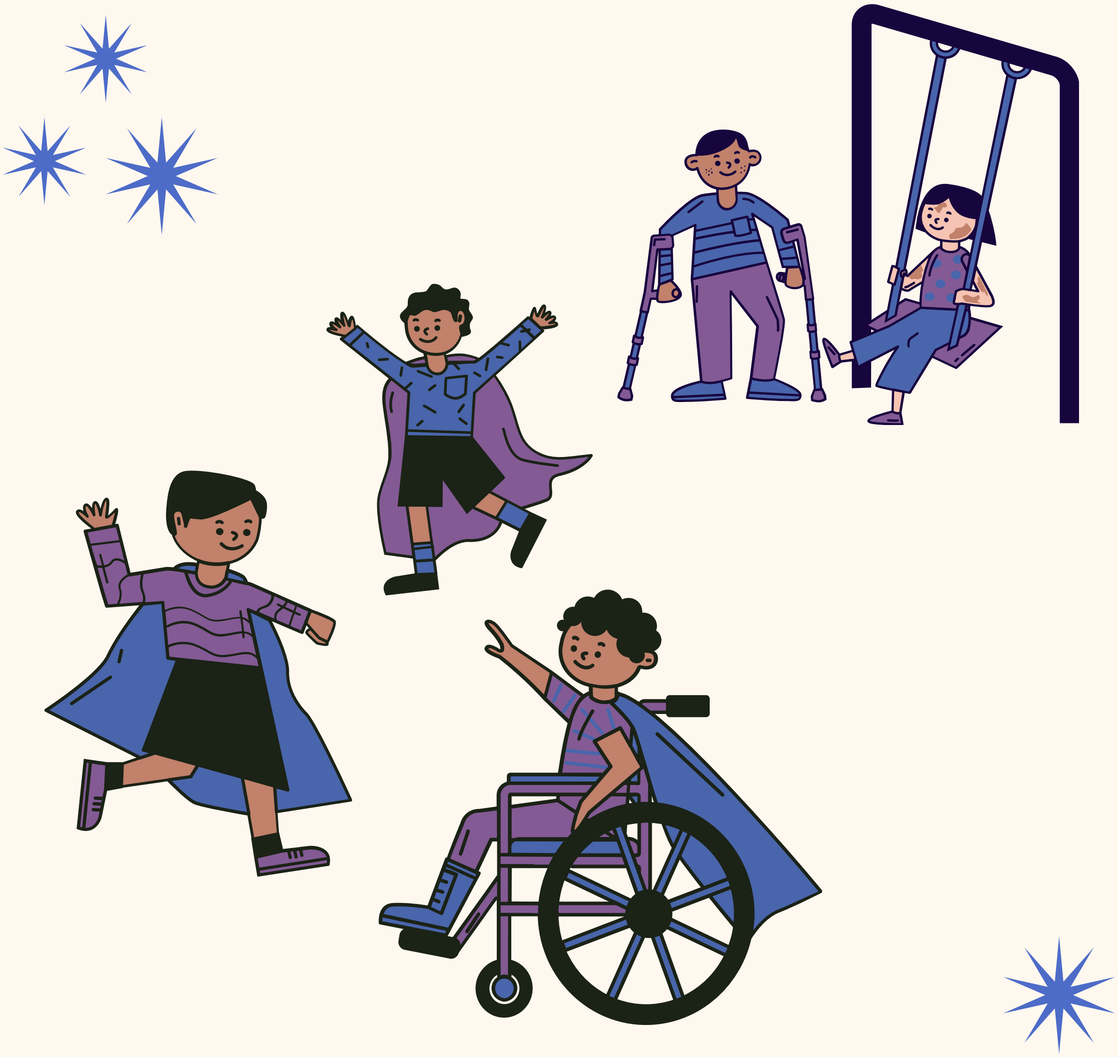
INSPIRED, INFORMED, AND CREATED WITH FAMILIES
OF CHILDREN WITH MEDICAL COMPLEXITY



Building Connections

A Language Guide for Healthcare Teams Supporting Children with Medical Complexity

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If you have any questions about including this resource in curriculum or other educational materials, please contact judyyjso@student.ubc.ca.

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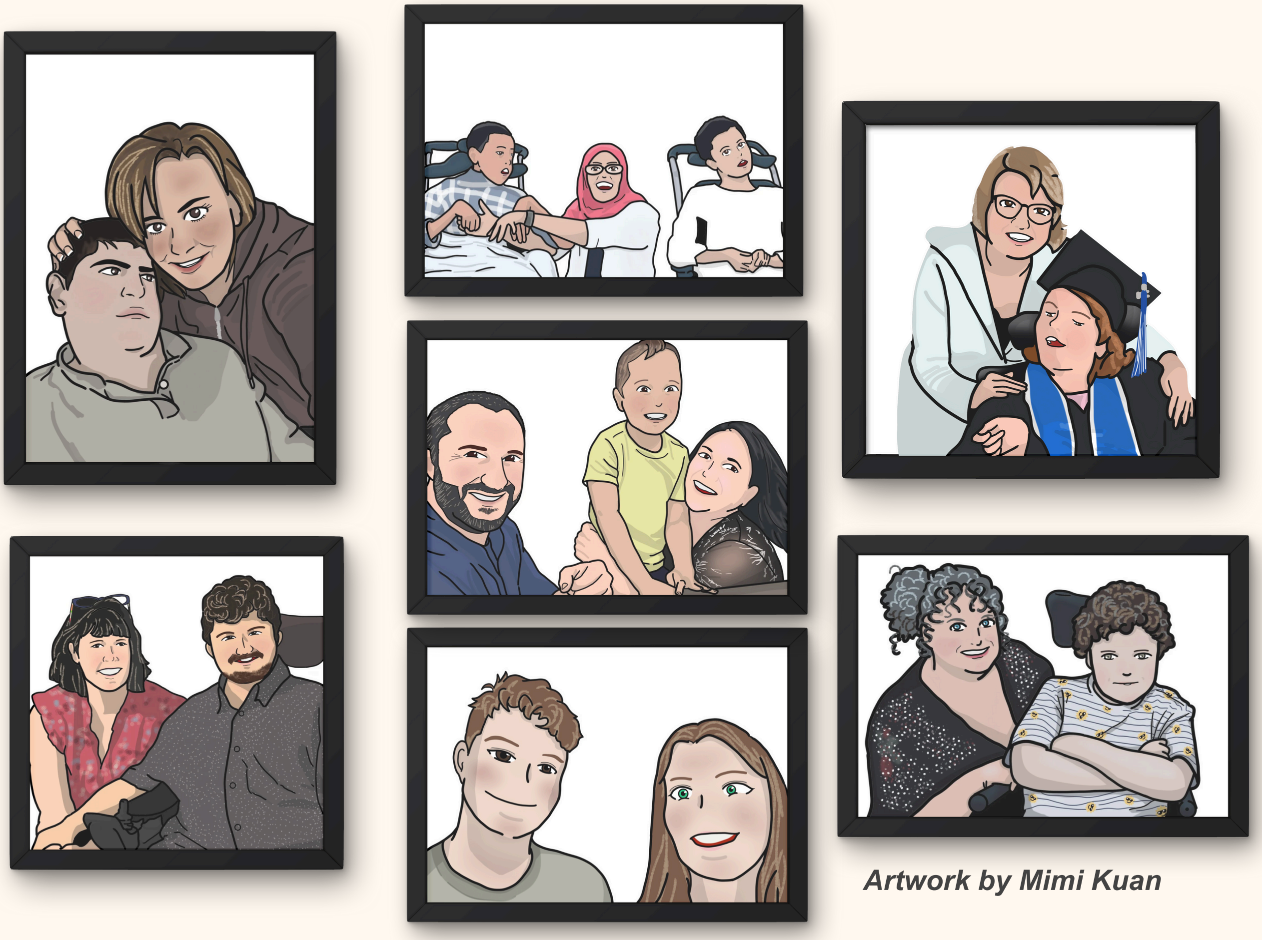
Introduction

This guide was created in partnership with eight parents of children with medical complexity (CMC). Below are their portraits. Their journeys span a wide spectrum—some are just beginning to navigate the healthcare system, while others have transitioned into adult care. Each family brings a unique perspective shaped by lived experience. Together, they have generously shared their insights to help improve communication between healthcare providers and families.

We recognize that **there is no single “right” way to speak with patients and families**. Language is deeply personal and contextual. This guide offers collective reflections from families, aiming to support more thoughtful, respectful, and inclusive conversations.

Also, we have used existing inclusive language guides to enrich this resource. These are referenced throughout the guide, along with a list of additional resources on the final page.



Artwork by Mimi Kuan

Why does language matter?

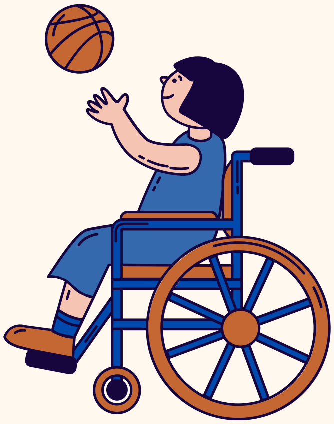
Inclusive language promotes respect, understanding, and support for diverse identities, experiences, and needs.[1]

Due to social constructs, the media's portrayal of disability, and medical training's focus on the clinical manifestations of various disabilities, clinicians can have harmful unconscious biases about disability. A study found that non-disabled people assume that people with disabilities have a lower quality of life.[2] Consider how this assumption could shape the ways a clinician might counsel families and speak to patients.

> **"Your [the doctor's] tone and your words can really 'make or break' a person, especially when they're at the start of their medical journey"**
>
> **– Ani, family partner**

Language is powerful. Words can shape a child's self-concept and their sense of belonging in society. Language also influences how families understand their child's medical journey, how they feel about school and activities, and how parents communicate with others about their child.

> **"Doctors should be empowering parents of children with medical complexity. If I only get negativity at an appointment, how am I supposed to leave and have the strength to be a mom?"**
>
> **– Ani, family partner**



General Approach

- Medicine teaches us to consider symptoms, exam findings, and lab values when assessing patients. This approach can lead to negative or clinical-sounding language. Drawing on a **strength-based approach** can expand a family's perception of themselves and what is possible.
- **There is no one right way to communicate.** Patients and families have varying preferences for the language used in clinical conversations. Being mindful of differences and adapting accordingly can foster trust and understanding.[2]
- Follow the platinum rule - '**Treat others how THEY wish to be treated**' instead of the golden rule - 'treat others how YOU wish to be treated'.[1]

> **"We're very aware of what he [my son] can't do. We don't need to go over that repeatedly at each appointment.**
> **Let's focus on what he CAN do instead."**
>
> **– Anne, family partner**

> **"Families have very little control and privacy while in hospital. Asking how we'd like to be communicated with gives us back some sense of control."**
>
> **– Katherine, family partner**

When we asked our family partners about their preference between '*disabled person*' and '*person with a disability,*' their responses varied based on personal experiences. What everyone valued most was being asked about their language preferences.

- Use the language your patient uses. By **mirroring the words, terms, names, and pronouns that patients use**, healthcare providers create a more affirming environment that respects each child's individuality and their lived experience.[1]
- Language evolves over time. It is essential to remain flexible, revisit terminology regularly, and **adapt to changes** so that communication stays relevant and respectful.[1]

> **"There's a difference between saying 'you can't do that, let me do it for you' and 'I know you can do this, but would you like some help with that?'"**
>
> **– Anne, family partner**

- Create a **brave space** and welcome **uncomfortable conversations as opportunities for growth**. Focus on calling people **in** rather than calling them **out** to encourage reflection and shared accountability.[6]
    - Focus on calling people in — not out — to foster reflection and shared accountability. Instead of pointing out ableist or outdated language, offer alternatives. For example: **"I've found it helpful to say a child 'uses gestures and sounds to communicate' rather than 'non-verbal,' which can imply they don't communicate at all."**

Person-first vs Identity-first Language

Person-first language (e.g. patient with cerebral palsy)

- **Acknowledges that someone's disability or diagnosis does not comprise their entire identity.[2]**
- **Some disability advocates argue it separates disability from personhood.[2]**

Identity-first language (e.g. autistic person)

- **Ensures that someone's disability or diagnosis is not seen as passive, but rather an important part of their identity.[2]**
- **Many communities now prefer this language.[2]**

>> Neither approach is wrong. If you aren't sure, ask. Or, mirror the language the family uses.

Language with Patients and Families

Instead of this...	Try this!	Rationale
"I am so sorry, but we suspect your baby has Down Syndrome."[2]	"We suspect your baby has Down Syndrome"	Communicates the diagnosis clearly and neutrally, without assuming or creating the expectation of a life impacted negatively by disability.
"Your infant has cerebral palsy. She will never be able to walk and will always be dependent on you for care."[2]	"Your infant has cerebral palsy. This means they will face challenges with movement and coordination."	Provides facts without making limiting assumptions about the child's future. The first statement undermines hope or potential.
"These people with intellectual disability."[2]	"People with disability" or "disabled people"	Use of "this" or "these" reinforces a sense of otherness and separation, alienating the patient.
"At least they won't look disabled"[2]	Do not say this	Disabilities exist on a spectrum. People with disabilities do not "look" a certain way.

Instead of this...	Try this!	Rationale
This patient... “suffers from”, “is a victim of”, “is afflicted with”[1]	“This patient has [diagnosis]”	This language reinforces negative stigma. People with disabilities live full lives and do not consider themselves to be “suffering” or “victims”.
"Confined to a wheelchair” or “Wheelchair-bound”[1]	"This patient uses a wheelchair” or “Wheelchair-user”	Uses neutral language without making assumptions about the person’s experience or emphasizing their limitations.
"Disabled” or “Handicapped” parking/bathroom/space[1]	"Accessible” parking/bathroom/space	Focuses on access and not disability. It is preferable to use neutral language rather than labels.
When referring to patient’s parents... “What are your thoughts, mom?”	"What are your thoughts, [mother’s name]?”	Knowing parents’ names helps build rapport

Our family partners shared that although they love being parents and are proud to be “---’s mom”, they appreciate when someone acknowledges they are their own person and have an identity outside of being a parent. This is especially true for families whose children have extended and/or recurrent hospital stays, and for those who regularly interact with the same clinician.

Instead of this...	Try this!	Rationale
"Special", "Special needs". "Challenged", "Slow", "Slow learner"[1]	Person with... [diagnosis], mobility impairment, learning disorder, intellectual disability	Use terminology that aligns with the person's preference — whether person-first or identity-first language. Avoid euphemisms, as they can 'other' individuals and imply that disability is something to be hidden.
"Retarded", "mental retardation"	Intellectual disability	"Mental retardation" is no longer used as a diagnosis. It carries a negative stigma due to its misuse in everyday language.
"Brave", "Resilient", "Strong", "Special"[3]	Use these terms in context while being mindful of the individual's experience.	Avoids "superhero framing" (see more below).[5] This language can pressure patients to embody such traits and be a 'model patient' during times of distress and hardship.

"Superhero Framing"[5]

Describing individuals with disabilities as "brave," "resilient," or "special" — without context — can unintentionally suggest that disability is an obstacle to living a full life.

These terms are often used for parents too, and while meant as encouragement, they can feel more like expectations than genuine acknowledgement. As our family partners remind us, they didn't choose this role — they show strength because their children's well-being depends on it.

Instead of this...	Try this!	Rationale
"Non-verbal"[4]	“Non-speaking”, “Uses sounds and gestures to communicate”, “Uses a communication device”	Assuming all communication is verbal overlooks the diverse ways people express themselves.
"Everything will work out in the end”	"We will try our best to support you through each step”	Avoid offering false reassurance or minimizing uncertainty.
“Normal” or “Healthy” children when referring to children without medical complexity	Children without previous medical conditions	This language implies that the patient, by contrast, is ‘abnormal’ or ‘unhealthy’
"I’ve never seen this before”	"I am going to learn more about this, and speak to my colleagues with more experience”	For families, this can be an alarming thing to hear from the medical professional they’ve come to for answers. Be honest about what you know and don’t know and explain the next steps — including how you’ll work together to find answers.
"Hey there buddy/sweetheart...” [speaking to a young adult patient].[2]	“Hey [patient’s name]”	Language that is age and development-appropriate fosters trust, supports shared decision-making, and reinforces the dignity of patients.

Language with Other Healthcare Professionals

Instead of this...	Try this!	Rationale
“They are probably over-exaggerating”	Patient reports symptoms that appear disproportionate to clinical findings. Will continue to monitor and assess for underlying causes. Plan includes validating patient concerns and exploring potential contributing factors.	Such comments can be harmful and may delay or interfere with necessary care. They can also influence how new healthcare providers perceive the family, creating unintended bias.
"They are just looking for attention”	It’s important to understand what might be driving this behavior. Let’s explore what they are trying to communicate and/or what support they might need.	

From ‘Am I Ableist’: “... certain abilities do not mean less fulfillment in life. As a future physician participating in quality-of-life discussions, consider how you find meaning and value in your life, and how different that could look for other individuals.”[2]

Instead of this...	Try this!	Rationale
“Frequent flyer”	"Patient with a history of frequent visits to the emergency and/or admissions”	Phrases that downplay emergency visits or hospital stays can minimize the seriousness of these experiences, which are often traumatic for families. They also normalize and trivialize the patient’s presence in hospital, overlooking the emotional and physical toll involved.
“He tried to die multiple times overnight”	“He had multiple life-threatening episodes overnight”	This shifts away from the idea that patients are responsible for their illness, helping to remove any sense of blame
"They are doing so well considering”	"They have made a lot of meaningful progress”	Avoid reinforcing bias or lowering expectations, which can undermine the patient’s dignity and resilience

Reflect on the following:

“If I were critically ill from a condition such as pneumonia, my healthcare team would assume that any and all necessary interventions must be done. No one would have negative assumptions about my quality of life or wonder if I would be better off dead.”

Exercise adapted from ‘Am I Ableist[2]

Instead of this...	Try this!	Rationale
"The parents are very difficult"	Provided reassurance to parents that we are working together toward the best outcome for their child. We agreed that clear and consistent communication will be essential to building a collaborative care plan.	There are many uncertainties in medicine, and our healthcare system can be difficult to navigate. Practice **trauma-informed care**. Consider how past experiences may affect the parents' responses. Could the parents' reaction be rooted in previous encounters with the healthcare system?
"They don't really seem to 'get it'" or "They are in denial"	A significant amount of information was shared with the family. They may need time to process and may benefit from clarification and reassurance.	Normalizes the need for time to process information and need for reassurance. Avoids blame and judgement.
"Broken home"	State the social history when relevant. E.g., 'The child's parents are separated,' or 'The child is from a single-parent household.	This phrase carries a negative connotation and reflects a subjective judgment rooted in narrow definitions of what a family should look like. It can stigmatize families and overlook the diversity and resilience of different family structures.

Instead of this...	Try this!	Rationale
"Disruptive", "Defiant", "Problem", "Difficult" "Non-Compliant"[6]	Describe the exhibited behaviour using objective, language. For example, rather than stating, "The child was non-compliant with the procedure," describe what was observed: "The child cried and pulled away when the IV line was being inserted" and "the child spat the medication upon administration and said yuck."	Behaviours may reflect fear, discomfort, or a lack of understanding. Use objective language that describes observable behaviour. This can guide personalized care and clinical decision-making. Subjective language such as 'non-compliant' can imply blame or resistance and may not reflect the child's emotional state or developmental capacity. Describing what was seen helps ensure clarity, empathy, and accuracy in documentation.
"High functioning", "Low functioning"[6]	Describe the specific presentations of the child's behaviour. For example, the child communicates through gestures, facial expressions, or a communication device, or that they need assistance with daily activities such as toileting.	These terms can be misleading and do not reflect the child's unique needs or abilities. These labels may also lead to inaccurate assumptions about the child.

> **"You [the healthcare professional] know medicine, I know the kid"**
>
> **"We don't want to be in the hospital... If I'm bringing my son to the hospital it's because I'm worried."**
>
> **-Ani, family partner**

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Other Resources

Rehumanizing clinical documentation for disabled children: A cascade of potential outcomes of critically reflective practice

This study examines how writing clinical documentation in a more humanizing way can improve communication and build stronger partnerships with families, clinicians, and schools.

Trends in Pediatric Palliative Care Research: The Use of Biased Language in the Care of Seriously Ill Children: A Pilot Study

This study demonstrates that biased language appears frequently in pediatric palliative care documentation and highlights the need for more reflective, bias-aware clinical writing to promote equity in care.

Teaching Doctors to Write for Patients

This article outlines new guidelines for patient-centered medical documentation, highlighting how word choice in clinical notes can influence patient trust, clinician perceptions, and the quality of care.

Trends in Pediatric Palliative Care Research: What Families of Children With Medical Complexity Say They Need: Humanism in Care Delivery Change

This resource summarizes family-led focus groups on caring for children with medical complexity, emphasizing the need for systems to counter bias, and prioritize whole-child, family-centered support. It offers recommendations to transform care through trust, communication, and focus on quality of life beyond the medical model.

The Future of Care for Children with Medical Complexity Virtual Café #2: Humanism in Clinical Care to Meet Whole Child/Family Needs

This video is part of a six-part series from the Boston University School of Social Work, where nationally recognized experts in the care of CMC, including family partners and pediatricians, discuss the future of care for CMC. This video focuses on humanism in clinical care.

Other Resources

F-Words for Child Development
This resource provides insight into the F-words in the Childhood Disability framework, offering tools, training, and multimedia resources to help families, clinicians, and educators apply the framework in practice.

Pediatrician looks for 'moments of connection, happiness and joy'
This is an article about a pediatrician who emphasizes finding moments of connection, joy, and positivity while supporting CMC and their families.

Discriminating against children with medical complexity
This commentary calls on providers to critically reflect, build disability competency, and recommit to the humanistic values of medicine so that children with medical complexity are cared for with dignity and respect.

Pediatric Project ECHO: Online Complex Care Course
Developed by the team at the SickKids Learning Institute, this four-part free online curriculum for healthcare providers offers training on caring for children with medical complexity