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Understanding the experiences and research priorities of children with disability and their families in a hospital setting in Australia

A novel multi-modal participatory research framework

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Research Summary

Why was the research done?

Our research, *Families in Focus*, leveraged seed funding from the LCC's Knowledge Transfer Innovation Award (awarded to the first author, 2023) and addresses the limited evidence embedding voices of children with disabilities and their families, despite growing policy needs. We report on our 5-phase participatory framework wherein we collaborated with consumers to co-design creative engagement methods – art, craft, games, poetry, short films, journaling, and 3-D installations – to amplify their educational, health, and social support experiences and priorities.

What were the key findings?

Success of the framework: *Families in Focus* successfully engaged 51 families, representing diverse ages of child and parent, disability type, geographic location, and socioeconomic background, and embedding lived experiences through interactive activities and post-activity engagement. Using a 5-phase framework (Draft, Develop, Deliver, Discuss, Present), we collaborated with consumers to authentically share perspectives, amplifying consumer voice.

Key research findings: Families of children with disability face noisy hospitals, long waits, financial burdens from healthcare and travel, and limited NDIS access. Stigma and poor cultural sensitivity delay diagnoses and isolate families. They need better hospital play spaces, quieter areas, tailored education, safe friendships, and coordinated care to support wellbeing, especially for rare diseases and or those in rural areas.

What does this mean for policy and practice?

Families in Focus facilitated bi-directional knowledge sharing, by presenting existing research on health, education, and social systems with participants and capturing their lived experience and priorities. We mapped key findings across wellbeing domains of ARACY's *The Nest* and presented these to government, health, and community stakeholders, including state health agencies, who embedded findings into strategic plan. Our findings allow for future research to build upon this framework and embrace more true co-design strategies.

Citation

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We acknowledge the Traditional Custodians of the lands on which we work and live across Australia.
We pay our respects to Elders past and present and recognise their continued connections
to land, sea and community.

Introduction

This working paper presents a multi-modal, participatory research project. Working with children with disability, their families, caregivers, and partner organisations we explored their health, social, and educational needs and research priorities. Research conducted *on*, rather than *with*, children with disability and their families and caregivers often fails to capture nuanced, intersectional experiences (Carey et al., 2025). Traditional data collection methodologies, such as surveys and structured interviews, often prioritise researcher-driven agendas over families' and other stakeholder priorities, particularly when developed without participant input (Beresford, 2012; Brooks et al., 2020). These approaches often limit authentic engagement or risk amplifying only readily accessible voices and serve to marginalise vulnerable groups, especially children (Kara, 2015). To overcome such limitations, we developed *Families in Focus*, a participatory research design that incorporated a two-day event held at Queensland Children's Hospital (QCH) during Children's Week, 2023. Guided by the International Association for Public Participation (IAP2) (IAP2 Australasia, 2019) stakeholder engagement framework, we included children and families with lived experience across all project phases. By integrating arts-based methods during the delivery phase, such as poetry, 3-D installations, and journaling, this study advances the literature related to participatory research methodologies, offering a model for amplifying marginalised voices in disability research. This paper critiques the limitations of traditional research methodologies and evaluates the potential of collaborative, arts-based approaches to address research priorities of children with disabilities and their families.

Limitations of traditional research methods

Traditional data collection methodologies, such as surveys, assessments, and structured interviews, have been critiqued for decades for their inability to fully capture the lived experiences of children with disability, their families, and caregivers, often marginalising their knowledges and experiences within research and healthcare (Bernardi, 2020; Brooks et al., 2020; Fujiura & Rutkowski-Kmitta, 2001; Galletta & Torre, 2019; Shakespeare, 2013). These methods frequently fail to accommodate the diverse needs, communication abilities, preferences, financial or geographic barriers, and cultural contexts of children with disabilities, particularly when studies *extract data from*, rather than generate *knowledge with* (Alwadi et al., 2018; Beresford, 2012; Mallett & Runswick-Cole, 2014). Such approaches leave many families feeling that their knowledge and expertise is not adequately acknowledged or valued in health, social, and education research contexts (Avis & Reardon, 2008; Hewitt-Taylor, 2008; Kervick, 2017). With regards to children, traditional methodologies are based on assumptions that children, especially those with disability, lack the capacity to articulate their needs. Their perceived innocence, immaturity, or cognitive differences are often misinterpreted as incompetence as research participants and co-researchers (Alwadi et al., 2018; Benjamin-Thomas et al., 2019; Facca et al., 2020; MacNaughton et al., 2007; Stevens et al., 2020). Such marginalisation reinforces unbalanced power structures that replicate adult-led institutional frameworks (Bernardi, 2020), contravening the United Nations Convention on the Rights of the Child (United Nations, 1989, Article 12), which asserts that all children have the right to freely express their views on matters affecting them, in accordance with their age, capacity, and maturity.

Inclusive, co-developed, creative research

Tailored modes of data collection with appropriate adjustments for children with disability and their families are essential for supporting alternative forms of engagement. Inclusive research requires the use of co-developed creative data collection and analysis methods that support participants to express themselves in ways that align with their strengths (Brooks et al., 2020; Kara, 2015; Kerr et al., 2023). Creative approaches such as visual arts (e.g., drawing, painting, 3-D installations), narrative techniques (e.g., storytelling, poetry, journaling), performance-based activities (e.g., drama, short films), and interactive games accommodate diverse communication needs, and foster empowerment and inclusion (Aldridge, 2014). Such methodological approaches can elicit rich, qualitative insights from children and families within healthcare settings (Buckle et al., 2024; Carter & Ford, 2013; Linder et al., 2017; Teachman & Gibson, 2013) and across research disciplines (Goodley & Runswick-Cole, 2012; Nathan et al., 2023, 2023; Woollett et al., 2023). Underpinned by the *least dangerous assumption* (Donnellan, 1984), that researchers should assume competence rather than incompetence of those with communication or cognitive differences, our approaches were designed to empower and support children with disability and their families and caregivers to participate, co-create, and influence research outcomes (Bernardi, 2020; Tisdall, 2012). By providing participants with diverse ways of expressing their perspectives and engaging with research, creative data collection methodologies support participants to communicate their lived experiences and expertise in ways that align with their strengths, preferences, and cultural contexts (Aldridge, 2014). In this working paper we outline a framework and multimodal participatory methodology in researching with children disability and their families.

***Families in Focus*: a multi-modal participatory research framework**

Families in Focus (ethics approval from Children's Health Queensland [HREC/23/QCHQ/100750] and The University of Queensland [2023/HE001760]) represents a transdisciplinary approach to research and knowledge translation (O'Brien et al., 2025). The approach rejects traditional siloes, crossing traditional disciplinary boundaries to create child- and family-centred participatory research.

Background to *Families in Focus*

Our prior research (Chawla, 2023; Chawla et al., 2021, 2022) with children and families with neurodevelopmental disorders, identified silence about needs and acceptance of systemic and personal difficulties families encountered, normalising these unchangeable circumstances of having a child with disability. In response, more detailed analyses of existing data were undertaken (Coles et al., 2023; Cooke et al., 2023), incorporating non-traditional academic data analysis methodologies, such as *crystallisation* that combines academic and creative writing (Ellingson, 2009; Richardson, 2000). Families' accounts of their experiences illustrated profound challenges navigating systems and accessing supports. We sought to identify research priorities from the perspectives of children with disability and their families to inform policy and practice actions. *Families in Focus* embedded experimentation with accessible, creative methods guided by *The Common Approach* (ARACY, 2024a) and underpinned by *The Nest* (ARACY, 2024b). *The Common Approach*, first developed in 2010 by Australian Research Alliance for Children and Youth (ARACY), is designed to facilitate child-centred, strengths-based conversations. *The Nest* is a framework of child wellbeing embedded within The Common Approach and was originally developed in 2013 (with subsequent updates and refinements) after consultations with over 4,000 children, families, and experts. *The Nest* outlines six interconnected domains of wellbeing: healthy; participating; learning; being valued, loved and safe; having a positive sense of identity and culture; and having material basics. We drew upon *The Nest* within several phases of *Families in Focus*, as outlined below.

Families in Focus was originally conceptualised by a transdisciplinary team of researchers across paediatrics, sociology, and developmental psychology, with quantitative and co-production methodological expertise. The design, delivery, and analysis of the *Families in Focus* framework incorporated five distinct iterative phases (Figure 1): (1) Draft, (2) Develop, (3) Deliver (listen, learn), (4) Discuss (refine); and (5) Present (refine). The team collaborated with a range of partners that included and advocated for children with disability and their families. Each project phase included consultation, involvement, or collaboration elements of consumer participation in research (IAP2 Australasia, 2019).

Guiding principles and project aims

The development of the *Families in Focus* framework was informed by four guiding principles:

1. *We recognise lived experience is expertise*: Children, families, and caregivers are recognised as experts in their lived experience, and should inclusively shape project design, implementation, analysis, and outcome dissemination through participatory co-creation.
2. *We recognise, value, and adapt to diverse abilities*: Research must recognise, value, and adapt to diverse physical, emotional, cultural, and communication abilities of participants to ensure inclusive and equitable participation, knowing that delivering high quality research relies on diverse perspectives and inclusive practices.
3. *We support inclusive engagement*: Research should employ accessible, engaging, and empowering data collection and dissemination methods, such as arts-based, creative, and interactive activities, that support inclusive participation regardless of (and with care and consideration to) ability, culture, identity, or of economic, geographic, or social barriers and elicit authentic child- and family- focused insights.
4. *We promote equitable partnerships*: Research must prioritise equitable partnerships, minimising hierarchical power imbalances by actively involving children, families, and caregivers in processes.

The broad goal of our participatory research design was to engage a diversity of children with disability and their families, who do not often have opportunity to participate and have their voices heard to inform policy, practice, and future research directions in matters that affects them. *Families in Focus* incorporated knowledge exchange and co-created data analysis and dissemination of findings through methods that enhanced participant engagement.

Guided by our key principles, we aimed to:

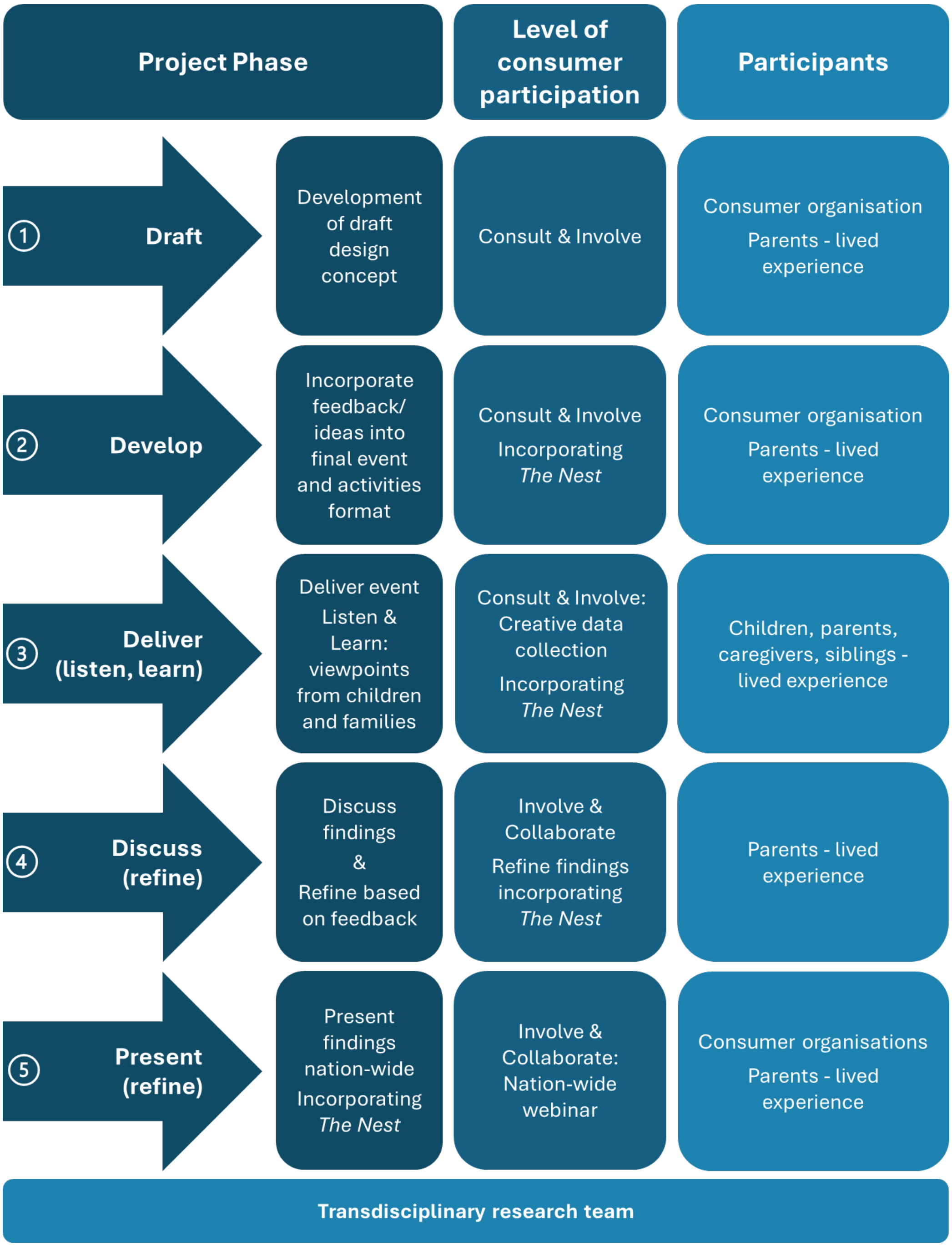
1. *Embed* the diversity of lived experience and expertise of families who care for a child with disability, incorporating their perspectives and ideas into all phases of *Families in Focus*.
2. *Share* with children with disability and their families and caregivers what is already known within the research literature about their experiences navigating health, education, and social service systems.
3. *Engage* children with disability and their families in ways that empower and support to identify gaps in research, policy, and practice.
4. *Co-develop* future research priorities and inform policy and practice actions.

Ethical Considerations

Throughout each phase of *Families in Focus*, we reflected on ethical considerations and power dynamics. While arts-based participatory research methods foster equitable engagement and position participants as experts, engaging with vulnerable children with diverse communication abilities requires researchers to carefully navigate communication differences, caregiver involvement, and child capacity (Teachman & Gibson, 2013). To ensure ethical research conduct, all researchers and support staff involved in the event had experience working with, caring for, or providing health services to children with disability and their families.

Families in Focus design

The development of *Families in Focus* involved five phases (see Figure 1). Each are outlined below:



Project Phase		Level of consumer participation	Participants
① Draft	Development of draft design concept	Consult & Involve	Consumer organisation Parents - lived experience
② Develop	Incorporate feedback/ ideas into final event and activities format	Consult & Involve Incorporating *The Nest*	Consumer organisation Parents - lived experience
③ Deliver (listen, learn)	Deliver event Listen & Learn: viewpoints from children and families	Consult & Involve: Creative data collection Incorporating *The Nest*	Children, parents, caregivers, siblings - lived experience
④ Discuss (refine)	Discuss findings & Refine based on feedback	Involve & Collaborate Refine findings incorporating *The Nest*	Parents - lived experience
⑤ Present (refine)	Present findings nation-wide Incorporating *The Nest*	Involve & Collaborate: Nation-wide webinar	Consumer organisations Parents - lived experience
Transdisciplinary research team			

Figure 1 Families in Focus Phases and Participation of Consumers with Lived Experience

Phase 1 – Original draft concept

The original conceptualisation of *Families in Focus* was a presentation of findings from our prior collaborative work (Chawla et al., 2022; Coles et al., 2023; Cooke et al., 2023) with the explicit aim of seeking feedback from community members with lived experience regarding gaps in our understandings and priorities for future research. This original conceptualisation was initially planned to be conducted within three locations throughout Southeast Queensland that were identified by Down Syndrome Queensland as local government areas with a high degree of socioeconomic complexity and healthcare need. However, further consultation with DSQ and consumers with lived experience highlighted three accessibility concerns. First, families might have difficulties attending an extra-ordinary activity beyond their daily routine. Second, families may not be able to access transport to attend. Third, the format we initially proposed was unlikely to meet accessibility and engagement requirements for children and families with diverse accessibility and communication considerations.

Phase 2 – Develop research event and six research activities

In accordance with IAP2 Spectrum of Public Participation (IAP2 Australasia, 2019) we re-designed our original scope to include elements of consultation, involvement, and collaboration with consumers across *each* phase of *Families in Focus*. To address the first and second concerns, in collaboration with consumers with lived experience, the main event was scheduled to be held at QCH during Children's Week, 23 and 24 October 2023. Delivering the event at QCH would ensure that children with disability and their families who were attending the hospital on these days for scheduled medical appointments could access the event at minimal additional time and transportation costs for families. To address the third concern, the research team drew upon their own expertise and experience working and researching with children and families, and involved consumers with lived experience, psychologists, early childhood educators, young people with disability and support mentor, and partnering and supporting organisations in the co-development of six creative and interactive activities.

Online companion "Event"

To reach families who were not in attendance at the hospital during the event days and provide an opportunity to engage we created a companion online 'event'. The online event (hosted on REDCap), included the same activities and prompts as the in-person event, re-designed for an online format, but aimed at being more interactive and engaging than traditional online surveys. Information flyers and signs at the hospital, and distribution through partner and professional networks, promoted online event, which remained available for one month after the in-person event.

Phase 3 – Deliver research event, listen & learn (viewpoints from children and families)

To promote the event and facilitate delivery, we engaged with stakeholders and organisations trusted by children with disability and their families (Down Syndrome Queensland, Juiced TV, Children's Health Queensland, Children's Hospital Foundation, ARACY, TQKP, Emerging Minds as well as clinical, research, and academic networks). The event was held within an under croft on the premises of QCH (Image 1). The activities were spread across this space, which supported participants with mobility aides, including large wheelchairs. QCH staff, including information and welcome personnel as well as Starlight Foundation entertainers and JuicedTV, promoted the activity to children and families over the two days of the event.

Image 1: Queensland Children's Hospital, Brisbane, Australia, and location of event (circled)

Twenty-four staff were rostered across the two-day event. Families were greeted by support staff, who explained the event's purpose and invited families to consent to participate and provide written consent. Each participant was provided with a participant ID, to link responses across activities, and given a 'sticker' so that researchers throughout the event could easily identify participants. While all members of the public could visit the event, those wishing to engage with the activities were required to provide informed consent. Support staff were stationed at each activity to assist families as needed. Assistance provided included reading information, discussing prompts, and/or assisting participants to record responses across the multiple response modes. Fieldnotes were transcribed and stored with collected data.

To support engagement, we created an inviting atmosphere for children and young people and their families and caregivers. To facilitate comfort and encourage families to stay, relax, and engage, any visitors were provided with refreshments (biscuits and juice), sticker activity books, and a gift bag. Families could relax in a 'chill out' zone with beanbags and books, regardless of whether they were consenting participants. Participants had full autonomy over how much or how little they engaged with each activity, and families were invited to remain within the space for as long as they wished.

The Activities

The event incorporated six interactive research activities that focused on different aspects of the lives of children with disability and their families and caregivers. The activities were designed to elicit responses to several prompts about their lives, experiences, and perspectives through creative and inclusive adaptations to traditional data collection methods (Table 1).

Table 1: Activity descriptions data collection and storage protocols

Activity	Target participants	Traditional data collection method option	Creative and inclusive adaptation*	Response modes	Data collation and storage
Activity 1: The Nest	Parents, caregivers	Open-ended questions	Drew upon *The Nest* Existing literature and 'gaps' presented on posters in shape of nest. Participants could walk around space – embodying 'nest'	Written responses on stick-on notes placed on posters	Stick-on notes photographed at end of day, collected, transcribed to Excel spreadsheet
Activity 2: Imaginations run wild	Children, young people Parents, caregivers	Open-ended questions Semi-structured interviews	Imagine ideal hospital or school setting, depicted through visual art. Children engaged with staff/artist while parents interviewed – children included in interviews	Visual art Recorded interview	Visual art collected and presented in temporary 'gallery wall'. Photographed at end of day, collected, stored as images
Activity 3: Let's get social	Children, young people	Open-ended questions based upon to two visual and audio prompts	Watch a video and read an excerpt about social experiences. Share experiences of being social, where they like to socialise, and importance of social experiences.	(i) Record verbal response on iPad, (ii) write response in a journal, (iii) send a 'text' response via QR code.	Responses collated, transcribed to Excel spreadsheet
Activity 4: Let's talk about sleep	Children, young people Parents, caregivers	Binary response questions Open-ended question	Creative, embodied response options to include diverse abilities Read a poem and respond to prompt	"Yes'/No" responses Written responses on stick-on notes placed on posters	Child responses directly transcribed to Excel spreadsheet Stick-on notes photographed at end of day, collected, transcribed to Excel spreadsheet
Activity 5: Another brick in the wall	Parents, caregivers	Adapted open-ended questions	3-dimensional papier-mâché metaphor installation to depict educational barriers and supports	Written responses on papier-mâché brick wall and rainbow	Written responses on papier-mâché installation photographed at end of day, transcribed to Excel spreadsheet
Activity 6: Words and emojis	Parents, caregivers Children, young people	Adapted multiple response-option questions	Questions and response options presented on magnetic whiteboards – physical manipulation of responses.	Pre-populated response options on white board Provided 'emoji' response options to child participants	Responses photographed after each participant, collated, transcribed to Excel spreadsheet

* Online adaptation involved presenting the posters and visual aids/prompts as per the face-to-face event, with more traditional online response formats (e.g., 'radio buttons' for multiple-response options)

Activity 1: The Nest (Appendix 1) adapted two open-ended questions. We employed ARACY's wellbeing framework, *The Nest* (ARACY, 2024b) to map the existing literature and gaps across the six wellbeing domains. Easy to read posters depicting the domains of the Nest were produced by a graphic designer. These were arranged in a circle to symbolise a 'nest'. Participants were invited to read the posters, consider what was missing inside their 'nest', and identify the needs of their child and their family to thrive. Feedback was provided on stick-on note paper that participants affixed to a posterboard.

Activity 2: Imaginations run wild (Image 2 and Appendix 2) adapted two open-ended questions and incorporated semi-structured interviews. Children and young people were invited to imagine their ideal hospital or school setting and depict this through visual art (e.g., drawing, painting, gluing paper) and had the support of a local artist who works closely with and is a mentor to young artists with disability[1]. While children were engaged, parents/caregivers were invited to participate in a recorded interview with a researcher. With parental consent and child assent, children were offered a polaroid photo of themselves and/or their art and to display their artwork on a temporary art 'gallery' wall.

Image 2: Parent and child with artwork, supported by art mentor

Activity 3: Let's get social (Appendix 3) adapted a series of open-ended questions based upon to two visual and audio prompts. Children, young people, and their families and caregivers were invited to watch a video (recorded by a colleague and her two sons with ASD) and read an excerpt (written by a ChildUnlimited young mentee) about social experiences. Reflecting a strengths-based approach, participants were invited to share their experiences of being social, their places of socialising, and the importance of social experiences in their lives. Participants could respond by recording audio on an iPad, writing in a pen-and-paper journal, or sending a 'text message' via a QR code.

Activity 4: Let's talk about sleep (Image 3 and Appendix 4) adapted binary response questions and an open-ended question, aiming to understand the experiences of sleep from the perspectives of both children and their parents/caregivers. Children were asked about their sleep, drawing on five short statements about their experiences that are regularly used in clinical settings with children of various abilities:

1. I find it easy to fall asleep at bed time.
2. I find it hard/it takes me a long time to fall asleep at bed time.
3. I wake up more than two times in the night.
4. When I wake up in the morning I feel refreshed.
5. When I wake in the morning I feel tired.

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[1] A young artist with Down Syndrome had been scheduled to attend with her mentor, however, she became unwell the day before the event and was unable to attend in person.

Children were offered the opportunity to respond in any way they chose, for example:

1. Shout or state “yes” or “no” verbally.
2. Shake or nod head to signify “yes” or “no”.
3. Point to a “yes” or “no” sign.
4. Stand on a “yes” or “no” mat.
5. Roll a “yes” or “no” dice.
6. Press a large, comical “yes” or “no” button that shouted “yes” or “no”, respectively.

Image 3: Researcher engagement with child during Activity 4

Children could answer with the support of their caregiver. Space was provided on the response sheet to record additional comments. Parents/caregivers were also invited to read a poem written by a ChildUnlimited youth mentee as a prompt to discuss the importance of sleep. They provided their experiences of their child’s sleep, and the impact on their own sleep, on stick-on note paper and affixed this to a posterboard.

Activity 5: Another brick in the wall (Image 4 and Appendix 5) adapted two open-ended questions, focused solely on education from a parent/caregiver perspective. We created a large stand-alone papier-mâché brick wall and crafted a papier-mâché rainbow traversing the wall as a metaphor. Parents/caregivers were invited to write on a brick on the wall one main barrier to education their child faced and to write on the rainbow one idea they thought would help make a brighter educational future for their child with a disability.

Image 4: Parent writing 'one idea that would help make a brighter education future for their child'

Activity 6: Words and emojis (Appendix 6) adapted a series of multiple response-option questions and provided families with an opportunity to reflect upon other aspects of their lives that had not been captured in the previous activities. Parents could respond to 11 questions adapted from *The Common Approach* (ARACY, 2024a) conversation prompts aimed at capturing diverse experiences across the six domains of *The Nest* (ARACY, 2024b). We printed and arranged on the whiteboard the questions with a range of possible corresponding answer choices, including one blank option for each question. Participants were invited to match the most relevant response(s) to each respective question. A smaller whiteboard with fewer questions was provided for children, with response options including words and 'emojis'. Photographs of each participants' responses were taken, and transcribed. Support staff assisted, if required, and discussed responses with participants.

Phase 4 – Discuss findings, refine based on feedback

In the fourth phase, we conducted preliminary analysis of data gathered from those participating in person and online. We developed a preliminary over-arching summary of the research findings, mapped to the six domains of *The Nest* (ARACY, 2024b). To ensure our key findings resonated with families with lived experience, the summary was iteratively reviewed, revised, and co-developed in collaboration with a consumer engagement group (that regularly meet with author 3 (Chawla) regarding aligned work) prior to broader stakeholder consultation. This process gave families opportunity to discuss findings, ask questions, and make suggestions for refining or clarifying, ensuring the authenticity of our reporting and reinforcing the methodological value of our co-developed process (Brady & Franklin, 2019). Based upon this feedback, we refined our preliminary findings in preparation for presentation and stakeholder consultation.

Phase 5 – Present research event and findings, refine based on feedback

The final phase comprised a webinar presentation by authors (Coles and Chawla) and alongside a consumer with lived experience who had also attended the event. The presentation describing the inclusive data collection summarised key family and child responses and sought feedback and ideas for future research directions and policy and practice actions. The webinar was attended by stakeholders from across the system, including state and federal government departments, academic researchers, representatives from consumer organisations, those within workforces that engage with children and young people, and young people and families with lived experience. To comply with ethics requirements, attendees provided informed consent upon entering the webinar, and invited to provide anonymous written feedback to a series of prompt questions (hosted on mentimeter.com) during the webinar. Responses were collated and incorporated into our findings.

Results: Outcomes and critical reflection on *Families in Focus*

In presenting results and critiquing *Families in Focus* we consider our broad aims:

1. *Embedding* diversity of lived experience and expertise of families who care for a child with disability, incorporating their perspectives and ideas into all phases of *Families in Focus*.
2. *Sharing* with children with disability and their families and caregivers what is already known within the research literature about their experiences navigating health, education, and social service systems.
3. *Engaging* children with disability and their families in ways that empower and support to identify gaps in research, policy, and practice.
4. *Co-developing* future research priorities and inform policy and practice actions.

Embedding diversity and amplifying voices

Participatory research practices that embed lived experience are essential to define research problems and engage in appropriate research. In the contexts of people with disability, participatory approaches an important recognition of rights (United Nations, 2016). Through consultation, involvement, and collaboration with consumer participants, *Families in Focus* embedded lived experience across all phases: Draft, Develop, Deliver, Discuss, and Present – (IAP2 Australasia, 2025). A total of N=51 families (n=34 in-person; n=14 online) participated, representing diverse ages of child and parent, disability type, geographic location, and socioeconomic background (Table 2).

Table 2: Descriptive data on child and family participants

Child/family characteristic	Category	n	%
Child Age[1]	M (SD)	9.22	6.32
Attendance	In-person	37	72.5
	Online	14	27.5
RRMA Classification	Metropolitan	24	47.1
	Rural	14	27.5
	No data	13	25.5
Disability Type	Genetic disorders	6	11.8
	ADHD and ASD	6	11.8
	Neurological disorders	3	5.9
	Other/no information	26	51
	No/did not respond	10	19.6
Relationship to Child	Mother	41	80.4
	Carer	3	5.9
	Father	2	3.9
	No data	5	9.8
Parent/Carer Age	< 25 years	2	3.9
	25–34 years	11	21.6
	35–44 years	14	27.5
	45–54 years	14	27.5
	55–64 years	4	7.8
	>65 years	2	3.9
	No data	4	7.8
Household Income	>$100,000	14	27.5
	$80,001–$100,000	7	13.7

$60,001–$80,000	6	11.8
$20,000–$40,000	4	7.8
$40,001–$60,000	4	7.8
< $20,000	4	7.8
Prefer not to say/no response	12	23.5

The diversity of participants informed the design of flexible activities that accommodated varied communication needs, ensuring inclusive engagement. For example, Activity 4’s “yes/no” buttons enabled a nonverbal child to express sleep experiences:

> *Just after lunch today, I was supervising station 4 (Let’s talk about sleep) and observed one caregiver with her little boy, who kept dragging at her arm and looking in my direction while the caregiver was engaged in a semi-structure interview with [colleague]. Caregiver looked frustrated. I caught the little boy’s eye and smiled – he smiled back. I walked over, and asked if I could take him to ‘play’ at my activity. She said yes (with a relieved smile, I think!). I offered my hand and his hand reached for mine. We walked to the activity.*
>
> *He sat down at the child-height table and looked at the strewn materials. I told him I’m here to find out about his sleep and would it be OK if I asked him some questions? He looked at me and didn’t respond, then returned his gaze to the table. His eyes rested on the “Yes!” and “No!” buttons. He looked at me then back to the buttons again. I said “Ah! You’re interested in these. I’ll show you what they do!” I pressed “Yes!”, and it emitted a loud, obnoxious, “YES!”. He grinned. I pressed the “No!” button, which shouted “NO!”. He laughed.*
>
> *I said “I ask some questions, and we can press these buttons. I’ll show you. Do* I *like chocolate?” and* I *pressed “Yes!”. He clapped his hands and grinned. I asked him if* he *likes chocolate, and he slammed his hand enthusiastically on the “Yes!” button. I asked him several other questions – including if he likes to eat shoelaces – to which he sensibly responded “No!”. He enthusiastically engaged each time. After a few minutes he began to speak. He was saying “Yes” and “No” out loud with each press of the button, laughing and gesticulating. I asked him the “sleep” questions from the activity, and he responded each time.*
>
> *After several minutes his carer had finished the interview and came over. She had tears in her eyes and informed me that he doesn’t say this much at school. She asked where I got the buttons from and that she will have to tell his OT [occupational therapist] to use them. Then they both left. But not after I received a hug from a child who – according to his carer – doesn’t like to hug many people.*
>
> *All abilities deserve to be included. All children deserve to have their say. All carers deserve to have a moment to share their story, too.*

This account of the data collection experience highlights the capacity of creative modes of engaging with participants that respect communication difference to elicit authentic voice.

Informing policy and practice through knowledge exchange

Families in Focus facilitated bi-directional knowledge sharing, by presenting existing research on health, education, and social systems with participants and capturing their lived experience, detailing participants’ identification of gaps and priorities. Our findings were presented to government, health, and community stakeholders, including Children’s Health Queensland who embedded the findings into their 2024-2028 strategic plan. The key findings, mapped to *The Nest* (ARACY, 2024b), directed to policy and practice were:

(1) *Healthy: meeting physical, mental, and emotional health needs.* Participants indicated a need for more hospital play spaces, quieter waiting rooms, and better accommodation, citing noisy wards, bored siblings, and challenges navigating disjointed healthcare systems with long wait times. Families trusted medical professionals but faced barriers like complex language, poor care coordination, and limited support for rare diseases or those living in rural locations.
(2) *Identity and culture: belonging & acceptance*. Stigma and prejudice impede timely and accurate diagnoses, leaving undiagnosed families in limbo. While some access cultural community support, judgment in hospitals, schools, and communities persists for many. Families indicated a need for hospitals to incorporate and enact greater cultural sensitivity.
(3) *Participating: having a say, empowered to speak out, involvement with peers.* Many emphasised the importance of safe friendships but sometimes group settings posed challenges. Families value autonomy in hospitals, yet isolation during treatments negatively impacts wellbeing.
(4) *Material basics: housing, transport, money for necessities*. Financial stress from healthcare costs and travel (many families travel from other cities or the urban fringe, some families sleep rough) was a profound burden for most families. Many reported limited NDIS access, particularly for non-citizens.
(5) *Learning: supported, encouraged, and opportunities to learn in a wide variety of settings*. Families reported the value of tailored education and allied health integration, but hospitalisations and inadequate school support lead to concerns about missed education for many children.
(6) *Valued, loved, and safe*. Relationships are vital for everyone. Trust-building strategies with teachers, allied health, and service providers were helpful. Yet, stigma, bullying, and parental isolation remain barriers to accessing healthcare, social support, and feeling safe and loved within communities.

Methodologically, the outcomes of *Families in Focus* demonstrates how participatory arts-based research methods are useful for translating diverse lived experiences into policy and practice recommendations (Gonzalez et al., 2021).

Engaging, empowering and supporting children and families in participatory research

Families in Focus demonstrated a meaningful and strengths-based approach to engaging families and children with disability through accessible, participatory methods that reflected and respected diverse experiences. The structure and setting of the event – which incorporated art, 3-D installations, and play-based data collection – provided flexible modes of participation. These approaches ensured an inclusive and child-friendly environment, as reflected in the following excerpt from fieldnotes, written by one the researchers conducting interviews on the day.

> *During an interview with a mother about her experiences of caring for her young child who had ASD and was nonverbal, the child – sitting in between us – showed interest in the dinosaur stickers sheet on the table. I peeled a dinosaur off the sticker sheet and held it out to him, and he proceeded to stick it onto a blank piece of paper. I peeled another, and he stuck it down. For twenty minutes, we repeated this activity… On one occasion when I peeled a dinosaur off the page with too much haste, the dinosaur soared midair on my finger, leaving its limb behind on the sticker sheet. The rhythm of this repetition was interrupted as he paused to inspect this dinosaur for some time… The child never spoke or used any sign language… but was nonetheless one of the most persistently engaged children that I encountered that day. I was moved by how this child communicated their strong desire for inclusion on their own terms.*

We designed the activities so that all who participated found value in the experience. Several caregivers indeed reflected on the value of having their child's and their own lived experience and expertise acknowledged and amplified within public and institutional settings. As one parent who participated in the event and collaborated with us to refine and present findings in stages 4 and 5 presented in a webinar held on 16 May 2025 said:

> *A lot of times when we are at appointments we don't get the opportunity. We don't have opportunities to share our frustrations or things we have going on. Some people don't feel confident talking in a one-on-one situation in sharing some of their frustrations or concerns. I'm one of those people; it's not something I like to do… So, it was actually really nice for me to be able to stop, take a step back, and really think about what are these barries that are stopping us from living our best lives. But also, what are the things that I haven't really thought about much, about how far we've actually come since we started our journey. I actually found a lot more positive experiences that came out… [But]… we don't think that there is something that can be done that can make our life easier, so the fact that the conversation was opened up and we could share, and seeing what the other parents were writing and experiencing, knowing they're in the same boat, it was really eye opening for us as well.*

Challenges identified: intentional spaces for child voice, linking data, inclusion, and co-design

We identified four key challenges in undertaking *Families in F*ocus. First, eliciting the perspectives of children with communication differences requires intentional design to create conditions for children to feel safe and confident to speak (Teachman & Gibson, 2013). Despite provision of communication options for children (e.g., art, "yes/no" buttons), caregivers sometimes interjected, highlighting the challenges of balancing adult support with the child's autonomy in research contexts (Slonecker & Klemfuss, 2023). While caregiver perspectives are valuable, future work may consider co-designing research activities more closely with children with diverse abilities to better support autonomous engagement and further amplify child voice. Second, to overcome geographic barriers, we included an online component. Yet, the relatively low online engagement (n=14) suggests challenges of digital inclusivity in disability research (Gonzalez et al., 2021). While digital tools offer convenience and can support those experiencing logistical barriers (e.g., geographic or socioeconomic constraints), they may not always be developmentally appropriate, engaging, or accessible to families navigating complex health conditions, abilities, or other constraints. Our findings suggest the need to co-develop engaging and accessible online platforms and formats that truly complement face-to-face methods. Third, we were unable to link participant IDs to responses, due to the event's flexible, participatory structure. Our approach thus limited demographic-specific analysis (e.g., by disability type, age), and suggests the need for more effective data-linking protocols in future to enable comparative analyses while preserving confidentiality. Our flexible approach responded to ethical considerations and prioritised participant comfort and accessibility, aligning with inclusive principles. Finally, although incorporating consumer participation across all stages, *Families in Focus* does not represent a blueprint for a *co-designed* framework (Kerr et al., 2023). Emerging literature in disability studies advocates for shifting the role of children and young people from research subjects to co-researchers (Brady & Franklin, 2019; Kerr et al., 2023). Future iterations of this work should more closely embed co-design principles from inception.

Discussion and Conclusion

The framework presented in *Families in Focus* operationalises the core principles of the IAP2 Spectrum of Public Participation (IAP2 Australasia, 2019), together with the "least dangerous assumption" (Tisdall, 2012) that assumes that children with disabilities are competent and can participate in research, unless proven otherwise. Unlike traditional methodologies that typically prioritise researcher-driven agendas (Beresford, 2012), *Families in Focus* embedded lived experience and *expertise* across all five phases – Draft, Develop, Deliver, Discuss, and Present – through consultation, involvement, and collaboration with consumers. This iterative, co-developed process aligns with participatory action research principles of inclusive partnerships and shared knowledge production (Galletta & Torre, 2019). Leveraging *The Nest* wellbeing framework (ARACY, 2024b) provided a holistic lens to map participants' experiences across six domains (Healthy; Participating; Learning; Valued, Loved and Safe; Identity and Culture; Material Basics). The use of arts-based methods supported diverse modes of engagement and expressing, supporting participants to communicate in ways that aligned with their strengths and preferences (Kara, 2015). *Families in Focus* has been successful in translating research into targeted, effective policy and practice recommendations and actions. The methods employed created a welcoming, child-friendly environment that enabled and empowered participants to inform and shape research outcomes, directly resulting in policy action in a state health agency.

Some methodological challenges were evident in the delivery of the event. Eliciting authentic child voice, particularly for those with communication differences, was difficult, suggestion blurring of child autonomy and adult support. Future work should consider co-developing activities more closely with children with disabilities. The low uptake of the online companion event challenges assumptions about the capacity for research conducted on digital platforms to be inclusive, as they may not suit families with complex health or socioeconomic barriers, reinforcing the imperative to provide multiple options – in person and online – for engagement (Gonzalez et al., 2021; Kerr et al., 2023). Additionally, the inability to link participant IDs to responses reflected the need to develop streamline data-linking protocols to enhance future analyses while maintaining confidentiality.

Compared to other participatory and arts-based methodologies in disability research (e.g., Andrä, 2022; Carey et al., 2025), *Families in Focus* integrates a transdisciplinary, multi-modal approach that traverses health, education, and social domains. Rather than focusing solely on arts-based data collection (e.g., Buckle et al., 2024), our framework combines arts-based methods with knowledge exchange activities, enabling bi-directional learning between researchers and participants. However, unlike fully co-designed studies, our approach did not fully position participants as co-researchers (Slattery et al., 2020), an opportunity for future projects leveraging from this framework.

Families in Focus offers a model for inclusive, participatory research that amplifies the voices of children with disabilities and their families. This work contributes to substantive research knowledge about family experience, yet most importantly this paper contributes to our understandings of the importance of participatory, creative, and inclusive methods within disability research. Our findings allow for learnings for future research to build upon this framework by embracing true co-design and exploring hybrid engagement strategies to continue to facilitate inclusive and impactful knowledge production.

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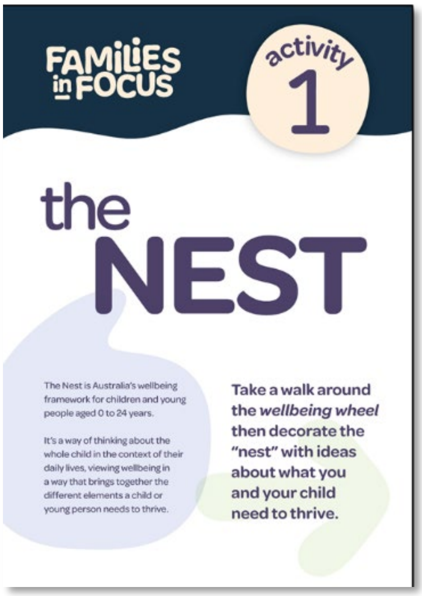
Appendix 1 – Activity 1 Displayed Materials – *The Nest*



FAMILIES in FOCUS

activity 1

the NEST

The Nest is Australia's wellbeing framework for children and young people aged 0 to 24 years.

It's a way of thinking about the whole child in the context of their daily lives, viewing wellbeing in a way that brings together the different elements a child or young person needs to thrive.

Take a walk around the *wellbeing wheel* then decorate the "nest" with ideas about what you and your child need to thrive.

HEALTHY

The things that help families & children feel happy & healthy.

What it's like at bedtime & sleep time for families.

Having access to the health care families need.

WHAT THE RESEARCH SAYS ABOUT...

...systems & structures for families

- Increased telehealth services since COVID-19 has reduced travel stress
- Mental health services are difficult to access
- Navigating supports can be challenging & stressful
- There is not enough post-diagnosis support
- Supports are not always available in different languages or culturally sensitive
- Delays in healthcare were made worse by COVID-19
- Information from healthcare professionals & services is inconsistent
- Lack of culturally safe supports for Aboriginal & Torres Strait Islander communities
- For some, COVID-19 provided new opportunities for building resilience & time for 'enjoying life'

...carers

- Have the potential to experience positive changes in mental health & wellbeing when they receive support
- Many experience sleep issues
- Can experience difficulties with physical, mental, & emotional health
- Feel isolated when there is a lack of access to services & supports

...child

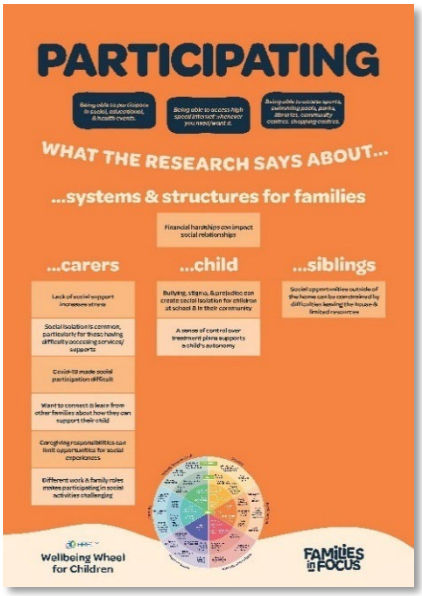
- Children want to be listened to in their healthcare & in research
- A sense of control over treatment plans supports a child's autonomy

...siblings

- Display patience, consideration, care, compassion, appreciation & understanding of disability
- Have better health outcomes when they choose to take on a care-giving role
- Can experience low wellbeing & high stress
- Can experience difficulty opening up about their own mental health struggles

Wellbeing Wheel for Children

FAMILIES in FOCUS



PARTICIPATING

Being able to participate in social, educational, & health events.

Being able to access high speed internet whenever you need/want it.

Being able to access sports, swimming pools, parks, libraries, community centres, shopping centres.

WHAT THE RESEARCH SAYS ABOUT...

...systems & structures for families

- Financial hardships can impact social relationships

...carers

- Lack of social support increases stress
- Social isolation is common, particularly for those having difficulty accessing services/supports
- Covid-19 made social participation difficult
- Want to connect & learn from other families about how they can support their child
- Caregiving responsibilities can limit opportunities for social experiences
- Different work & family roles makes participating in social activities challenging

...child

- Bullying, stigma, & prejudice can create social isolation for children at school & in their community
- A sense of control over treatment plans supports a child's autonomy

...siblings

- Social opportunities outside of the home can be constrained by difficulties leaving the house & limited resources

Wellbeing Wheel for Children

FAMILIES in FOCUS

IDENTITY & CULTURE

Belonging to clubs, churches, groups that help care for children & families.

Where families & children feel like they can "be themselves".

Learning about language, culture, or religion. Where this is supported.

WHAT THE RESEARCH SAYS ABOUT...

...systems & structures for families

- Supports are not always culturally sensitive or available in different languages
- Lack of culturally safe supports for Aboriginal & Torres Strait Islander Communities

...carers

- Parents want to connect with families who have shared experiences
- Different work & family roles makes accessing supports & using strategies for coping difficult

...child

- Children want to be listened to in their healthcare & in research

...siblings

- The caregiver role can become a part of siblings' identities

Wellbeing Wheel for Children

FAMILIES in FOCUS

MATERIAL BASICS

Being able to easily get around to work, school, appointments.

Being able to meet financial needs.

Having children's favourite foods, toys, devices, space within the home to play & relax.

WHAT THE RESEARCH SAYS ABOUT...

...systems & structures for families

- Out-of-pocket costs limit access to treatment/services
- Accessing NDIS can be stressful, onerous, & complex
- COVID-19 prompted improved access to telehealth, reducing travel burden
- Financial hardships can impact social relationships

...carers

- Financial hardships can strain social relationships
- Caregiving is associated with increased living costs, poor financial wellbeing, & reduced income

...child

- ?

...siblings

- Would like more things to do during their sibling's appointments (like games & entertainment)

Wellbeing Wheel for Children

FAMILIES in FOCUS

LEARNING

The kinds of activities families & children like to do.

What children & young people like about kindy/day care/preschool/school/uni/work.

Where children like to learn.

WHAT THE RESEARCH SAYS ABOUT...

...systems & structures for families

- Coping strategies & resources post diagnosis assist in supporting families
- Modifications of learning milestones & environments are lacking
- There is not enough information about early childhood development & disability
- Strength-based language can improve educational outcomes & experiences for families

...carers

- Need for improved access to mental health support for parents & carers
- Parents & carers know how to support their child when there is a concern
- Parents want to connect & learn from others about how they can support their child

...child

- Students experiencing chronic illness may miss more school than their peers, which can impact their education
- Children do not always receive adequate supports or appropriate inclusion practices
- Remote learning can make it difficult for some children to engage, while for others it can help improve engagement
- Individual adjustments are not always made or applied for all children

...siblings

- Siblings report learning resilience, greater understanding of disability, & sometimes additional skills, e.g. sign language

Wellbeing Wheel for Children

FAMILIES in FOCUS

VALUED, LOVED & SAFE

Where children & families feel confident, safe, happy.

How supported children & families feel in online & in-person communities.

Where families go for advice & support.

WHAT THE RESEARCH SAYS ABOUT...

...systems & structures for families

- Lack of culturally safe supports for families from Aboriginal & Torres Strait Islander communities
- Resilience comes from good communication, positive belief systems, adequate social support, helpful routines, & hope
- Covid-19 increased resilience for some families & enabled some to have time to 'enjoy life'

...carers

- Financial hardships can strain social relationships
- Caregiving is associated with increased living costs, poor financial wellbeing, & reduced income

...child

- ?

...siblings

- Love their sibling with disability
- Value learning new skills like sign language
- Wish others would be more supportive & understanding of their sibling

Wellbeing Wheel for Children

FAMILIES in FOCUS

What is missing?

Research that amplifies children's perspectives & opinions

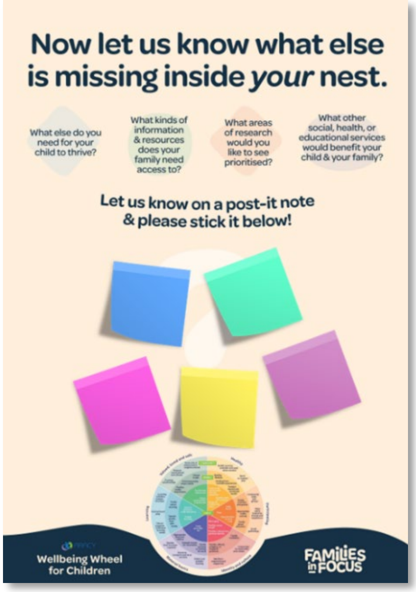
Evidence about the ideal educational environment & perspectives of children with a disability

The voices of other caregivers – siblings, fathers, grandparents, relatives, friends.

The voice of Aboriginal & Torres Strait Islander families who care for children with a disability

Wellbeing Wheel for Children

FAMILIES in FOCUS



Now let us know what else is missing inside *your* nest.

What else do you need for your child to thrive?

What kinds of information & resources does your family need access to?

What areas of research would you like to see prioritised?

What other social, health, or educational services would benefit your child & your family?

Let us know on a post-it note & please stick it below!

Wellbeing Wheel for Children

FAMILIES in FOCUS

Appendix 2 – Activity 2 Displayed Materials – *Imaginations Run Wild*

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activity 2

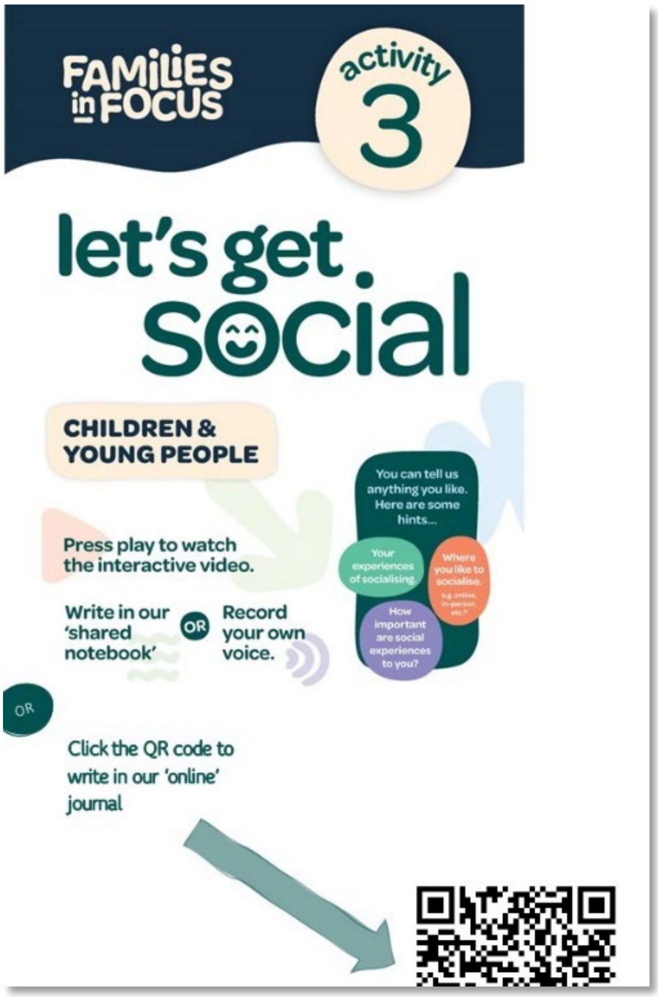
imaginations run wild

CHILDREN!

You can draw and talk about your ideal school and ideal hospital.

NO IDEA TOO BIG OR TOO SMALL!

Appendix 3 – Activity 3 Displayed Materials – *Let’s get social*



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activity 3

let’s get social

CHILDREN & YOUNG PEOPLE

Press play to watch the interactive video.

Write in our ‘shared notebook’ OR Record your own voice.

You can tell us anything you like. Here are some hints...

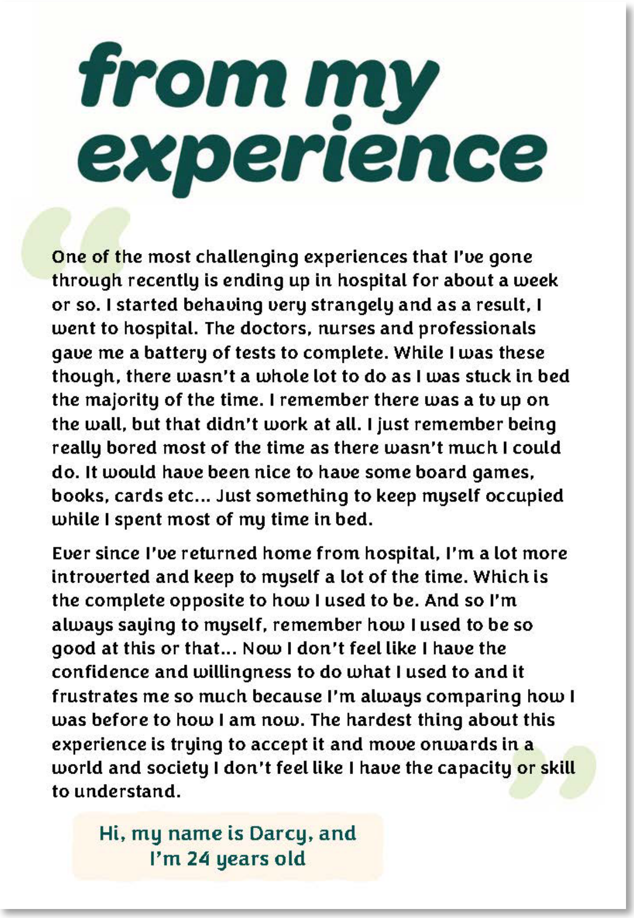
Your experiences of socialising.

Where you like to socialise. e.g. online, in-person, etc.?

How important are social experiences to you?

OR

Click the QR code to write in our ‘online’ journal



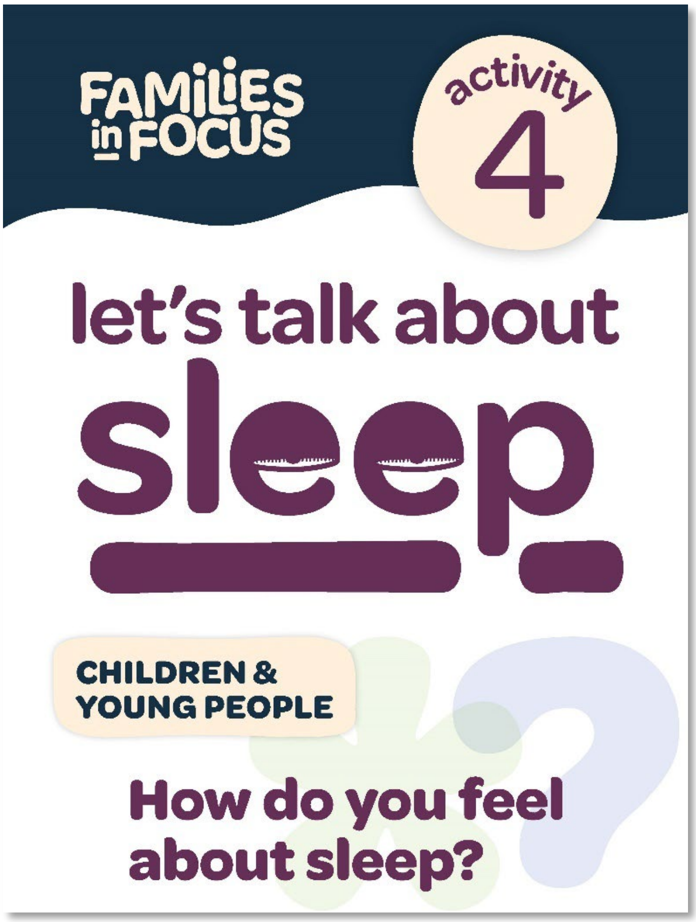
from my experience

One of the most challenging experiences that I’ve gone through recently is ending up in hospital for about a week or so. I started behaving very strangely and as a result, I went to hospital. The doctors, nurses and professionals gave me a battery of tests to complete. While I was these though, there wasn’t a whole lot to do as I was stuck in bed the majority of the time. I remember there was a tv up on the wall, but that didn’t work at all. I just remember being really bored most of the time as there wasn’t much I could do. It would have been nice to have some board games, books, cards etc... Just something to keep myself occupied while I spent most of my time in bed.

Ever since I’ve returned home from hospital, I’m a lot more introverted and keep to myself a lot of the time. Which is the complete opposite to how I used to be. And so I’m always saying to myself, remember how I used to be so good at this or that... Now I don’t feel like I have the confidence and willingness to do what I used to and it frustrates me so much because I’m always comparing how I was before to how I am now. The hardest thing about this experience is trying to accept it and move onwards in a world and society I don’t feel like I have the capacity or skill to understand.

Hi, my name is Darcy, and I’m 24 years old

Appendix 4 – Activity 4 Displayed Materials – *Let’s talk about sleep*



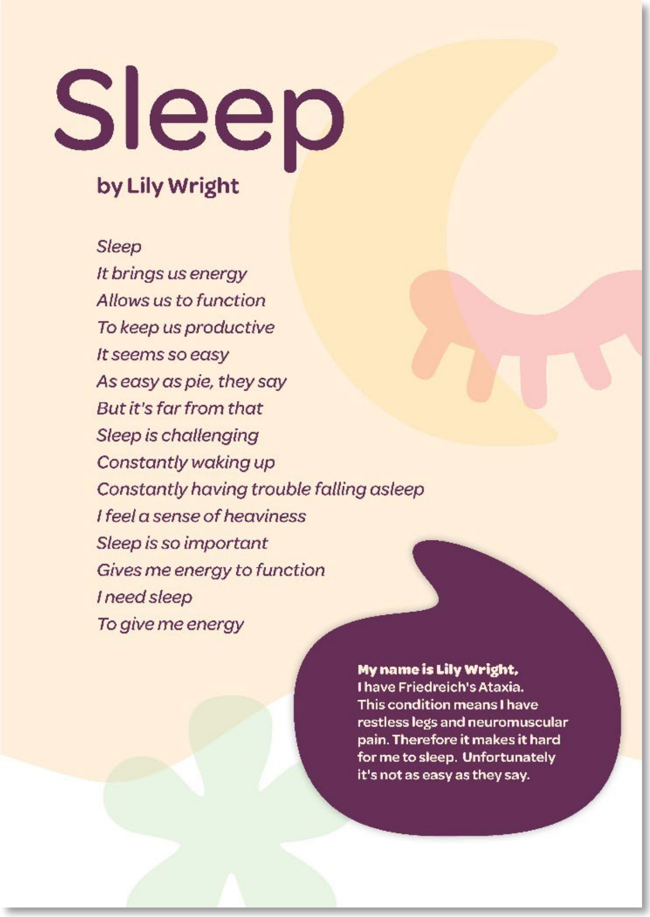
FAMILIES in FOCUS

activity 4

let’s talk about sleep

CHILDREN & YOUNG PEOPLE

How do you feel about sleep?



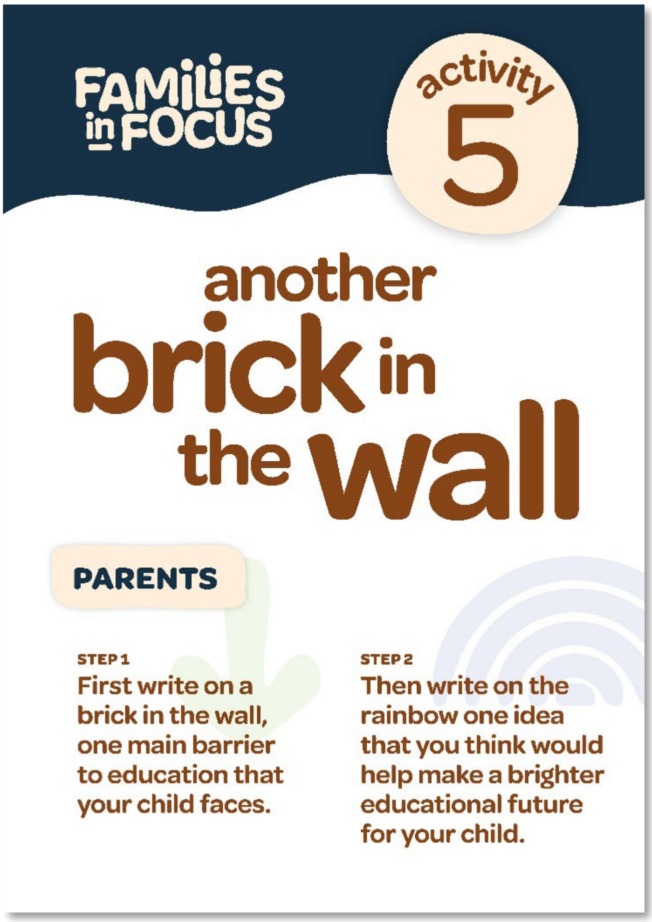
Sleep

by Lily Wright

Sleep
It brings us energy
Allows us to function
To keep us productive
It seems so easy
As easy as pie, they say
But it’s far from that
Sleep is challenging
Constantly waking up
Constantly having trouble falling asleep
I feel a sense of heaviness
Sleep is so important
Gives me energy to function
I need sleep
To give me energy

My name is Lily Wright,
I have Friedreich's Ataxia.
This condition means I have restless legs and neuromuscular pain. Therefore it makes it hard for me to sleep. Unfortunately it's not as easy as they say.

Appendix 5 – Activity 5 Displayed Materials – Another brick in the wall



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activity 5

another brick in the wall

PARENTS

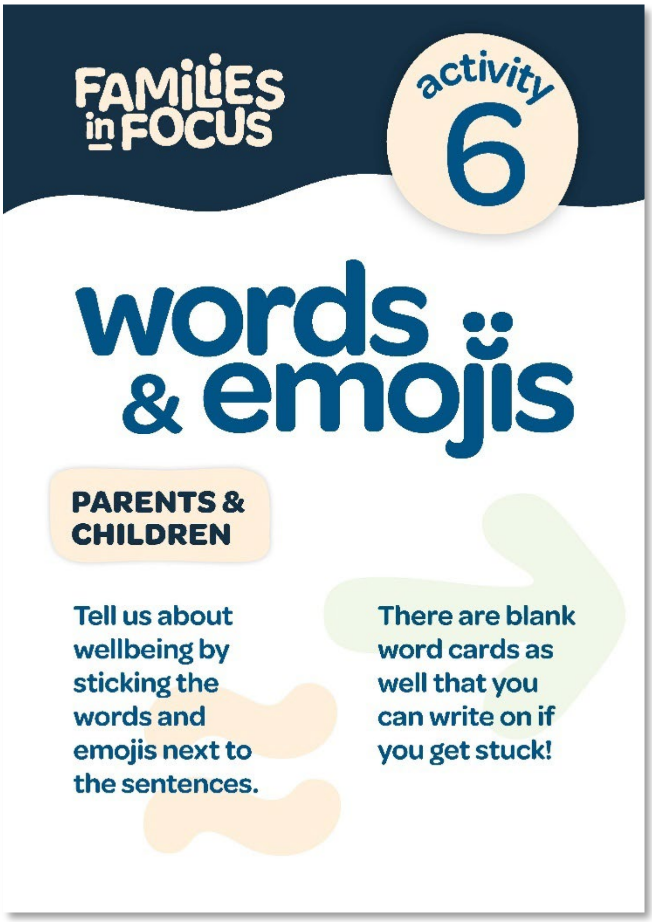
STEP 1

First write on a brick in the wall, one main barrier to education that your child faces.

STEP 2

Then write on the rainbow one idea that you think would help make a brighter educational future for your child.

Appendix 6 – Activity 6 Displayed Materials and whiteboard example



FAMILIES in FOCUS

activity 6

words & emojis

PARENTS & CHILDREN

Tell us about wellbeing by sticking the words and emojis next to the sentences.

There are blank word cards as well that you can write on if you get stuck!