

Integrating parent-partners as research team members: Creating the role of Family Liaison

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Abstract

In caring for children with serious illness the clinician's approach is always family centred. As such our clinical research team has continuously involved families in our studies beyond their role as participants in our research. A Family Advisory Group reviews our project proposals and protocols and participating families provide feedback on their experience after graduating from one of our studies. However, in learning about patient-oriented research strategies through our engagement with the CHILD-BRIGHT network, we have come to realize that in order to fully partner with families, specifically parents of children participating in our research, we need to have an embedded team member who acts as a parent-partner in all our endeavours. Therefore we have created the role of Family Liaison as a fixed part of our team makeup and hired Laesa Kim to fill this position.

Laesa's job goes beyond that of advisor for two important reasons: She holds a paid position within our staff group and her contribution to our program supersedes that which can be expected of volunteer committee members. The Family Liaison is a bridge between researchers and participants, not just in the connections she makes when translating the research objectives and protocols to participants, but also in bringing a parent or patient perspective to every stage of study design and roll out.

Along with Laesa's specific job description comes expectations of rather unique credentials to successfully fill the role. Laesa shares in the lived experience of our participants as the mother of a medically complex child, with years of learning to understand and navigate health care systems. Her experience coupled with a disposition for connecting with health care providers as well as fellow parents of children needing health care while understanding and advocating for the specific needs of this population, positions her perfectly to fill this role.

We will describe the value of the Family Liaison within our team as an integral part of our research program while showing the power of investing in patient-oriented research strategies to advance our projects.

Institution

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