CanChild

BEING FAMILY-CENTRED:

A guide for our journey

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INTRODUCTION

Family-centred service is an approach to providing services to families. It involves a set of ideas and behaviours that look at every child within the context of their family. It recognizes that every family is unique, and it values parents as experts on their child's needs and strengths. In this approach, families and healthcare providers work together as a team to make decisions about care and support—not just for the child, but for the whole family.

CanChild has a longstanding interest and research engagement with Family-Centred Service (FCS). Since the 1990s we have been exploring what FCS means to families, how to assess parents' experience of it, and whether it matters. The following FCS tipsheets share parents' feedback about how FCS looks like to people on the ground, framed by comments from the service provider members of our team. These ideas are grounded in global frameworks, including World Health Organization's International Classification of Functioning, Disability and Health (ICF), and UNICEF's Convention on the Rights of the Child.

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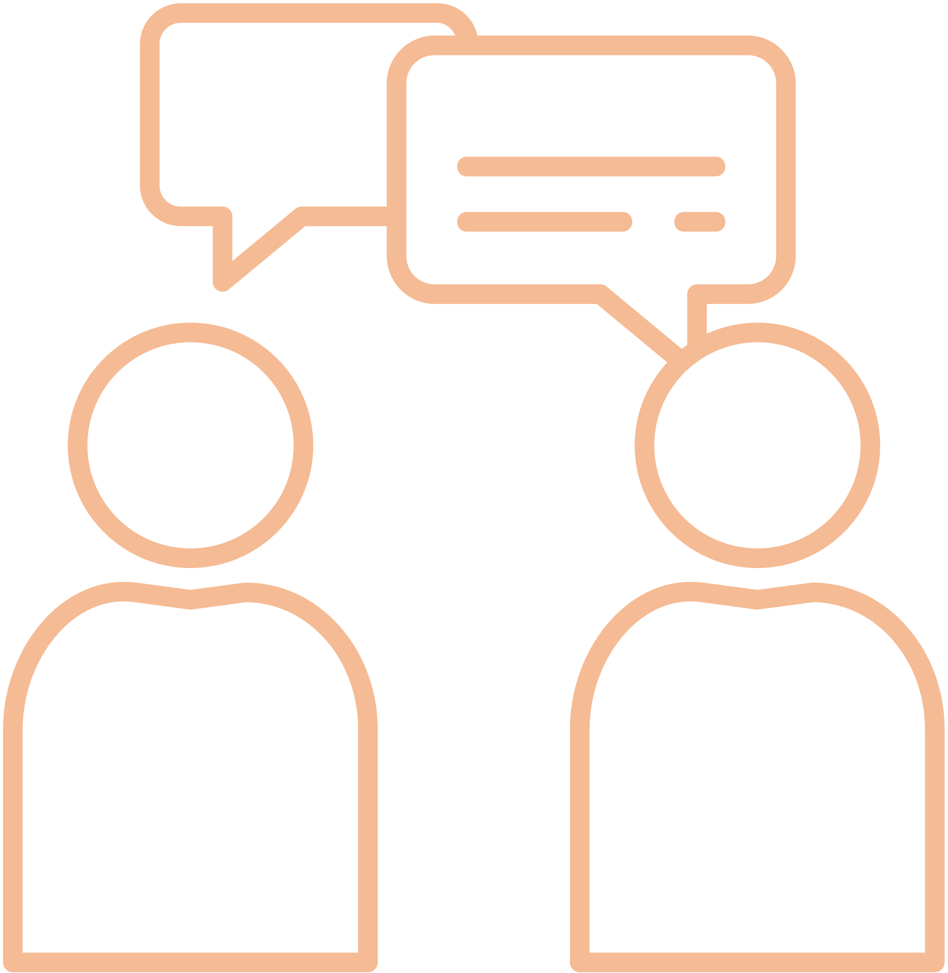
Communicating in a Supportive and Collaborative way

Communication is the foundation of the clinical relationship! It involves not just speaking and listening, but also pausing to ensure mutual understanding, and revisiting or rephrasing when needed. Communication can be both verbal and non-verbal.



Supportive and collaborative communication recognizes that:

- **Parents are the experts on their children.** They are the ones who are most invested in their child's well-being. Recognizing this expertise fosters trust and lays the groundwork for a successful relationship. When parents raise concerns, they do so for a reason—and they may bring valuable ideas to the table. Inviting their input and acting on it shows them that they are essential members of the team.

- **Transparency builds trust.** Being open about our thoughts—and honest about what we don't know—helps create a safe, respectful space. Parents trust providers who acknowledge uncertainty and work together to find solutions.

- **Information can be overwhelming.** Parents often receive a lot of information all at once, so summarizing key points in plain language can be incredibly helpful.

- **Ultimately, parents are responsible for making decisions about their child's care—but they shouldn't have to do it alone.** Providing clear explanations and support empowers them to make informed choices that are right for their family. Taking the time to walk them through options is essential to building lasting trust.

- **Engage with the child, not just the family**. No matter the child's medical condition or diagnosis, they are a person first. Parents appreciate healthcare providers who recognize and connect with their child as an individual. This can include addressing the child by their name, speaking to them directly (even if we do not expect a response), and noticing things about them (e.g. "What a joker").

Communicating in a supportive and collaborative way

In practice, we should....

- Listen and pay attention to what caregivers tell us
- Acknowledge caregivers' expertise and knowledge regarding their child
- Communicate with caregivers in an open, clear and honest way
- Explain to caregivers what choices **they have**, including what reasons we have for recommending certain options
- **Admit** when we don't have the answer

> **I have, for 14 years. gone to lots of research conferences, have talked to physicians, have read research articles... I'm a well-educated mother professionally and I have something to offer about what works for him and what doesn't. If I have a question, my questions are valid and if somebody tries to answer, and if they don't know the answer, say "I don't know but I'll try and find out for you".**

> **The parent is the one who is there day in and day out,.. they have all the pieces of the information in a way that no healthcare provider will ever be able to do because they don't have all the time and thought that goes into their child in the same way that a parent does... As a mother you are the most invested person on the team. Whatever happens to your child, happens to you.**

Communicating in a supportive and collaborative way

In practice we should....

- Share just the right amount of information with caregivers, based on what believe are their needs
- Use terms and words that are easy to understand (as little jargon as possible)
- Check to make sure caregivers **understand** the conversation. For example, ask how they would explain this to their family member or friend
- Ensure caregivers have access to written reports or summaries of meetings

> **[The surgeon] was watching for my reaction, and he could tell from my eyes when to slow down, when to give me a moment, and when to say the right thing... I knew wow this guy is actually paying attention to how I feel.**

> **I don't think the onus is on the parent to meet the medical professional at their level, especially linguistically... because it's not possible for a lot of people and it shouldn't be part of something that we have to do as parents.**

Supporting family well-being

Every family is different! Care plans should reflect their individual circumstances. It’s essential to ask how our recommendations align with their daily realities—considering factors such as time, cost, availability, and their belief in the proposed approach.

Supporting Family Well-Being looks like...

- Taking the time to learn who the key caregivers are. These may include grandparents or other family members who want—or need—to be involved in care discussions.
- Remembering that parents are more than just caregivers (which is how we know them). They may have work responsibilities, personal commitments, and other life priorities beyond healthcare. Families may need to plan around events like vacations or special occasions. Respecting these realities builds trust and makes it more likely that care plans will be used and sustained.

Supporting family well-being

In practice we should...

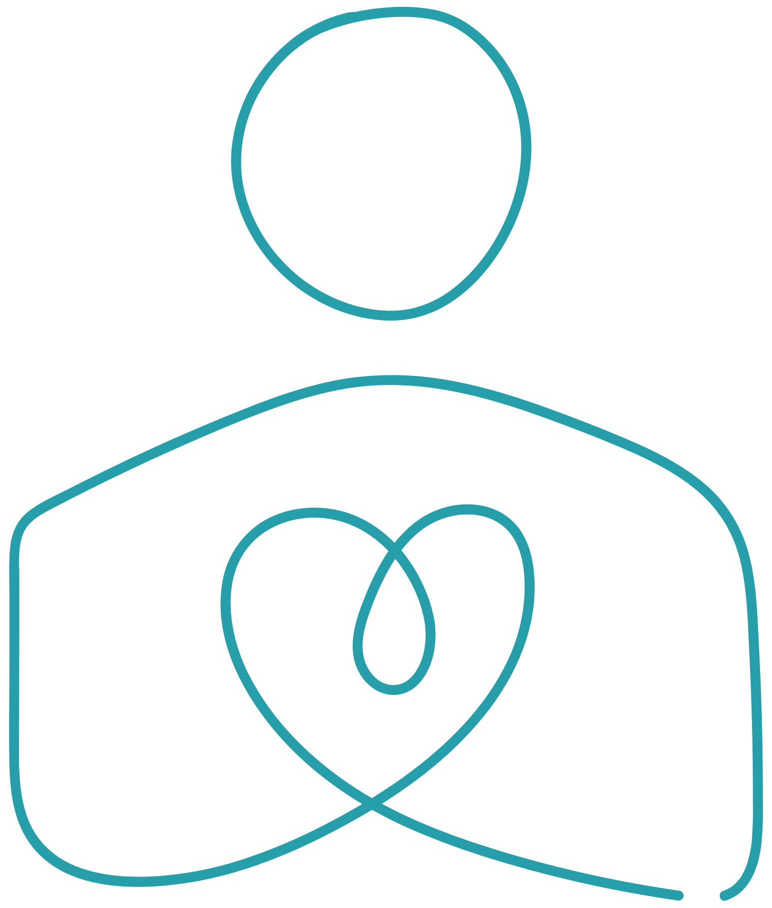
- Take the needs of the entire family into account
- Show concern about the well-being of all the family members (e.g. impact of care plan on siblings)
- Involve family members who are part of child's care team (e.g. grandparents)
- Show we appreciate caregivers' situation outside of their caregiving role (e.g. work commitments)

> **[A]llowing us to talk about our lives outside of just the diagnosis – what is your family life like? One of our doctors is really good with that: we could try this medication, but I want your quality of life too, I want your family to have a quality of life, because if you medicate her too much, then you might lose that. Or encouraging us to travel, because we're freaked out that she could have seizures on a plane, and they're like "You'll be able to figure it out and it'll be fine," and the risk is worth the benefit. So, knowing our whole family and knowing that we have other children to think about as well, and giving our whole family the quality of life, and it's not just about protecting our one child in a bubble that doesn't allow us to live life.**

> **See us as caregivers and it is not just our child that is impacted. It is recognizing the family, so like, "hey Mom, how are you doing"? In general our healthcare providers don't even stop to think about how hard it was to even get there that morning.**

Providing supportive care

“Care” is at the heart of healthcare.
Families need healthcare providers who are not only skilled but also caring and empathetic.



- Parents work tirelessly to support their children, and it means a lot when someone sees and appreciates their efforts. At the same time, don’t assume that a family who appears to be coping doesn’t need help. Many families keep going despite significant stress.
- Appointments often focus on what a child can’t do, which can be discouraging. Noticing and commenting on a child’s strengths or progress helps families feel seen—and gives them hope. A strengths-based approach shows parents that we recognize the whole child, not just their challenges.
- Families need practical, meaningful help—support they perceive as useful. Coordinating care, advocating, and navigating systems is exhausting. When providers take steps to ease this burden—by making referrals, introducing services, helping with forms, or programming a device—it has a tangible impact. These actions can make a big difference in helping families access the support their children need.

Providing supportive care

In practice, we should...

- See the child as a person beyond their diagnosis
- Show that we care for/about caregiver and child
- Work to develop a relationship with caregivers AND child
- Show interest in the family's life situation
- Recognize and acknowledge the family's strengths and resources
- Comment on the child's strengths and progress
- Provide tangible, hands-on support when possible
- When making a recommendation, help connect families to appropriate services

> **Families do notice when you don't seem to be there or want to be there or when you don't really care about someone's kid**

> **[Pediatric neuropsychologist] actually took it one step further and looked at where we lived and looked into addresses, names and phone numbers of people or companies that could help us with those services .... He phoned three local places that provide this type of tutoring and specifically spoke to someone there saying, "I have this five-year-old and this is what I came up with for him and would you service him?" Then he let us know which one of three would service our child**

Providing respectful care

Every person—child or adult —deserves to be treated with respect and dignity. Respect is more than politeness - it means treating everyone equitably and without prejudice.

In healthcare, respect begins with recognizing that every family is unique. First impressions may not tell the full story. Let's assume that caregivers are doing the best they can for their child, and tailor our approach to meet each family's specific needs.

- Seeing families at their scheduled appointment time demonstrates respect for their time. Reviewing the child's chart before the appointment shows respect for the family's energy and emotional bandwidth. Asking parents to repeat the same information again and again is not only frustrating—it can also be re-traumatizing.
- It's also essential to show respect to our patient – the child. Let's speak to the child by name and address them directly, even if we don't expect a verbal response. This builds trust, reassures the parents, and reinforces the child's personhood. If a child is upset, in pain, or crying, pause and offer comfort before proceeding with any tests or procedures.

Providing respectful care

In practice, we should...

- Assume that all caregivers are doing their best
- Ask caregivers and children how they would like to be addressed
- Treat the child with respect and dignity in a developmentally appropriate way
- Take the time to answer all of the family’s questions
- Provide individualized care that meets the needs of child and family

> **I basically got told that it was my fault that she had behaviours the way that she did, and it was our parenting style...**

> **We very much focused on what is important to him and I talked to them about how he wanted to keep up with his brother doing the things he could do like climbing on the play structures at the park and being able to pedal a bike and doing those things with his brother who is really important to him, and they really embraced that. They would spend his OT session in the yard, teaching him to climb the bars and the quality-of-life impact that had on him I cannot even express. The park brought him more joy than anything else in the world and the clinician would say, “we recognize this kid is not feeding himself and chokes all the time but climbing on the playground is important to him so that is what we will focus on.**

Providing respectful care

In practice, we should...

- Speak directly to the child
- Respect family’s time
- Be prepared and up-to-date for meetings with the family
- Ensure therapy plans are feasible for the family's life situation

> **[T]hat doctor walked in and said, ‘So I read these studies, there are 10 other [rare diagnosis] kiddos’. My jaw just hit the floor... You are the first person that I have not had to give the Cole’s notes of what [rare diagnosis] is... He walked in and had done his work and I was floored. I could have just kissed the man.**

> **Their focus plan is on parent training. When they come, they train me how to work with my son, but I just find it is so overwhelming with everything that is already going and all the care that I already have to provide for him. To become his therapist is adding so much to the pile... When the therapist comes to my home I want you to take him and work with him during this hour please and do the best job you can. For me personally, that is an hour break where I don’t have even think about what you are doing - I can relax and enjoy how he is progressing. But instead as a parent we are being taught how to do this therapy at home and given this pressure of, “okay, at the next check-in we are going to see how well you did it”. That is really hard. I think maybe the whole system needs to change the approach.**

Working together with families

Parents are the people who know their child best—they see them every day and are deeply attuned to their needs, strengths, and challenges. Parents want to collaborate with healthcare providers to support the best possible outcomes for their child. They also often value having their child involved in their care, as appropriate for the child's age and development.

- ·Just as children grow and change, so do family dynamics. There may be times when parents want to take a more hands-on role in their child's care, and other times when they may need to step back and rely more on the healthcare team. The best way to support them is to check in regularly to understand how they want to be involved.
- It's also important to remember that parents may not always know what services or supports are available, or what they need. Proactively sharing information about programs or resources their child may be eligible for—and helping them navigate access—can make a meaningful difference.

Working together with families

In practice we should...

- Acknowledge caregivers’ expertise and knowledge regarding their child
- Help caregivers feel like they are partners in their child's care
- Share decision-making responsibility with caregivers to the extent that they choose
- Involve the child in their own care, as appropriate
- Provide opportunities for parents to view their child’s medical information and add or clarify as needed

> **“I actually had a really amazing interaction with a neurologist at [hospital. I called. He called me back. I have never met him. He listens to my story and the very first thing he says to me is, “what do you think we should do moving forward? Do you have any ideas?” It blew my mind because of course I did. I said, “maybe we could reduce this medication and maybe we could look at this medication”... and he listened. He said, “that all sounds very reasonable and you know your son best, so I do not see a problem with that plan of action so why don’t we do that, but can I just add this”. That was six years ago, and I remember it like it was yesterday and I tell this story all the time because I think it is so impactful.**

Working together with families

In practice we should...

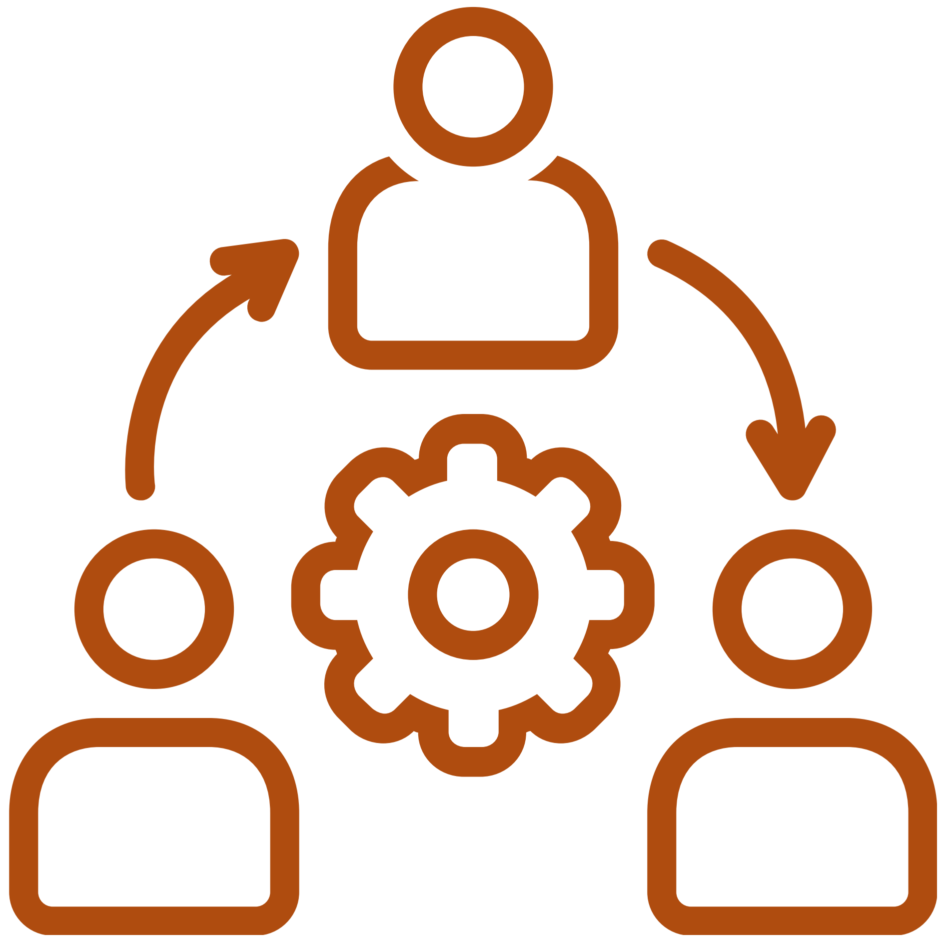
- Accommodate changes in caregivers' involvement depending on their situation
- Inform caregivers about relevant services and treatments for which their family qualifies
- Ask family about their ideas about issues and take them into account
- Try to find answers to family's questions when we don't know

> **She just took charge and I didn't want to think right? That was great, I want someone to tell me what to do when you're overwhelmed, I just want someone to take over... and I don't even want to be in there sometimes, right?**

> **Our neuromuscular doctor...He sent me some research articles he found for me to look at and he said to me, and this guy is brilliant, he said "if you come across anything please send it my way and I will look into it". To have that open dialogue and someone that respects that invisible parent backdoor research stuff we are doing all the time and to say, "share with me what you find". That was everything to us.**

Coordinating family’s care

Families often navigate care from multiple healthcare providers, which can sometimes result in conflicting advice. Each specialist may focus on a specific aspect of the child’s health, making it easy to miss the bigger picture.



- Collaborating as a team helps create a more complete understanding of the child’s needs. When families know that their providers are communicating with one another, it builds trust and provides a sense of security.
- ·Clear communication between professionals reduces the burden on parents to act as go-betweens. No parent should have to carry messages between providers or reconcile differing recommendations on their own.
- True family-centred care means including parents in team conversations—but it also means asking how they want to be involved. Not all families are ready or able to take on the same role, and it's important to respect their preferences and capacity.

Coordinating family’s care

In practice we should....

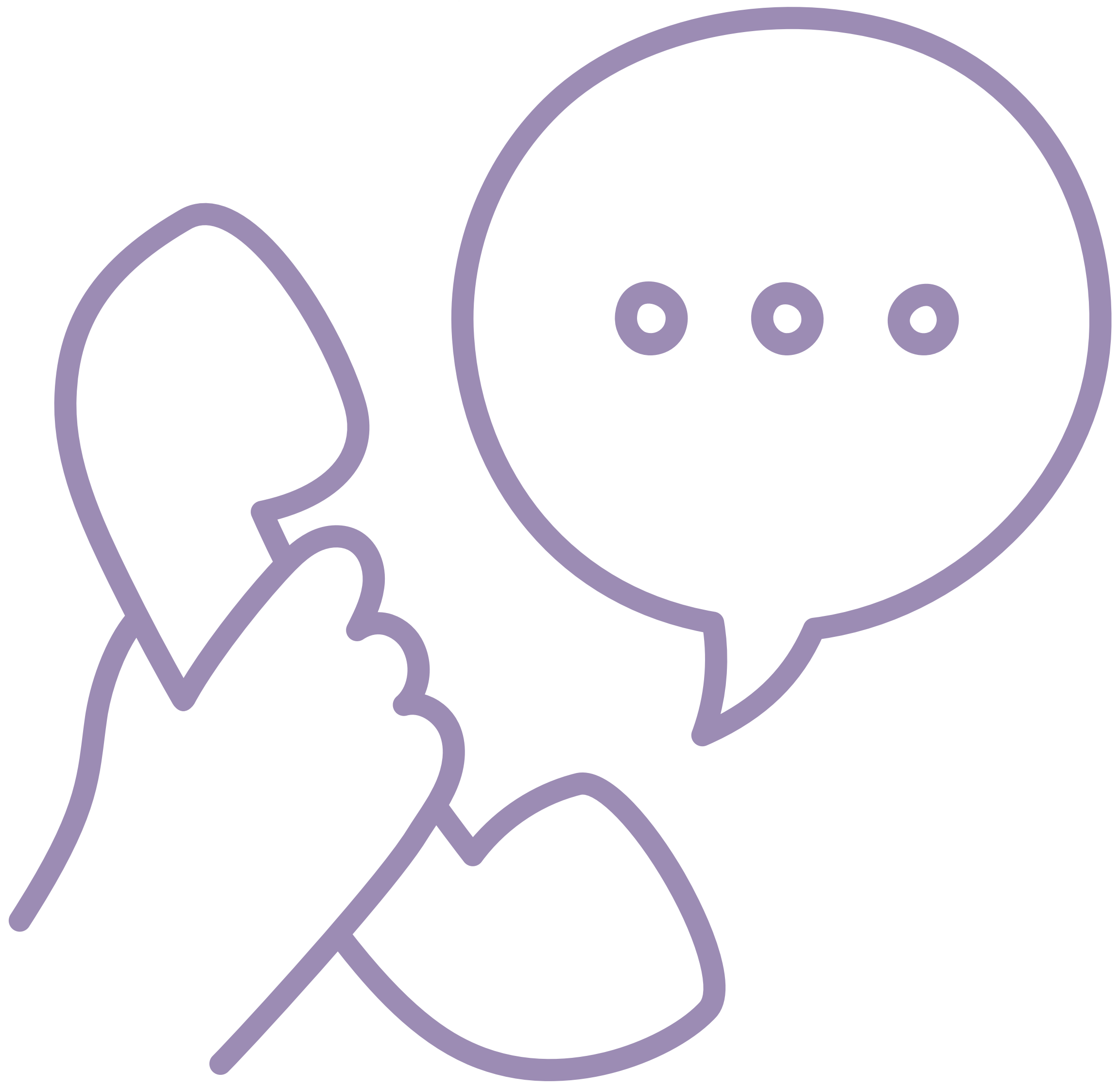
- Consult with other service providers as needed – do not force parent to be the messenger
- Involve the caregiver as part of the care conversation with the service team (to the extent they wish)
- Work with other members of the family’s care team to ensure that care plans are integrated
- Send reports to other involved service providers

> **Sometimes as parents, we need help and we need help coordinating the care, and we're just flying by the seat of our pants for the most part... you see 15 different specialists, nobody's putting it all together and you're the one doing that.**

> **I stand by the secretary - watch the fax send, and I am on the phone with the other end ensuring that it got there, as it has happened to us many times when things were supposed to happen, and the fax never arrived and my child’s procedure that he needs to live, is delayed six months. That is a burden that should not be placed on families.**

Making Services More Available and Accessible

Families lead busy and stressful lives. Many juggle multiple appointments, long travel distances, and complex schedules that include work and care for other family members. Their routines are already heavily disrupted—so it makes sense to reduce additional burdens wherever possible.



Simple steps by service providers can make a big difference. For example:

- By answering phone calls during business hours and responding to emails promptly, we help families feel supported and ensure they can access help when they need it.
- Providing our work phone number and email fosters a sense of security. Families rarely misuse this access and deeply value the connection.
- Telehealth can save families time, reduce travel and parking stress, and minimize disruptions to their child's/family's routine—all while avoiding time spent in waiting rooms.

By designing services that fit more easily into families' lives, we show respect for their time and circumstances—and strengthen the therapeutic relationship.

Making Services More Available and Accessible

In practice we should....

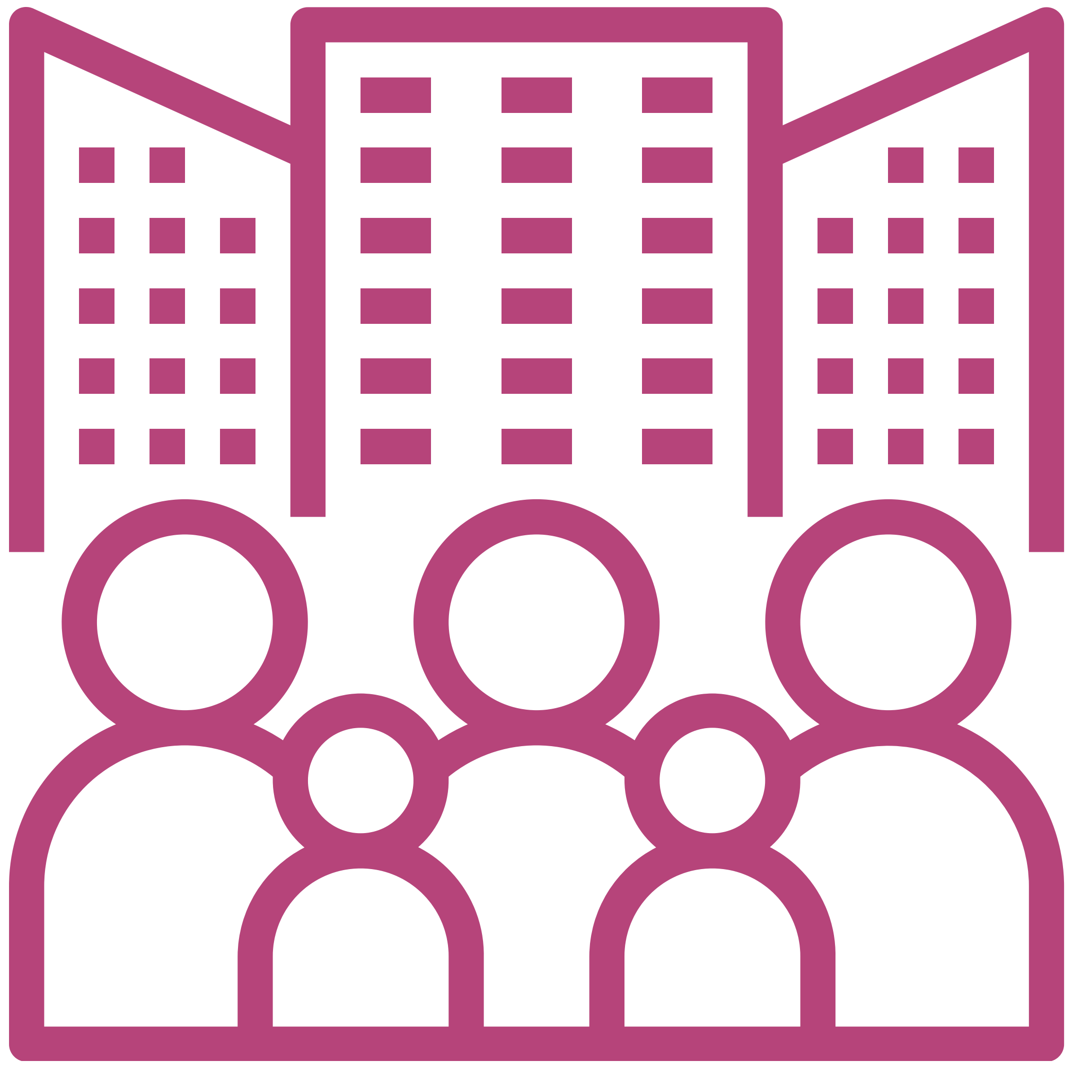
- Help to make sure appointments take place at times that are convenient for the family
- Give caregivers options for meeting in person or virtually
- Respond to caregivers' calls in a timely way
- Arrange for longer appointments when needed and requested

> We live 20 minutes from the appointment but I have to take half a day off work to have it and she has to miss half a day of school. Why does a clinic appointment take half a day when we are seeing the doctor for two minutes total and waiting for all the nurses and professionals to come in? Most of that could have been a Zoom call.

> With my healthcare team... we are emailing videos and we are texting back and forth. And I can talk to my daughter's rheumatologist when he is out of the country for a conference or if there is an emergency.

Structuring Organizations and Programs

The way services are structured and delivered has a significant impact on how families experience care.



- Transparency about waitlists and available services is essential. Families appreciate clear, timely information—and organizations should strive to communicate openly about what's available, how to access it, and how long it may take.

- Posting regular updates (e.g., monthly) on the program's website or landing page fosters trust and shows that the program is holding itself accountable.

- ·Accountability also means creating meaningful opportunities for families to share feedback—and showing that their voices lead to action. For example, a suggestion box at the front desk - as long as there is a good follow-up process in place!

- A monthly update highlighting a few suggestions that have been implemented shows families that their ideas are heard and valued.

Structuring Organizations and Programs

In practice we should...

- Provide caregivers with options for how to receive information and communicate with service providers. (Not all caregivers are tech-savvy)
- Provide services within a reasonable timeframe
- Provide transparent and clear information about wait times and wait lists
- Integrate medical records into a shared record system accessible to all professionals and families
- Actively seek caregivers' feedback on procedures and policies
- Take account of, and act on the basis of caregivers' feedback
- Provide waiting areas and therapy spaces that are friendly to families
- Provide caregivers with a range or menu of services that are relevant to their child and family, and information about how to access these services

> **Every centre has their own system in terms of how they provide services - they do not have to provide justification in terms of how they service their children.... [My children's centre], they are not transparent in terms of their documentation, their policies, their assessments, they will not provide it to families, even though it's considered public information**

HOW TO IMPLEMENT THESE IDEAS IN OUR PRACTICES?

Discussion Prompts at Team Meetings:
Use one tip as a weekly question for group reflection or huddles.

Pair-and-Share Exercises:
Colleagues can partner to discuss how they used one tip in practice each week.

Challenge Boards:
Post a tip in the staff room with space for team members to add examples of how they implemented it

Badge Reels or Lanyards:
Include micro-reminders or symbols (e.g., an icon for inclusive language).

Mini Case Studies or Comics:
Turn tips into real-life micro-narratives or visuals that show "what it looks like" in action.

Visual Reminders:
Create small printable cue cards or desk visuals with 1-2 key takeaways per card.

Sticky Note Series:
Share a digital or physical sticky-note-sized version of each tip, rotated weekly.

Screensavers or Wallpapers:
Convert main ideas into slides or graphics that can be used on clinic or personal devices.