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Co-development of the ENVISAGE-Families programme for parents of children with disabilities: Reflections on a parent–researcher partnership

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Co-development of the ENVISAGE-Families Program for Parents of Children with Disabilities:
Reflections on a parent-researcher partnership

Abstract

Introduction

In childhood disability research, the involvement of families is essential for optimal outcomes for all participants. ENVISAGE (ENabling VISions And Growing Expectations)-Families is a program comprising five online workshops for parents of children with neurodevelopmental disorders. The workshops aim to introduce parents to strengths-based perspectives on health and development. The research is based on an integrated Knowledge Translation (iKT) approach, in which knowledge-users are involved throughout the research process. This article is co-authored by the ENVISAGE health service researchers (N=9) and parent partners (N=3) to describe the process through which we co-developed and implemented the workshops.

Methods

Collaborative auto-ethnography methods, based on a combination of interviews, qualitative surveys and discussions held to complete the Guidance for Reporting Involvement of Patients and Public-2 tool, were used to describe the co-design process, the benefits gained and lessons learned.

Findings
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Parents (n=118) were involved in developing and implementing the ENVISAGE workshops across the different phases, as partners, collaborators or participants. Three parents were involved as investigators throughout. We identify seven key ingredients that we believe are necessary for a successful parent-researcher working relationship: i) Consistent communication; (ii) Clear roles and expectations; (iii) Onboarding & feedback; (iv) Flexibility (v) Understanding; (vi) Self-reflection; and (vii) Funding.

Conclusion

Patient and family engagement in research is a rapidly growing area of scholarship with new knowledge and tools added every year. As our team embarks on new collaborative studies, we incorporate this knowledge as well as the practical experience we gain from working together.

Keywords

Family engagement in research; childhood disability; participatory research; parents; co-development; co-creation

Key Points for Occupational Therapy

- Engaging families in childhood disability research is essential to produce research relevant to the needs of families.
- Successful family-researcher partnerships require both relational qualities (e.g. communication) and infrastructure (e.g., funding).

- New knowledge, experience, and reflecting together on the partnership helps teams grow and improve.

Introduction

The active involvement of patients and family members in the research process has become a widely-accepted practice in health research. Patient and family engagement in research (also known as Patient and Public Involvement, or PPI) refers to conducting research “with” or “by” patients or families rather than doing research “about”, or “for” these groups (*INVOLVE*, n.d.). This approach is advocated for reasons that are both moral and pragmatic, including: the right of patients and families to influence publicly-funded research that concerns them; production of more relevant and culturally sensitive research; improved research quality; ultimately leading to more effective health-care system and better health outcomes.

In childhood disability research, engaging families, including parents, caregivers and others, is recognised as essential to undertake research relevant to the needs of children and families (Morris et al., 2011, Flynn et al., 2019, Shen et al., 2017, Molloy et al., 2019). Furthermore, given the prevalence, in child health, of family-centred frameworks that recognise parents’ expertise and advocate for the inclusion of parents as partners in their children’s care, it logically follows that research in this area should incorporate parents as partners in the research process.

In this article, a group of health services researchers and parents describe the process of working in partnership to co-develop and implement an intervention – a series of workshops for parents raising children with neurodevelopmental disabilities (NDD) – that aims to introduce parents to strengths-based perspectives on health and development. The concepts underpinning

ENVISAGE-Families emerged from many years of work, conversations and collaborations among parents, researchers and service providers in Canada and Australia. These discussions highlighted the difficulties and challenges parents face in understanding and managing their child's diagnosis and development, navigating childhood disability services, collaborating with professionals, and adopting a new and more positive outlook on their child, family and future. These challenges can leave parents feeling disempowered, lacking in confidence and sense of competence, which in turn negatively affects their overall wellbeing and relationships with their child and other family members (Cohn et al., 2020). Together we recognised the need for a program to empower parents to adopt a strengths-based perspective to their child and family's situation, and to empower them with the confidence and tools to collaborate effectively with people who work with them and their child.

Table 1: Description of the five ENVISAGE workshops (based on a previous ENVISAGE-Families publication) (Miller et al., 2022)

Workshop Title	Description
Workshop 1: Modern concepts of health: The WHO's International Classification of Functioning, Disability and Health and F-words	The World Health Organization's biopsychosocial framework for thinking and talking about 'health', and how the 'F-Words in Childhood Disability', have taken these ideas to families through the concepts of: Fun, Family, Friends, Fitness, Function, and Future.

Workshop 2: Child, sibling and family development	Explores how all children, siblings and families change and develop at their own pace.
Workshop 3: “Parenting is a dance led by the children!”	Focuses on promoting an understanding of parenting as a transactional process and the importance of following the child’s lead.
Workshop 4: Looking after myself so I can look after my family	Parental self-care: maintaining and promoting parents’ mental and physical health and wellbeing over the long-term.
Workshop 5: Communicating, Collaborating, Connecting	Strategies for how to belong to the community and be an effective connector to services.

ENVISAGE-Families was designed within a five-phase research program founded on an integrated Knowledge Translation (iKT) approach, according to which knowledge-users are involved in every step of the research process (Boland et al., 2020). In the ENVISAGE-Families research program, over 100 parents were involved in various capacities (either as partners, collaborators or participants) across the different phases (see Fig 1 below). For the purpose of this article we define *partners* as co-investigators and equal members of the research team. We define *collaborators* as parents who contributed to, and provided feedback on, certain aspects of workshop planning and design but were not members of the research team throughout all phases. *Participants* were those parents to whom the workshop was delivered in a feasibility pilot study.



Figure 1: Parent engagement in ENVISAGE-Families over time

Methods

As the ENVISAGE-Families study unfolded, we recognised the value that co-design was bringing to the study. We had not planned to study the process of parent engagement when initially developing ENVISAGE-Families, but by Phase Three, we identified the importance of capturing and reporting on what we were doing and learning to inform our ongoing work. During Phase Three, we decided to explore how parents and researchers on the team were experiencing the process of working together. We sought feedback from parents who were involved in the study as co-investigators or collaborators up to that point in time: this included three parent investigators as well as other parents who were involved in Phases One and Two (i.e. priority setting and workshop development). The study was approved by [Removed for peer review] Integrated Research Ethics Board #5571.

The process through which we collected, reflected on, and interpreted data can be described as collaborative autoethnography (CAE). CAE is approach that explicitly uses the researchers' own experiences and reflections as data and connects these experiences to larger social or cultural phenomena. It “brings together the self-reflection associated with autobiography, the cultural interpretation associated with ethnography, and multi-subjectivity

associated with collaboration” (Chang et al. 2016, 17). CAE is carried out collectively by a group of researchers who work together to collect, analyze and interpret their own combined data in order to gain a meaningful understanding of the phenomena reflected in their individual accounts (Chang et al. 2016). Through its emphasis on collaboration and reflexivity CAE addresses several critiques of traditional approaches to research, including issues of power imbalances and representation that occur when researchers “speak for” their research participants and when they fail to situate themselves in the story by acknowledging their own backgrounds and positions (Lapadat 2017). Researchers can employ a range of data collection methods, including interviewing each other, analyzing each other’s reflections, or collecting archival data about each other. The process is iterative: it typically occurs through several sessions of conversations and negotiations among researchers, with individual and collective meaning-making informing each other.

The parents and researchers on the study were asked to complete either an anonymous qualitative questionnaire online or a semi-structured interview with a postdoctoral trainee [Author 1] who had not been involved in Phases One or Two of ENVISAGE-Families. This step ensured that participants were able to share frank reflections about their experiences on the study. In total, four researchers completed an online questionnaire and two researchers took part in a semi-structured interview. Four parents took part in a semi-structured interview and one parent contributed feedback through e-mail due to scheduling difficulties. Researchers were asked about their previous experience with working with parents; how parents’ insights contributed to the ENVISAGE study; what surprises or challenges they encountered; what they learned from the process; and what they would like to do differently in future studies. Parents were asked to describe how they came to the ENVISAGE study and their role(s) on the research

team; what surprises or challenges they encountered; whether (and how) their feedback was used to inform the study; what they gained from the experience; and what recommendations they would have for other parents and researchers who are embarking on research studies together. These questions were informed by existing literature in the field of patient/family engagement as well as by the interests and concerns of the research team. The data from questionnaires and interviews was analysed and coded by [Author 1]. Initial codes were informed by the interview questions, with new codes generated inductively.

At the end of Phase Three we felt it would be premature to report on the trajectory of parent engagement in ENVISAGE-Families since Phase Four of the study was still ongoing and three parents continued to be actively engaged as co-investigators on the project. At the end of Phase Four, the entire research team discussed and completed together the Guidance for Reporting Involvement of Patients and the Public (GRIPP-2) checklist (Staniszewska et al., 2017). This team discussion provided another opportunity to reflect on and discuss, individual and shared experiences. [Author 1] revisited the transcripts and the codes from the interviews and surveys, comparing them with the comments from the GRIPP-2 discussion (BLINDED FOR PEER REVIEW, n.d.).

Based on the discussion with the team regarding the focus of this article, [Author 1] organised the codes into themes pertaining to the lessons about engagement that the team has learned in the course of working together. For example, codes pertaining to “hesitation to commit” due to “time” and “childcare responsibilities” were initially subsumed under a larger theme of “barriers/challenges”. Following the team discussion, they were moved to the new theme of “flexibility”, because the overarching lesson learned is the importance of allowing each family partner to adjust their participation based on their preferences and circumstances. The

GRIPP-2 discussion also generated the new theme of “self-reflection”, with both parents and researchers reflecting on what they learned throughout the study, with parents additionally being careful to note that their individual experiences were not necessarily representative of the experiences of all parents. Based on this thematic framework [Author 1] drafted the first version of the manuscript. All the team members were invited to provide feedback and add additional insights through an online document sharing tool, a process that allowed for further reflection and interpretation of each other’s experience.

As a research method, CAE has been critiqued for being subjective, non-generalisable, and “having too many voices” (Roy 2021). In the story that follows we aim to describe the process of working together on the ENVISAGE-Families study and to share the insights we gained about parent-researcher partnerships. Although this article is written in a collective voice, we acknowledge individual experiences within the team. Furthermore, as with all qualitative research, we aim for “theoretical” or “analytical” generalisability (Burchett et al. 2013, Maxwell & Chmiel 2014) by connecting our team’s experiences with other literature on the topic.

Findings: Parent engagement in ENVISAGE-Families

(i) How we found each other (Phase 1)

Parents assumed varied roles throughout the study based on individual preferences and availability. In Phase One, we started with sharing our concerns and research ideas with parents: we conducted a webinar in each country and collected asynchronous feedback from parents through a private Facebook group for parents who are affiliated with [Removed for peer review] at [Removed for peer review], where our Canadian researchers are based. Canadian parents were recruited through this Facebook group, and Australian parents through an Australian parent

support organisation. Between the two webinars, approximately 30 parents provided feedback on issues that were important to address in the workshops. Their feedback shaped the content of the workshops. For example, we added a session on communication and collaboration, and we expanded the workshop on development to include child, sibling and family development. After these Phase One webinars, the initial research team of four health services researchers and two parents (one each from Canada and Australia) applied for and obtained a research grant which enabled us to begin Phase Two of the study (workshop development). We also expanded our scope of parent engagement by inviting parents who participated in the initial webinars to become collaborators on the project and partner in co-creating workshop content. Six parents joined as collaborators during Phase Two.

(ii) How we worked together (Phases 2 - 4)

In Phase Two, eight parents (including the two parent investigators) formed small working groups with the health services researchers to co-create the content for the five ENVISAGE-Families workshops over a period of four months (June-August 2018). Some groups worked through synchronous meetings using Zoom, while others collaborated asynchronously, dividing tasks up through email, other groups used both methods. All members were responsible for finding resources, providing input into the content and activities, and developing and reviewing workshop outlines and content. The workshop materials created were reviewed and refined by the entire research team with parent researchers actively involved in final decision-making. During Phase Two, one of the Australian parents became very engaged with the project and was asked to join the research team as a co-investigator.

In Phase Three, 15 parents not previously involved in workshop development (i.e., Phases One or Two) reviewed the workshop content and plan for delivery to assess usability, feasibility and acceptability. These parents completed surveys regarding the acceptability and usability of the workshops and participated in interviews to provide their perspectives on the content and proposed delivery methods of ENVISAGE-Families. Their feedback was used to refine the workshops prior to implementation. The results of Phase Three are reported elsewhere (BLINDED FOR PEER REVIEW, 2022).

In Phase Four, the workshop series was delivered to a new group of 65 parents, most of whom completed a series of pre- and post-workshop measures and participated in follow-up interviews immediately post and at 12 months following ENVISAGE-Families. Workshops were held in Canada and Australia, and each workshop was co-facilitated by a Canadian or Australian health services researcher and parent. Following the workshops, the parent participants were asked to provide feedback via questionnaires and follow-up interviews on workshop content and delivery as well as impact. They also reported on their experiences of taking part in the research (e.g., completing measures). Data from Phase Four shows that the program offers a conceptual guidebook to help parents make sense of the experience of raising a child with a disability. ENVISAGE-Families empowered parents' strengths-based approaches to their child, family, disability, and parenting; provided tools to support connection, collaboration, and wellbeing into the future; affirmed parents' expertise and increased their confidence. The complete results of are reported elsewhere (BLINDED FOR PEER REVIEW, n.d.).

In every phase, the parent investigators have consistently been an integral part of the research team and shaped all steps of the research. The entire team met weekly throughout the duration of the study (more than four years), which forged a culture of sharing and created a safe

place for working together and trying out ideas. Parents' feedback shaped: i) research questions and study design; ii) workshop content; iii) workshop delivery method (for example, online delivery, the timing of workshops in the evening); iv) developing/selecting study instruments (developing interview questions, selecting measures that were strengths-based); and v) coding and interpreting results from the feasibility study. The parents and researchers who co-delivered ENVISAGE-Families workshops met weekly to prepare for, and then to debrief after, each workshop. In the follow-up interviews, workshop participants commented on the value that the presence of parent-facilitators brought to the workshops. Parent investigators subsequently contributed their insights to the analysis and interpretation of qualitative data from follow-up interviews by reading transcripts, writing summaries and participating in group discussions.

Over Phases Three and Four, dissemination of findings occurred using local, national and international forums. In some presentations, parents were the primary presenters and in others they co-presented with researchers. When a parent was not able to attend a presentation, video footage recording the parent voice, observations and experiences were included.

As the ENVISAGE-Families study was underway, the reflections of parents engaged in Phase Three led us to identify the need to develop a study specifically aimed at service providers (SPs), to be called ENVISAGE-SP. All three parent investigators are named co-investigators on the now-funded Canada-Australia ENVISAGE-SP study, along with one additional parent (who participated in Phase Four as a participant in the pilot ENVISAGE-Families study). A further six parents from the original ENVISAGE-Families study are now involved as collaborators in co-creating content for the new ENVISAGE-SP program.

Figure 2 illustrates the various roles that different groups of parents assumed throughout the research program, using the Involvement Matrix (Smits et al., 2020): listener; co-thinker;

advisor; partner; and decision-maker. Although the Matrix was originally developed for use with patient and family partners who are engaged in research as team members only (rather than as study participants), for the purpose of this article we use it to map the activities of all parents involved throughout the ENVISAGE-Families program of research, including those who were participants in workshop usability/feasibility testing and pilot delivery.

			INVOLVEMENT MATRIX				
			ROLE IN PROJECT/RESEARCH				
			Listener <i>Is given information</i>	Co-thinker <i>Is asked to give opinion</i>	Advisor <i>Gives (up) solicited advice</i>	Partner <i>Works as an equal partner</i>	Decision-Maker <i>Takes initiative, (final) decision.</i>
STAGE OF PROJECT/RESEARCH	Study Preparation	Priority setting (e.g. topics)		30 parents (Phase One)		2 parent co-investigators	
		Developing study instruments (e.g. deciding on measures)				2 parent co-investigators	
		Developing workshop materials			6 parent collaborators (Phase Two)	2 parent co-investigators	
	Workshop Implementation	Workshop feasibility testing			11 parent participants (Phase Three)		
		ENVISAGE workshops: participation and facilitation	65 parent participants (Phase Four)			3 parent co-investigators	
		Post-workshop surveys and interviews		65 parent participants (Phase Four)			
	Data analysis and next steps	Interpreting results				3 parent co-investigators	
		Planning ENVISAGE-SP study				4 parent co-investigators	
		Developing materials for ENVISAGE-SP workshops			6 parent collaborators (ENVISAGE-SP)	4 parent co-investigators	

Fig 2: Involvement Matrix on ENVISAGE study. Note: different groups of parents are indicated by use of different coloured text.

Benefits gained

In this section, we describe the lessons we learned throughout the ENVISAGE-Families study. We reflect on how the process of working together enriched this study, how we benefited as individuals and researchers, and what could have been improved.

Parent investigators identified the presence of a “culture of mutual respect where everyone's opinion was valued and encouraged”, which they attributed to the leadership style of the co-investigators. This culture was cultivated through “all the little things” such as: including parents on all e-mails; actively asking parents for their perspective; being flexible and understanding when parents were not able to contribute; including parents’ names on documents and publications; and remunerating parents for their time and work. Parents noted that they felt “as equal partners” who were “respected and needed, not just there to fill a seat”, and contrasted this feeling with the tokenism they had previously experienced in other research situations.

In all, parent investigators reported the process of engaging in research validated knowledge gained from their lived experience, gave them a sense of value, and helped them to manage their own grief. One parent stated:

I would always encourage parents to be part of a research group because it gives them a sense of value, personal value. It gives them some purpose, makes them feel valued, enables them to be part of a community/group – belonging is very important – and helps them manage the grieving journey and adjust to a life of raising a child with disability they did not anticipate.

Researchers reported that engaging parents throughout the study was essential to the study’s credibility and success. They emphasised that they felt motivated by the parents and that their understanding of the issues covered was enormously enriched by parents’ perspectives.

Their positive experience of working together also reinforced their commitment to partnering with parents in the future. As one researcher put it:

Parent partnership is the essence of ENVISAGE – you cannot say your overall aim is to empower parents and then not have them front and centre to your program.... As a researcher, I have a much stronger sense that we are doing something important, and we are doing it the right way, for the right people, for the right reasons.

Lessons learned

Parents and researchers also identified a number of lessons they learned in the course of this study, and considerations for future studies. We present them here in the form of seven key ingredients that we believe are necessary for a successful family-researcher working relationship.

(i) Consistent communication. Research takes time. There should have been more consistent communication with parents who took part in earlier phases (as collaborators) in our work to keep them updated on the progress of the study, especially since in the research world things move slowly. For example, the researchers initially reached out to parent collaborators in March 2017 but did not receive funding until August of that year, and workshop development only started a full year after first contact, in March 2018. The team started to communicate with parents more consistently in Phase Four; for example, the research assistant began sending regular updates to study participants. The team presented early findings at Luke’s Legacy Research Rounds, a research forum for families (CanChild, n.d.-b). A Facebook group for ENVISAGE-Families graduates was also established to allow workshop participants to keep in touch.

(ii) *Clear roles and expectations.* The role of parents in the study was not predetermined, but rather evolved organically. While this allowed for creativity, it might have been helpful to discuss potential roles and responsibilities from the outset of the study – potentially using a tool such as the Involvement Matrix (Smits et al., 2020) – although parent investigators indicated that they were comfortable “going with the flow”. Our approach at the time also reflected our stage of learning about partnering and co-design as researchers: being committed to doing it, but not necessarily having structures or known processes in place.

(iii) *Onboarding & feedback.* Many parents, even those with professional backgrounds, are not familiar with the research process. Parents with limited research background would appreciate being “on-boarded” to research processes and conventions, addressing topics such as: what is the usual life-cycle of a research project; how does the research ethical approvals process work; what are the expectations regarding attending meetings and reviewing documents; what is authorship and do I want it; what roles do team members hold – project manager, investigator, student, research assistant; as well as project- or institution-specific information. While there are some training opportunities for patient and family partners (CanChild, n.d.-a), researchers also need to check in with parents throughout the study to make sure that everyone is on the same page. Furthermore, all parents appreciated receiving positive feedback for their contributions, having their opinions validated and their recommendations implemented

(iv) *Flexibility.* Parents may be hesitant to commit to research because of their other life responsibilities, and at times may need to reduce their input or time commitment. The research

process needs to be flexible to allow for that, and this also needs to be communicated clearly to the parents. Not all parents may want to be involved in all research-related tasks, so the research process and opportunities for engagement need to allow for fit with personal goals and interests.

(v) *Understanding.* For many parents, partaking in research (either as a study participant, or as a member of a research team) entails revisiting their own challenging and often painful personal experiences and grief. This is not necessarily a bad thing – as one parent put it, this can be an opportunity for parents to be “open and honest about the hard truths of the ‘perpetual grief’ of raising a child with a NDD”. However, both parents and researchers need to be aware of this and researchers should be prepared to support parents and to assist in obtaining support services as needed. There are resources available for research teams on trauma-informed research (Johns and Saxena, 2019).

(vi) *Self-reflection.* Parents were keen to note that their individual experiences do not “speak for” all other parents. In their feedback, they tried hard to draw on the broader experiences of other parents they know and to offer experiences rather than answers. However, they were particularly mindful of their own positionality as white, middle-class women, and the limitation this posed to knowing the experiences of other parents from diverse backgrounds. Self-reflection was also important for researchers, who indicated that they began the study with both enthusiasm and uncertainty about partnering, but as they reflected on their experiences along the way they both built confidence and developed new strategies.

(vii) *Funding*. The lack of funding upfront, to compensate parents for their time in Phase One, and the limited amount of funding for payment of time throughout the phases, is problematic. However, it did not appear to act as a barrier to our partners, whose commitment continued. This is an issue of considerable interest to researchers, who express concerns about exploitation of good will. It is also very important for funding agencies to recognise partner compensation as a legitimate cost of health services research where partnerships with ‘patients’ and parents is expected. Sufficient resources to remunerate parent and other consumer involvement in the earliest phases of research (setting the agenda and question), prior to formal grant funding, is required and is often very difficult to obtain, as is sufficient funding for genuine recompense of time (Richards et al., n.d.).

Discussion

Our experiences as health services researchers and parents who are working together to co-develop and implement a program for parents who have children with disabilities provided a rich opportunity for us to observe and reflect on what is involved in partnering in research. Being thoughtful and overt about the benefits and lessons we have learned supports our continued engagement and the development of new studies to advance this research program. Many of the challenges and ingredients for success identified by our team are echoed in the existing literature (Pinsoneault et al., 2019, Flynn et al., 2019, Bailey et al., 2015, Heckert et al., 2020). This reinforces the importance of anticipating and addressing these issues in research studies that engage patients and families. Scholarship in this area evolves rapidly, with new knowledge and tools added every year. Staying current with new guidelines and best practices in the field and utilising new tools can help set the tone for successful family-researcher partnerships right from

the start. For example, as we design the new ENVISAGE-SP study, we have learned to establish roles more clearly from the beginning by using tools such as a team charter. We are also establishing a rigorous plan to study the process of engagement on the team and research products, to formally evaluate engagement quality.

Our team's experience illustrates that successful family-researcher partnerships require both relational qualities (e.g. communication, understanding, flexibility) and infrastructure (e.g., funding). Furthermore, our experience speaks to the need to balance potentially contradictory expectations, such as outlining roles and responsibilities from the beginning of the study with staying flexible to accommodate changing circumstances and leverage individual team members' strengths. Many of these potential contradictions can only be worked out "on the ground", by treating our partnership respectfully as a process, a work-in-progress, and a learning experience for all.

Authors' Declaration of Authorship Contributions

[Author 1] conceived of this work, collected and analysed the data, drafted the manuscript and prepared it for publication. The remaining authors contributed to the interpretation of data and provided feedback on the manuscript.

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Conflict of Interest

The authors have no conflict of interest to declare.

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