

Aim

The Learning With Families (LWF) program was designed to address the barriers experienced by families in their healthcare journey that negatively impact the quality of their care with the health system.

The program aims to improve client- and family-centred care by co-designing solutions with Family Leaders (caregivers to children with extra needs) that address challenges they identify and prioritize.

The Family Leader works with a team of healthcare clinicians and staff to build understanding and to make purposeful and meaningful changes in the delivery of health services.

The LWF program is based on three frameworks: the Canadian Interprofessional Competency Framework, International Association for Public Participation and Knowledge to Action.

Lastly, the LWF program aligns with the British Columbia's Ministry of Health Guiding Framework for Public Health to ensure an efficient, high quality and sustainable health system.

Methods

The LWF program allows a family member to share their lived experiences with staff and then for staff to share their learnings to make meaningful improvements with their respective teams/units.

- Pilot session consisting of 11 managers/directors and two family leaders held in September 2018
- The LWF runs over four 1.5 hour sessions covering 4 different themes (figure 1)
- Sessions are facilitated and include evaluations and completion of reflective journals
- Identification of key learnings with family leaders to improve the LWF program and clinical service delivery to improve the client/family experience
- At the end of the four sessions, each cohort identifies gaps then selects and designs a solution to address these identified area(s) with the support of a knowledge translation consultant

Looking Forward

- The LWF program supports high quality engagement and intentions by healthcare staff to use learnings in practice to enhance the client/family experience
- Offering across C&W campus; integration with staff professional development and interprofessional collaborative practice competency training
- Three co-designed solutions for change in practice have been proposed and are currently being implemented
- BC Children's Hospital and BC Women's Hospital + Health Centre Team Award of Excellence for Interprofessional Collaborative Practice, 2019
- Nominated as a Leading Practice with Accreditation Canada
- LWF selected as presenters for the Beryl Institute Conference, 2020

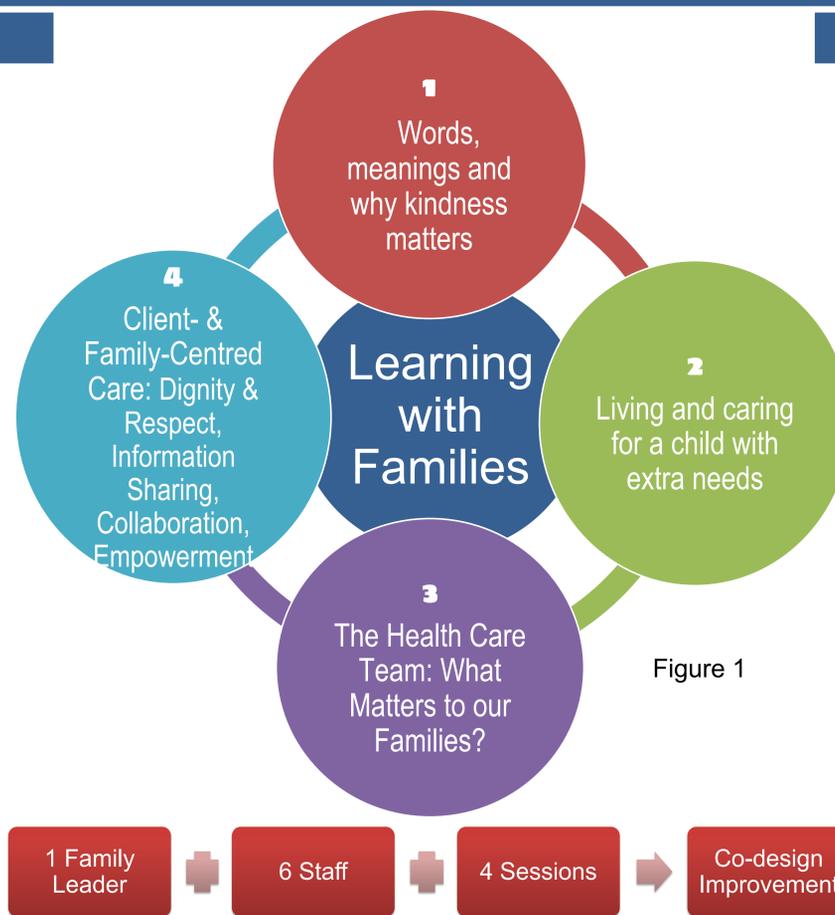


Figure 1

Background

The discussion topics (figure 1) for LWF were designed to promote dignity & respect, information sharing, collaboration and empowerment; to have meaningful dialogue and focus on understanding and better supporting these areas of concerns, as identified by families to improve communication and partnerships:

- The choices families have to make;
- Barriers families confront;
- Frustrations families encounter;
- Obstacles and supports within the environment;
- Communication, listening, and language used and their impact;
- "What matters [to the family]?"



Data and Feedback

- In 2018-2019 three cohorts (n=15 staff participants + 3 Family Leaders) participated in and completed the program.
- 87.5% of participants strongly agreed that their views were heard and 100% strongly agreed that they were able to express their views freely on the PPEET following the last session.
- On the CPDR, 96% of participants intended/strongly intended to make interprofessional collaborative practice improvements.

Examples of qualitative feedback from LWF cohorts are as follows:

"Very powerful and engaging. Ample opportunity to provide my thoughts and comments. Great, productive discussion. Really enjoyed this experience and I look forward to the three following sessions and what may transpire." Participant

"One of my hopes is that participants will take back and share with their staff, colleagues the importance of compassion and kindness and learn from my experiences" Family Leader

"Wonderful rich, honest sharing of experiences, reflections and ideas." Participant

"I feel this session was invaluable in starting a much needed dialogue between health professionals and families. Excellent communication and follow up with parents of patients (and sometimes the patients themselves) is essential. I hope that other parents will never go through the same experience that myself, my son and my family did, in part because of my story being told...I felt heard, which leads to more healing" Family Leader

"I think that hearing about healthcare experiences directly from families is incredibly powerful. In the room, I could see by the power of the family voice in engaging and educating healthcare providers and galvanizing them to think of how they could implement even little things to make a difference for families and children; like how their phone calls might be managed and responded to, or how they communicate in each care event" Participant

"Participating in this group is sparking ideas for items to discuss with my team!" Participant

LWF has been a truly wonderful experience for me personally. As a parent it is not everyday I get to sit down and have meaningful conversations with the people that offer care to my daughter. Even though the individuals on my team don't offer direct care to my daughter, they do however, offer me insight that I can use in our everyday practice. It's so important to me to give back and if my story can help even one family have a smoother journey I feel I have done a good job. Family Leader

References

1. BC Ministry of Health. *Setting Priorities for the BC Health System* (2014).
2. Canadian Interprofessional Health Collaborative (CIHC) (2010). *National Interprofessional Competency Framework*.
3. Abelson J, Wilson G, Schneider C and Shields K. *The Public and Patient Engagement Evaluation Tool*. Creative Commons Attribution - Non-Commercial-Share Alike 4.0 International License. Research-Practice Collaborative, 2014.
4. Legare F, Borduas F, Freitas A, et al. *Development of a simple 12-item theory-based instrument to assess the impact of continuing professional development on clinical behavioral intentions*. PLoS one. 2014;9(3):e91013.