, beliefs, worldviews, ways of knowing, and ways of communicating. Culturally significant factors encompass, but are not limited to race/ethnicity, religion, social class, language, disability, sexual orientation, age and gender.

culturally-appropriate practices: practices that are responsive to the cultural concerns of racial and ethnic minority groups, including their language, histories, traditions, beliefs and values.

decision making: process of collecting information, establishing selection criteria, developing possible alternatives or options and evaluating the most appropriate option based on selection criteria.

diversity: a broad term that refers to the variety of differences among people, often within the context of culture, education, organizations or workplaces.

empowerment: the process of enhancing the capacities or abilities of individuals to influence or make informed choices and to transform those choices into desired actions and outcomes.

equity: fairness; creating equal access and opportunities; achieved by removing barriers that prevent access to mental health care or engagement opportunities, particularly barriers related to gender, race, sexual orientation, income, education and many other identities.

evaluation: systematic collection and analysis of information to understand whether a project, service or process is doing what it was intended to do and how well (or not) it is doing so.

evidence-informed: practices and decision-making processes that 1) recognize clinical and practitioner knowledge and expertise and the lived experience of children, youth and families as evidence, alongside academic or research evidence and 2) systematically search, select, appraise and use all the best available evidence to deliver measurable benefits.

family: is a circle of care and support that offers enduring commitment to care for one another, and is made up of individuals related biologically, emotionally, culturally or legally. This includes those who the person receiving care identifies as significant to their well-being.

family engagement: an ongoing process that includes families as active decision-makers and partners at the organizational and system levels.

inclusion: striving for equity and maintaining a culture where difference within the collective is embraced, respected, accepted and valued; the process of improving the ability, opportunity, and dignity of participation for those disadvantaged on the basis of their identity.

inclusive: *see inclusion.*

learning opportunities: coaching, training or other learning events supporting the pursuit of knowledge and skills to achieve a goal; building on strengths among individuals, organizations and communities.

partnership: collaborative relationship between two or more people. People or organizations in a partnership collaborate to advance their mutual interests. A partnership involves sharing individual skills and resources, while working together towards a common goal.

quality improvement: systematic approach to making changes that lead to better patient [client] outcomes and stronger health system performance. This approach involves the application of Quality Improvement (QI) science, which provides a robust structure, tools and processes to assess and accelerate efforts for the testing, implementation and spread of QI practices.

research: process of creating new knowledge or the use of existing knowledge in a new and creative way to generate new concepts, methodologies and understandings. This includes synthesis and analysis of previous research to the extent that it leads to new and creative outcomes.

resources: the supply of money, materials, staff, physical facilities, attributes, capabilities and other available assets that can be used to support processes and activities.

strengths-based approach: an attitude and way of working that focuses more on individuals' internal strengths and resourcefulness and less on weaknesses, failures and shortcomings; putting the spotlight on opportunities, hope and solutions, enabling a positive mindset that helps those involved to build on their best qualities and develop reasonable expectations of self and others.

tokenism: the practice of making only a symbolic effort; trivial engagement of underrepresented groups.

transparency: an open flow of information, and clarity about decisions.

transparent: *see transparency*.

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