



Review of Best Practice in Early Childhood Intervention

Findings from the Young People's Study

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The University of Melbourne



**Healthy
Trajectories**
A Child and Youth Disability Research Hub



Acknowledgements

The University of Melbourne acknowledges the Traditional Owners of the unceded land on which we work, learn and live: the Wurundjeri Woi-wurrung and Bunurong peoples (Burnley, Fishermans Bend, Parkville, Southbank and Werribee campuses), the Yorta Yorta Nation (Dookie and Shepparton campuses), and the Dja Dja Wurrung people (Creswick campus).

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We recognise the unique place held by Aboriginal and Torres Strait Islander peoples as the original owners and custodians of the lands and waterways across the Australian continent, with histories of continuous connection dating back more than 60,000 years. We also acknowledge their enduring cultural practices of caring for Country.

We pay respect to Elders past, present and future, and acknowledge the importance of Indigenous knowledge in the Academy. As a community of researchers, teachers, professional staff and students we are privileged to work and learn every day with Indigenous colleagues and partners.

This document has been developed by a University of Melbourne-led Consortium as part of an independent review of best practice in early childhood intervention in Australia.

Funded by the Department of Social Services, the consortium is led by Professor Christine Imms of the University of Melbourne in partnership with Murdoch Children's Research Institute (MCRI), Professionals and Researchers in Early Childhood Intervention (PRECI), SNAICC - National Voice for our Children and Children and Young People with Disability Australia (CYDA).



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1. Introduction

This Consultation Report has been prepared as part of an independent review of early childhood intervention (ECI) best practice commissioned by the Department of Social Services (DSS). The review is being undertaken in fulfilment of Action 2.4 of the Early Childhood Targeted Action Plan, which is part of the implementation of Australia's Disability Strategy 2021-2031.

The purpose of the action is to:

review guidance for best practice in ECI and prepare a framework for best practice in ECI that reflects current research and evidence.

This project will contribute to the second objective of the Early Childhood Targeted Action Plan (TAP):

to strengthen the capability and capacity of key services and systems to support parents and carers to make informed choices about their child.

The primary objective of this work is to co-produce an Australian ECI Practice Framework that is informed by the best available evidence, is practical and can be implemented and evaluated for effectiveness and impact. The goal is that all children growing up in Australia live in thriving families and communities that support their health, development and wellbeing, and that children with developmental concerns, delay, or disability receive the support they need to participate fully in their families and community.

1.1 Aim

The aim of the consultation was to use the results of the desktop reviews (the first stage of the independent review) to support the consultation and co-production processes to inform and to contribute to development of the new Practice Framework.

1.2 Our overall approach

Our goal was to provide the right conditions for participation, collaboration and engagement in the consultation, which includes providing space (opportunity to participate), voice (support to express views), audience (access to decision makers) and influence – that decision makers are open to being influenced by the views expressed (Lundy, 2007). The consultation activities were completed in four parts, each aiming to reach differing groups with the goal of broad reach across Australia to those with an interest in ECI.

The four consultation processes were led by different members of the project consortium:

- Professionals and Researchers in Early Childhood intervention (PRECI) conducted consultations with early childhood practitioners and providers, professional organisations, peak bodies, advocacy groups, researchers and academics
- SNAICC - National Voice for our Children (SNAICC) held targeted engagements with Aboriginal and Torres Strait Islanders state and national

peak bodies, Aboriginal and Torres Strait Islander community-controlled organisations and families

- The Association for Children with a Disability (ACD) completed consultations with parents and caregivers
- Healthy Trajectories undertook a qualitative study with young people aged 15-30 years to explore their experiences of childhood interventions and supports.

The draft consultation reports were shared with our national and international expert panel members for their input thought engagement in a 3-hour workshop or individually in writing.

1.3 Report structure

The findings of the different consultations are presented as separate reports, which will be available on the [Healthy Trajectories ECI website](#).

Section 2 of this report provides the findings from the study of young people's experiences of childhood interventions and supports.

Now that this round of consultations has been completed, the next step of the project is to bring together what was heard in the consultations with what was synthesised in the desktop reviews to inform the development of the framework. We will seek stakeholder input, via consultation, to the draft framework and proposed resources through the next phases of the review.

2. Findings from the Young People's Study

2.1 Introduction

This is one of four consultation reports that provide insights to inform the development of the new Practice Framework. The *Healthy Trajectories* team at the University of Melbourne completed a qualitative study to explore the experiences of childhood interventions and supports of those aged 15 to 30 years. This part of the consultation and engagement strategy did not address the need for or structure of a proposed ECI framework, but rather focused on young people's perspectives on their lived experience as children and their consideration of the value and impact of ECI on them as adolescents and young adults.

Including a young persons' study in the consultation process aimed to meet their rights to have a voice in issues that have been pertinent to their lives (United Nations, 1989; United Nations General Assembly, 2007), and to seek a deeper understanding of their experiences. Findings from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission into Violence Abuse Neglect and Exploitation of People with Disability, 2023) and the NDIS Review (Commonwealth of Australia, 2023) highlighted concerns raised by some young people about the interventions they received during childhood.

Theoretically, this young person's study is informed by the Life Course Health Development framework, proposed by Halfon et al (Halfon et al., 2014; Palisano et al., 2017). The life course health development framework describes health as a resource for living that is developed across the life course as a consequence of person-environment transactions. The six main ideas of the Life Course Health Development framework help us think about how to design interventions to promote development and to consider what might influence (positively or negatively) health and wellbeing outcomes. Importantly, this framework calls for future focused thinking from the very earliest days of life, the need for continuity of health and disability care throughout life and reinforces the importance of providing and enabling development within the natural settings where children and youth spend their time.

The team involved in developing and implementing the project included:

- Researchers: Christine Imms (project lead), Meghan Wilson, Francesca Lami, Sarah Knight
- Research assistants: Miriam Yates, Carolyn Pinto
- Young adults with lived experience of disability engaged to contribute as consumer co-investigators: Nicole Kozelj, Rohan Symonds
- Research partners: Skye Kakoschke-Moore (CYDA), Denise Luscombe (PRECI)

2.1.1 Study protocol in brief

This study aimed to explore and describe the experiences of young people who had received early childhood intervention or support in Australia during their childhood years because of developmental concerns, delay or disability. We wanted to learn more about young people’s experiences (including what worked well and what didn’t work well) and their ideas about best practice in early childhood intervention.

The findings of this study are intended to inform the design of a new ECI best practice framework, and to consider what future research might need to be undertaken to enhance experiences, outcomes and impacts of ECI on children.

This study forms part of the Review of ECI, which aims to improve provision of services and supports for young children with developmental concerns, delay or disability, and their families, so they have the very best start in life. Table 1 provides a summary of the research protocol.

Table 1: Summary of the study protocol

Title	Young people’s experiences and perspectives of childhood intervention and supports: A qualitative study
Objectives	To explore and describe the experiences and perspectives of young people who received ECI services and to broaden our understanding of impacts and outcomes of ECI. Study findings will contribute to a review of best practice in early childhood intervention in Australia.
Study design	The study was guided by qualitative description methods (Bradshaw et al., 2017). A qualitative approach was chosen to support gathering, understanding, interpreting and valuing knowledge gained through exploration of lived experiences (Creswell, 2003). Qualitative description helps us explore the subjective experiences of people about a particular circumstance or problem (Bradshaw et al., 2017). The goal is to understand and describe the experiences. For this study, participants with lived experience of childhood interventions were asked to recall and reflect on their earlier experiences and talk about their perspectives of those experiences, including views about impact on their development and their lives more generally.
Study population	Youth aged 15 to 30 years: <ul style="list-style-type: none"> • who received intervention through their childhood related to a developmental concern, delay or disability. • who had intervention or support beginning in the early childhood period (when aged <9 years). • who could recall their childhood intervention and supports experiences.

Title	Young people’s experiences and perspectives of childhood intervention and supports: A qualitative study
	<ul style="list-style-type: none"> • who were able to communicate their experiences using their usual communication methods (including any needed devices and/or supports) <p>Across all those involved, we aimed to include participants with diversity related to gender identity, geography, diagnosis, type of functional impairment (physical, sensory, cognitive, behavioural) and cultural and linguistic diversity.</p>
Recruitment	<p>This project was reviewed and approved by The Royal Children’s Hospital Human Research Ethics Committee (HREC). Advertising via our networks began on 27th August 2024 and closed on 30 September 2024.</p>
Data collection procedures	<p>To support purposive sampling and describe the participant group, demographic characteristics were collected via an expression of interest (EOI) survey. Survey data were collected using an online form with responses either entered directly by the interested person, or by the researcher via a brief telephone or online interview with them.</p> <p>From the EOI data, the research team determined (i) eligibility and any indicators of imposter participants; (ii) interest to take part, (iii) support needs to ensure effective communication; and (iv) gained consent and booked an interview for those in agreement. The EOI process was also used to support sampling so that the interviews were conducted with young people bringing diverse experiences.</p> <p>To address the research aim, data were collected through semi-structured interviews designed to explore experiences and impacts of ECI. Interviews were conducted using online video-conference technology (i.e., Zoom), or in person, based on participant preference. In addition, where individual’s communication methods were text based, written responses to the interview questions were collected via email or chat functions in Zoom.</p> <p>Interview questions were provided to participants prior to the interview. Easy-to-read versions of materials were available and used as required. A copy of the interview questions is included at the end of this report. Participants received a voucher of \$50 in recognition of their time and contribution to the study.</p> <p>Data collection was completed on 9 October 2024 (the final interview).</p>
Analysis approach	<p>Every participant received a transcript of their interview to check, amend or add information prior to analysis.</p> <p>Qualitative analysis was led by two members of the team – MW and CI – with team members reviewing transcripts and reflecting on the development of the codes and themes as the analysis progressed. Involvement of the diverse experiences of the full team was used to</p>

Title	Young people’s experiences and perspectives of childhood intervention and supports: A qualitative study
	<p>ensure multiple perspectives could be considered, questioned and interpreted thoroughly.</p> <p>Once the full draft of the findings was prepared, a second round of member checking occurred with participants. We asked participants if they could ‘see themselves’ in a summary of the findings, if there were errors of fact, or areas where clarity and relevance could be improved. We also asked them to confirm the confidentiality of their identity in the way in which findings were presented.</p>

2.1.2 Characteristics of participants

Fifty-three young people expressed interest in the study using the Expression of Interest (EOI) form, and 21 took part in interviews. Figure 1 displays the flow of participants through the recruitment process.

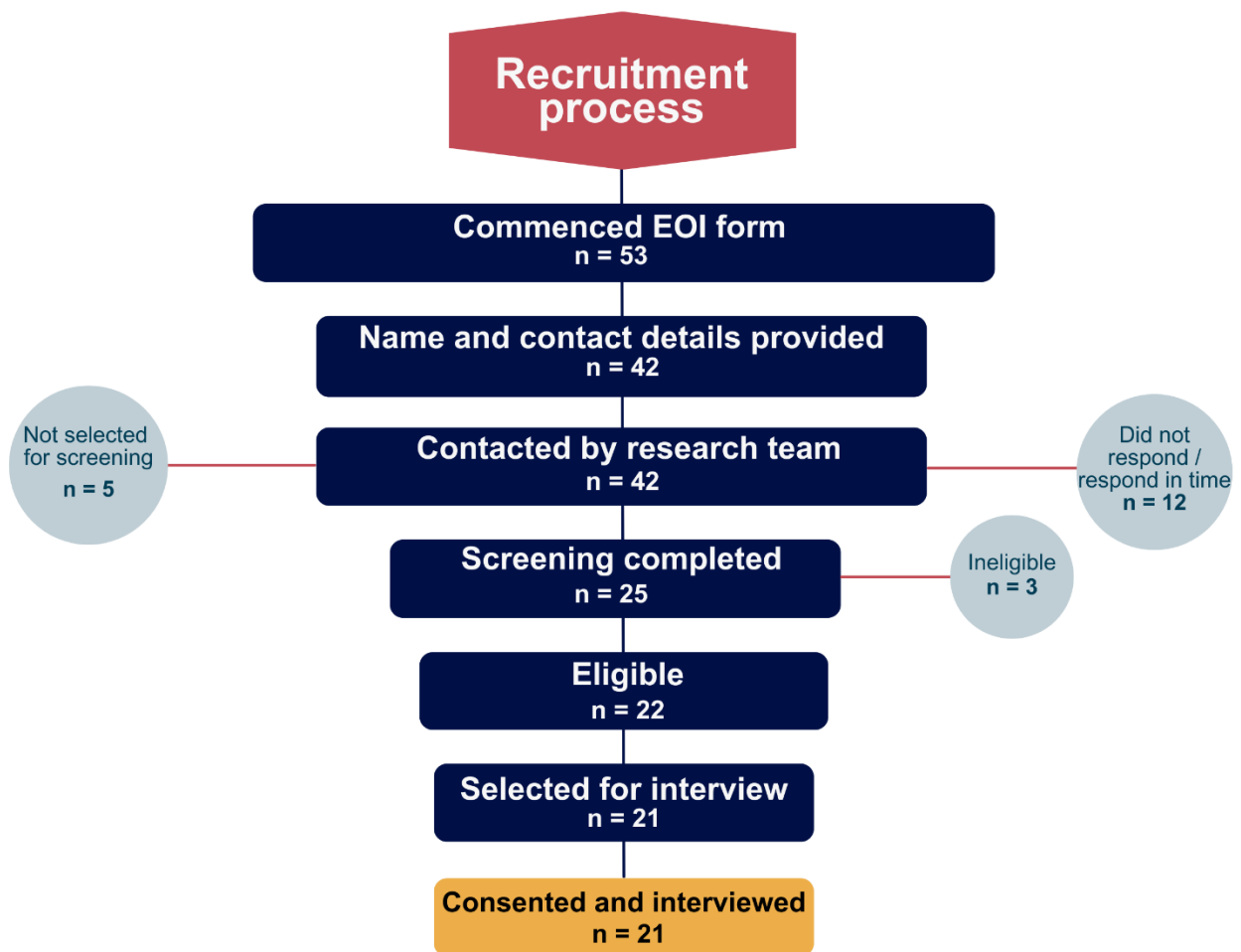


Figure 1: Recruitment process for study participants.
Note: EOI = expression of interest.

Figure 2 (see page below) provides an overview of the 21 young people who took part in the study.

Interviews were conducted with young people from each of the age groups, with the largest number aged 18-21 years ($n = 10$). Approximately half of the participants identified as female ($n = 11$), as having a diagnosis of autism ($n = 10$) and as living in Victoria ($n = 11$). The study sample's diversity was supported by inclusion of individuals with a range of conditions; identifying as non-binary or other genders and/or belonging to the LGBTQI+ community; identifying as Aboriginal or Torres Strait Islander or otherwise culturally diverse.

Ten participants used additional supports to communicate within the interview, including AAC, a communication partner, an Auslan interpreter, using a combination of text and verbal responses, and turning on closed captions. One person took part in a face-to-face interview and all others were conducted online. The interview duration ranged from 27 to 59 minutes.

Additional information about participants, including the characteristics of who completed the EOI (defined as providing a name and contact details; $n = 42$) and those who consented and were interviewed ($n = 21$) are displayed in the Appendix, in Table A1.

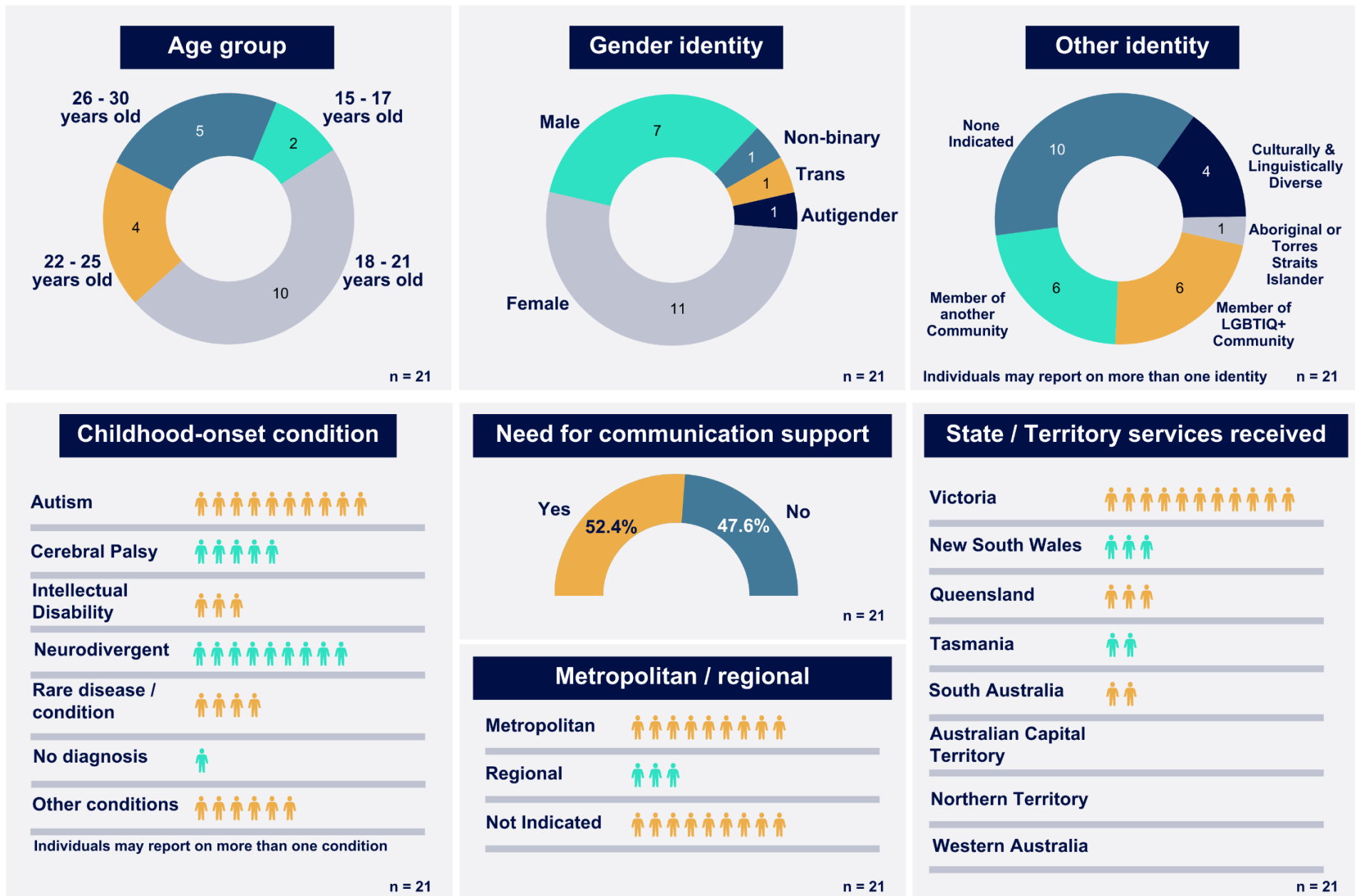


Figure 2: Summary of characteristics study participants.

2.2 Findings

This report represents the first phase of the analysis. The reported findings remain close to the key messages and ideas expressed during interviews. The findings presented in this report are based on categorising and coding of the 21 interviews by two researchers and reflections on transcripts and early summaries by the team. In addition, a draft of this report was considered by the expert advisors during the Deliverable 3 consultation workshop. The summary of findings was also shared with participants for their comments or feedback. The qualitative analysis provides an interpretation of the findings and their implications and will be used to inform the development of the ECI framework.

The following sections summarise the findings. First, we provide a description of the childhood therapy and supports experienced by the young people. Then we present the findings according to the following categories and themes:

- (i) messages to myself as a child: I'm ok as I am, but therapy has benefits
- (ii) messages to parents: I'll be ok, please worry a bit less
- (iii) messages to therapists: know me as a child first; and
- (iv) guidance for early childhood intervention.

These themes provide an overview of what has been heard. Quotes have been provided to highlight the sentiments and perspectives of participants and support the summaries of findings. A range of quotes are provided to ensure all voices are represented.

2.2.1 Early childhood intervention services and supports

Participants were interviewed about their experiences of early intervention or supports that they received for developmental concerns, delay or disability. The participants were asked to focus on their early childhood (i.e., when they were less than 9 years of age). Given that participants reported a wide range of child-onset disabilities, and that some participants had not received a diagnosis in early childhood, the definition of early intervention and support was not restrictive and aimed to capture diverse experiences.

Examples of intervention and support reported across interviews included: psychology or counselling, physiotherapy, occupational therapy, speech therapy, school supports (i.e., clinician school visits; school-based teachers, aides or therapists; visiting teachers; specialised classes or streams; individual learning plans), specialised schools (e.g., autism specific school), recreational activities (e.g., swimming or dance lessons), medical appointments (e.g., paediatricians), and group programs (e.g., social skills groups).

Early intervention was described as occurring within a range of settings including early childhood settings (e.g., kindergarten), school, private clinics, early intervention organisations or centres, home, and in hospital.

Some participants provided specific details of the supports that they received, including recollections about the focus of intervention or the types of therapy activities. For example,

“Physio, OT and speech therapist and being able to work through with them with my various issues with CP, a lot of my sessions to do early on in life for physio was always about working with the mobility I did have, keeping active and the more active I was, the more flexible I was, and the more comfortable I was and try to keep myself as flexible and less tired in the muscles as much as possible through exercise, and on other slightly less conventional physio sessions.”



In some instances, participants provided a general sense of the type of intervention or support but could not recall or were uncertain about some details. For example,

“I went there all the way through my childhood, and I remember a particular time that I was working with... I'm not exactly sure who she was. I'm not sure if she was a physio or an OT or something like that.”



2.2.2 Messages to myself as a child: I'm ok as I am, but therapy has benefit

The messages participants wished to send themselves as 5-year-olds focused on either reassurance that there was nothing wrong with them as people, that they were ok, or on the value of persisting with therapy.

Messages about self-worth were situated in experiences of feeling judged – by parents, other children, therapists and teachers. Some participants expressed that their need for therapy and other supports resulted in them feeling less valued than other children, and they were not acceptable as they were. Participants shared messages of care and protection. Reflecting on their early childhood experiences as young adults, some participants expressed a wish that they could have advocated for themselves earlier, understood themselves better, or been better understood by others.

These quotes are participants' messages to themselves as young children.

“My darling, the problem is not you. It is not you. The problem is not you no matter how much you are told that it is. The adults do not always know you better than you do.”

“Run away. I know that's really bad. It's just, and I'm excluding the teachers ... in this situation. I'm more talking about the like, the more allied health that I utilised just because. Yeah, it just was not helpful.”

“There's nothing wrong with you. Yes, the fact you can't catch a ball, and you might stumble or trip over when you run isn't great, but it doesn't mean you are inherently broken.”

“One of the things I wish I could say to myself is even though it doesn't look like it, you're not the only one that does therapy. You know, you're not just a black sheep.”

“To myself, I would say you're not defined by your challenges

“Perfection doesn't exist. You don't have to be perfect. You don't have to speak perfectly. Don't have to lip read someone perfectly. Just do your best and accept whatever happens.”

Participants expressed that ECI can have lifelong benefits.

There were also clear messages of value and longer-term benefit of “sticking with it”. These messages were sometimes related to experiences of therapy as fun and engaging, but more often appeared connected to the idea that it will be worth it in the end, giving a sense that therapy was sometimes challenging, something to be endured.

“I would try to say to them [my younger self] like it's hard, but like once you push through it, it is worthwhile. You will be very grateful that you went for everything that you have, that you had everything that you had yeah, like, the main thing I would say is, try to keep going with it.”

“I liked the games, but not the homework. It was important to help kids understand things. It needs to be fun.”

“It absolutely made a really big impact in terms of where I can now go. And now what I can now do.”

“As a 5-year-old, I would say that therapy is good and fun, and you can learn lots.”

“... could have long term benefits.”

“And you know, obviously without the therapy I wouldn't be anywhere near where I am now.”



“It’s important to learn how to learn those skills, learn those physio, learn OT. Because it helped a lot, it helped a lot in the future.”



“We just decided no more physio tape and I cracked on with it. And look at me now, I’m doing all this sport, I’m going to the gym and all this, and I’m still in communication with different physios and all that. So being able to stick with it, and you know is probably the biggest one is to stick it out and do it.”

2.2.3 Messages to parents: I’ll be ok, please worry a bit less

Messages to parents predominantly spoke of reassurance and care – a sense of knowing that things were not easy for parents and the family, but that things would be ok in the future. Participants also shared suggestions of what they would have valued in ECI. The key messages for parents and carers were: ‘I am ok, and I need you to be ok, so that you can advocate for me.’

Appreciation and concern for what parents were experiencing was evident, but so too was the sense that children wanted to be accepted for who they were. Many participants expressed gratitude for the support and effort of the parents (or parent), even in cases where the participant reported some negative experiences in ECI.

These quotes are messages of gratitude to parents, shared by participants.



“I do appreciate everything that they’ve [my parents] done for me with regards like going through all that, listening to all these seminars, trying to understand as much as they did like, the biggest part of my early intervention was definitely the fact that my parents were so committed to doing it.”



“I don’t necessarily think I’d say anything to my parents, because I know they were just trying.”



“I would say to my mum, thank you for supporting me and giving me all the opportunities, and like it’s not her fault that the therapies I was put into were maybe a bit kind of, you know, neither here nor there...”



“Well, they’re absolute legends. I don’t know how they managed to organise it.”

Some participants shared messages of concern for the wellbeing of parents.

- “Keep fighting but don't let your mental health be ruined because of it.”
- “I think they may have been made to feel a bit more worried than they needed to. So, I would just tell them it's okay, all your children are fine the way they are.”
- “I would just like to give them a big hug. Honestly, they were going through it... And they're sort of, I reckon they would have been really overwhelmed. So, I would have liked to just thank them for the support that they were giving me.”
- “I would say, thank you for being so patient and showing up for those appointments, you know. Thank you for always being attentive to my needs. Don't be too hard on yourself for not being able to know these things, you know. What's important is that we're all learning.”

Key messages about valued approaches were shared by participants.

Many participants shared messages about what they liked or did not like about what their parents did, or organised, to support them. Participants also suggested what they would have valued. Some of these views were focused on therapy and services. Other messages were focused on approaches to raising them as children, parents' values, and the 'why' of intervention.

- “Not necessarily my dad, but my mum was quite advanced with her thinking of how autistic people should kind of be within society or not necessarily within society, but like how autistic people should be perceived and supported. ... she was very much into what [expert in the field] was doing back then with the autism and girls... I think that kind of helped her understand a little bit more as to how I may be feeling. And my again I love my dad dearly, but he just not. He does not understand it.”
- “I think one of the things I wish I could say to them was to speak to the providers about doing more group therapy and doing... for example, even taking my siblings to do it. So I don't feel so isolated... And they were really, really good at getting what I needed... So then, when I was older, and I could have the confidence to say, I go to therapy, and I don't care what you say. But I didn't have that confidence. And I still needed intense therapy... and making that normal, I think, has to be the first step.”

“Figure out how you want to raise your children, and then stick with it, because that's what my parents did. ... it depends really depends on what you want your kids to do in life. Do you want them to fit into a neurotypical society and have them be like, successful in life in like the traditional sense like, have a job, buy a house, do that. Help them shape them. But if you want them to be themselves and stuff like that. You choose ... because again, it's again, it's really about how, figure out how you want to parent what principles and values do you want to instill in your children and run with it.”

“What are your goals or your intentions when you're doing early childhood, and then, on top of that advocate for your child but try not to control them.”

“But you can be independent with safeguards, and that's what a lot of parents don't get, I think, especially with people like with autism and other kinds of disabilities. You can still allow your child to have that freedom and have that choice to be independent. If you don't try, you don't know.”

“I would say to my mum, like you're obviously overwhelmed and maybe confronted by what you're seeing in your child. But like, maybe like, have a conversation with [participant] about it, and listen to them when they're saying, “This isn't right”, or “I'm not enjoying this”. Or whatever you like, but be open to a conversation rather than shutting down because of overwhelm.”

“Communication can come in many forms and it's not being a "baby" if you don't use what the adults want, e.g. talking when upset. I always remember mum saying, "I can't understand you when you are crying" I feel if I knew and it was supported [that I] communicate in other way, e.g. typing or writing, then that would have made some of those frustrating times easier.”

Some participants reflected on distressing experiences or feeling unsupported.

Two participants spoke about their experiences of the consequences of a parent not valuing them as they were, and of damaged relationships because of the interventions agreed to.

“He [my father] asked doctors. He asked therapists, and he did what they said was best for me. But what they said was best for me involved things like leaving me without food, and physically and chemically restraining me... so that hurt me. And it did hurt our relationship. And it's something that's never going to truly be fixed, because I understand why he did it, and I forgive him, but he's still always going to have done that.”

“[my mother], she was definitely pro... ‘the goal is my child being what I want, not who they are.’”

“I think I would probably say, ‘You clearly don’t know how to support your child’... Like, yeah, because my dad, like I guess context... is that my dad was quite abusive to me throughout all of my childhood. And so like, I think that maybe part of yeah, that was almost like he wanted something to reinforce that his approaches were rational or whatever which they obviously weren’t.”

2.2.4 Messages to therapists and teachers: Know me as a child first

Participants emphasised the importance of ECI being child-centred

Messages to service providers and teachers were typically related to focusing on children as children – knowing the child before focusing on therapy goals. Participants valued what could be learned from therapists when they were patient, encouraging, and explained the ‘why’ of therapy.

“Don’t forget to get to know the child. That when you start with the child and know the child... You can then integrate therapy. You can’t do it the other way around. It just doesn’t work.”

“Be patient. Be patient like it might not work the first time but try to make it work eventually.”

“I would tell the therapist to keep explaining to me what you are doing and what you want me to do. Keep showing me what I am supposed to be doing, so I know what I am to do.”




“Teach them different things.”

“I’m a person. Don’t judge me by my diagnosis and challenges. Don’t talk about me. I could go on forever about this.... Don’t talk about me in the 3rd person... like I was understanding more than you thought I was understanding. Yeah, I would really want them to keep an open mind.”

“Sometimes I want to be able to tell you how I feel like. I may not be comfortable, but like I would really appreciate it if you could also ask me for my opinion, instead of just looking at my parents for that information.”




Some participants expressed gratitude for the efforts of their therapists, teachers and other service providers.

While nearly every participant recalled negative experiences with early intervention and supports, most also recalled positive experiences.

-  “Thank you for, yeah, letting this be about me, I guess. And like, for helping yeah, helping me to understand my own brain.”
-  “I always had physios and OTs that were willing to learn along the way, because you can get some support staff that you know come out of, you know, uni [university] and get their little slip paper and they've learned everything in the world. So, you know the willingness to learn and adapt is the big one for support staff.”
-  “It’s not your fault. Your university training didn't fully prepare you for working with students with diverse needs. Thank you for doing your best with what you had.”







Participants explained that assessments need to be navigated with care.

Several participants reflected on the negative experience and impact of assessments. Participants offered advice related to raising awareness about the need to change those experiences for children.

-  “And I ended up, you know, being, I think I was like 7 or 8 at the time in this room with a complete stranger, and spent an hour with them, and they were asking me some pretty, you know, significant questions. And I just felt overwhelmed the whole time.”
-  “And really think about how and when you do those assessments and reports. But we need to remember that these are little children, not test subjects.”
-  “Make tests less invasive. I remember sitting in testing rooms for hours on end. And by the end of it I would be so overstimulated that I would have a meltdown in the car.”

Participants shared advice for early childhood intervention service providers.

Across participants, there were contrasting perspectives, and some specific advice. Participants had advice for therapists based on taking a holistic approach, making therapy fun, building rapport with children, keeping an open mind, and working collaboratively across all those supporting the child.

- 
 “Approaching things with care and conscientiousness.”
- 
 “Try and do it in a way that makes the kid look forward to it.”
- 
 “Keep an open mind. Don't be afraid to look into different ways of rapport building and things like that.”
- 
 “I think sometimes just taking a step back and listening to the person is still important.... But taking a moment just to have a breath and re-evaluate what the goals are and ask the person what they think is working and what isn't working. And then from that that discussion being able to tailor the therapy approach. That's the only sort of feedback I think I would give them.”
- 
 “I'm saying work together with other practitioners, and build and do a very much around the table approach...”
- 
 “Fun fact, folks: trying to squish a child into a mould causes more damage to them. Unless you are trying to hustle yourselves perpetual work you make for yourselves, I recommend not trying to break mental arms off.”

2.2.5 Guidance for early intervention

When asked about guidance for ECI, perspectives covered several areas:

- respect children’s rights – protect them from harm, allow children to have a good childhood, provide opportunities for choice and input
- ensure equity of access to early diagnosis and timely supports
- situate therapy within the family by knowing the family and working collaboratively
- tailor approaches to child and family values and goals and ensure meaningful outcomes are being met
- provide support and interventions in the everyday settings where children are, with their peers
- value lived experience and provide access to role models with disabilities

Participants shared views on recognising and protecting children’s rights.

Perspectives on protecting children focused on ensuring that those who are supporting children and families do not make them feel broken, othered, or less than. Therapists, teachers and other supporters need to protect children from harm.

- “...and really reinforce to them that they are not less because they have disabilities, or they're not less because they need to have therapies, or because they need to be pulled out of class... whatever it is.”
- “And I, I think things like social skills training have to be approached with a special care because of the messaging that you are sending. You know, like the undertone is that in a neurotype (sic), in a predominantly neurotypical world, for example, you, as a non-neurotypical person must do your best to conform to the status quo. The status quo is not obliged to, you know, realise that communication is a two-way street, for example.”
- “Frame it in a non-medicalised way. Do not treat children as deficits, treat them as three-dimensional human beings. Really, really ensure that parents are not being made to feel afraid, or as if they don't do this thing, if they don't start this intervention at just the right time for just the right amount, their child's life is going to not, is going to be absolutely awful. But you know what I mean. That fear mongering message.”

Messages were strongly focused on seeing children as children first (not problems to be fixed) and respecting who they are as people. Many participants raised the importance of “listening to the child” and ensuring that they have choice and input. Some participants explained that the child's goals or needs may not necessarily align with their parents' perspectives.

- “That we need to put the child first. We need to put the child first. They are a child that wants to be more... like more than anything... they want to be a child.”
- “I would love to see holistic approaches taken to intervention where again, like I mentioned just before, the child is treated like an all 3-dimensional human being that they're not made liked forced to do things and that if they're receiving quite a lot of interventions that they're still allowed to be children. They're allowed to make mistakes. They're allowed to have flaws. They're allowed to just be growing and learning like any other child. It just so happens that they as children again, have this set of things they need to work on, and other children have another set of things they might need to work on.”
- “Change the world around your child, not your child.”
- “Get down to the kids on their level, because I kind of felt like, everyone's like standing over me. Not like kneeling down, and I didn't really like notice how I felt, though. Just like doing it all. I'm just sitting there like, ‘Please stop’.”

“...it's not all about the parents, but the child. They're doing this [therapy] to the child, not just the parents.”

Many participants experienced barriers to receiving services and raised the importance of timely diagnosis and support.

Participants raised issues about the accessibility of ECI, barriers experienced, and the potential for missing out on supports. This was particularly evident in the experiences of participants who were diagnosed later than early childhood, reported misdiagnosis, or felt that their disability or needs were misunderstood. Issues around cultural barriers, language barriers, discrimination, availability and cost were discussed.

“I had a bit of a shitty time going through high school and primary school because I hadn't been properly diagnosed yet, and so I didn't receive any of the proper supports. I was given some, but I was misdiagnosed for a lot of it. So, it wasn't quite right.”

“The need that my parents were trying to have met was about me being autistic, and I wasn't diagnosed until I was 16. So, I think that that's a layer that I'd like to bring in terms of like seeing supports, for. I guess, autistic presentation that was not picked up as being autistic.”

“All the interventions support were geared towards, you know, audio verbal hearing and speaking, it was good for me, but it's not everything. I wasn't given every option.”

“I'd really like it if hospitals were a little bit more accessible because I feel like hospitals are all in the city, and it's hard for some people that live far from the city to go to their appointment.”

“If you think that there might be something different about your child. Go and look into it as soon as you can... I found it so beneficial to get diagnosed young, because it meant that I could have access to supports and things like that when I was younger.”

“So my parents said to me it's very sad because they had no money. They couldn't afford private speech therapy because it was so expensive. I remember lots of other deaf students in my class came from similar low socioeconomic families and my parents advocate to the teacher, you know, for oral education as well as sign language education.”



“[what] I wish is that the early intervention providers were not racist towards me, and were not English-, you know, -centric in their worldview and that they respected choice, and all children were different, and didn't have to fit one particular mould, or approach.”

Participants acknowledged that families need support.

Most participants spoke of the need to situate services within the context of family and to know that families need support too. They also spoke of the need to both focus on what is important to families, and to re-evaluate often to ensure desired outcomes were being met.



“Acknowledge the experience of the family members as much as the child.”



“And so one of the biggest parts of their development is the people around them, which is their family, so something that I think therapists should consider with early intervention is not just the interventions the child needs to be doing, but also like how the family can implement them, how they can like work with the family, but also make sure it's not too much for the family to cope with.”



“Just acknowledging to the families that it is tough to raise a child with a disability. Yeah, like validating them, for that is, they can get so caught up in like the child with the disability like, it's important not to lose sight of their own problems and their own experiences with that.”



“If people have a disability, I think that they should go to an early intervention centre when they are little. I loved the group setting environment where I was motivated by others there. It was fun, and my mother learned so much about how I move and how I can move my body at home. It is good to try different therapies, so you know which ones will be good for you or works for you and your family.”



“It's taking a holistic view. It's not just supporting the child. It's the child's part of a family one, because I see sometimes like often siblings or brothers and sisters that don't have that disability in this case, deafness, they feel like there's a lack of attention, or the intentions on the child with disability. The siblings are like, what about me? And how they engage as well, you know, with that deaf and disabled sibling.”

“Ensuring that the therapy is what the child and the family wants and it aligns with their, I guess their goals also ensuring that expectations are sort of set at the start of the therapy period, because sometimes, often a clinician and a family, or even the client will have different expectations of what therapy can and should look like and that is where conflict or pushback will come from.”

Participants shared perspectives on meaningful and individualised support.

Tailored, individualized and flexible approaches that are aligned with child and family values and goals were valued by participants.

“And then it needs to be re-evaluated, ongoing, not just sort of at the start and at the end it needs to be this dynamic process of evaluation of what's working and what's not working...”

“Tailoring it so that each person has a therapy plan that reflects their individual needs and not what the book says.”

“And I loved them [teachers at school] because I wanted to do that [activity].”

“It's very much a case-by-case situation and depending on the disability and depending on people's current experiences and what they're going through and what should be taken into account. But I guess, I guess really, only that's kind of like the main thing taking into account the whole, that more holistic approach, taking into account what they are going through.”







“It is good to try different therapies, so you know which ones will be good for you or works for you and your family.”

“The ones that really stick out are where the therapist would, you know, ask me what I wanted out of the session what my goals were. So, they were listening to my preferences and what I wanted to essentially get out of therapy.”

“I would say they weren't tailored to what I wanted to do. You know, it was like puzzles and putty, and I don't care about puzzles or putty when I was 5 to 8 years old.”


Participants explained that ECI should happen in everyday settings.

Some participants spoke of the need for therapy to be situated within the settings where children spend their time. The importance of relationships with peers was raised, with experiences of being removed for therapy from classroom described as times that left participants feeling 'othered', as well as lost opportunities for peer relationships. Some participants described feeling different, excluded or isolated during early childhood, while others explained that engaging in early childhood services felt normal to them and was just part of their regular routine.

-  “And make it a childhood memory, and not a therapeutic memory.”
-  “[Important things] are hanging with friends.”
-  “Probably the group stuff [preferred therapy approach] I feel like I did get a lot out of that, and I liked [that] it didn't socially kind of exclude me as much as one to one services.”
-  “I understood that it would be valuable, and it would help me with like my physical and my mental strength, but missing out on those experiences kind of brought a negative to my experience, because I just wanted my appointments to be formatted in a way where I didn't have to miss out on those subjects, and I understood the availability in the doctor's schedules and the hospitals. But I wanted, like, I hope in the future they can take into consideration that children's lives could be like, they're just as important.”
-  “I think something like just in general, is like, remember how normal this is for these, for these kids. To me it was like... I think the normalisation of kids having these therapies is important.”
-  “...and best, best case scenario, do all of those things [follow the child's lead and interests], plus do it in my home.”

Learning from those with lived experience of disability and having role models was valued by participants.

Several participants expressed the idea that listening to lived experience of disability is important for the development of the practice framework and that young children with disability would benefit from having role models with lived experience.

-  “The one thing I really wish I had all the way through that process is... I wish I had access to either adults who have disabilities or encouraged to have relationships with other children with disabilities.”

“Listen to and seek out the perspectives of people who have your child's disabilities. Realise that what they say is more important and accurate to your child's welfare than what other parents say.”

“I do remember being young, like a teenager and seeing a role model, and that was really of great benefit to me. So, I think that the younger, like the younger the child is exposed to a like role model, the better.”

2.3 Summary of findings

Participants gave strong voice to the need to respect children's rights. Many participants heard, through their childhood experiences that they were not ok, not good enough, or they were different or less. This was countered when supports/therapy were provided in everyday settings, with peers, and when the focus was on engagement and empowerment rather than the child's disability being perceived as a problem to be fixed.

They advocated that children should be children first. Therapy is about children being supported to understand themselves and how their minds and bodies work, to learn what works for them to achieve the things they want. Therapy should be fun and not anxiety producing, frightening or boring, and children should be engaged in the process. Participants spoke of the importance of being supported to form friendships, to connect with others with disability, and be protected from bullying. They wanted to know the 'why' of therapy, for therapy to be a 'normal part of life' and so not to be judged for needing it.

Nearly all the participants saw value and benefit in at least some of the therapy and supports they received, although many also spoke of aspects of the childhood intervention that were not helpful or were experienced as harmful. Thus, childhood intervention had long term impacts that could be positive or negative. For example, skills introduced in early childhood could be really useful in later life and set the scene for a good quality of life, but when experiences were negative, they could lead to distress and trauma.

Participants clearly articulated the need for early childhood interventions to be supportive of parents and the whole family. Many participants recalled and understood that their parents were overwhelmed, and worried about them, wanted what was best for them, and sought therapy and supports with the goal of achieving what was best for them. Whole of family wellbeing was seen as an important goal of early childhood intervention and supports.

While not overtly asked about, aspects of 'best practice' can be derived from these participants' experiences. Best practice for children happens when it: is focused on functional meaningful goals aligned with child and family values and based in their interests; is provided in settings with family and peers (where children spend their time); is strengths-based; supports choice and autonomy; protects children's emerging identities and sense of self; is delivered by skilled professionals who value

‘childhood’ and can explain the ‘why’ of therapy; and is set within a system that provides continuity.

2.4 Implications of findings for a best practice framework

In relation to a practice framework, messages from young people can be related to the following elements:

Aims of early childhood intervention
<ul style="list-style-type: none">• Be clear about what the aims and desired outcomes are. Goals should be meaningful for children, meet their needs, and be planned with their future in mind.• Focus on building autonomy, self-determination of children and families – help children know themselves.• Effectively support family and align aims with family and child values and goals.
Outcomes that are valued
<ul style="list-style-type: none">• Functional capacity outcomes for daily living – the “everyday life” skills that have life-long benefit.• Self-knowledge – learning how my body and mind work, how I learn, what I need to be able to take part in different settings/situations.• Social connectedness and peer relationships.• Family wellbeing and mental health of parents/carers.• Avoidance of undesirable outcomes – trauma, feelings of not being good enough or different or less than others.
Principles
<ul style="list-style-type: none">• Respect children’s rights – including the right for children to be children; the right to be listened to and believed in, to exercise choice and have input.• Do no harm and promote safety, including cultural safety. Respect children for the person they are right from the beginning, protect children from harm.• Tailor ECI to the values, goals and interests of children.• Implement ECI in everyday settings where children spend their time – with friends, in class, in interest-based settings, and normalise the experience/need for therapy or support.• Be family focused and supportive of the whole family.• Recognise that we need to adapt the environment for children and not solely focus on individual capacity building. The focus should not be on “changing the child”.

Practices

- Start with knowing the child.
- Identify need for support, and/or diagnosis and provide support early.
- Listen to children and provide opportunities for choice and input.
- Follow children's interests and provide opportunities for children to have fun.
- Work within the activities children already do (in school, at home, within interest-based activities).
- Explain the 'why', and 'what for' of therapy/supports to children and families.
- Help children learn who they are, how they learn and what they need.
- Support children to build peer relationships.
- Protect from bullying and judgements.
- Provide support that is individualised and flexible.
- Implement assessments and therapy in ways that recognise and support strengths.

2.5 Conclusion

The findings from our interviews with young people have increased our understanding of the experiences and outcomes of ECI and/or supports for those with developmental concerns, delay or disability. This understanding helps us to recognise good quality early intervention. What we have learned from this study will be combined with other perspectives that are part of our consultation (e.g., with families and service providers) as well as findings from research literature.

We aim to create a framework that helps service providers and organisations implement supports that are safe, effective, and lead to good outcomes for children and their families. The framework will also help families know what good quality early childhood intervention and/or support looks like and how to make choices for their child and family.

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4. Appendices

Appendix 1: Young people's study – Interview questions

1. Tell me a little bit about yourself and why you decided to take part in this study
2. I am interested in your experiences of intervention when you were a child. Think back to the time when you were five to eight years old.
I am wondering what you remember – if there were key experiences that 'stick in your mind'?
 - a. Prompts to explore more detail about the experiences – who was there, what was happening, why, what happened next
 - b. Why they think they remember this experience as key, how they felt about the experience/s
3. What is your earliest experience of childhood interventions?
 - a. Prompts to explore more detail about the experience, what was remembered – who was there, what was happening, why, what happened next,
 - b. Why they think they remember this situation, how they felt about the experiences
4. Can you tell me about all the different types of interventions and supports you were involved in?
 - a. Prompts about – what else? When, why
5. Were some interventions/supports better than others – can you tell me why by giving me some examples, if possible?
 - a. Prompts about what made services 'better' in your eyes?
 - b. Prompts about who was involved, role of different people and places that changes the experience
6. Are there things you would rather didn't happen?
 - a. Prompt: Can you tell me a bit more about those – what was happening, why. What would you rather had happened
7. Now you are older, what parts of your earlier childhood experiences of interventions and supports do you value now?
 - a. Prompts to understand the detail, why it is important to them now
 - b. Are there things they really don't value now that they would like to share
8. If you were talking to your "5, (or 6, 7 or 8-) year old self" – what would you want to say about the interventions and supports in childhood?
 - To yourself?
 - Parents?
 - Therapists?
9. We hope to provide guidance for interventions for children and families when the children are young. What do you think is most important for us to include?
10. Is there anything else you would like to tell us about?

Appendix 2: Characteristics of who expressed interest and who participated

Table A1: Characteristics of those expressing interest and who were interviewed

Characteristic	Number expressing interest (n = 42)	Number interviewed (n = 21)
Age group (years)		
15 - 17	6	2
18 - 21	14	10
22 - 25	10	4
26 - 30	10	5 ^a
<i>Missing</i>	2	0
Gender identity		
Female	23	11
Male	12	7
Non-binary	3	1
Other	3	2
<i>Trans</i>	1	1
<i>Genderfluid</i>	1	0
<i>Autigender/neurogender/intersex</i>	1	1
<i>Missing</i>	1	0
Other identities		
Aboriginal or Torres Strait Islander	2	1
Culturally or linguistically diverse	8	4
Member of LGBTQI+ community	14	6
Member of another community	10	6
<i>Deaf</i>	1	1
<i>Disabled</i>	4	2
<i>MAD</i>	2	1
<i>Neurodivergent</i>	2	1
<i>Other^b</i>	2	1
None indicated	17	10
Self-reported childhood-onset condition^c		
Autism	20	10
Cerebral palsy	7	5
Down syndrome	0	0

Characteristic	Number expressing interest (n = 42)	Number interviewed (n = 21)
Intellectual disability	6	3
Neurodivergent ^d	19	9
Rare disease/condition	7	4
I do not have a diagnosis	3	1
Other conditions reported	12	6
<i>Acquired Brain Injury</i>	1	1
<i>ADHD</i>	3	2
<i>CHARGE syndrome</i>	1	1
<i>Chronic Fatigue Syndrome</i>	1	1
<i>Chromosomal deletion</i>	1	1
<i>Deaf</i>	4	3
<i>Developmental Coordination Disorder</i>	1	1
<i>Dyspraxia</i>	4	4
<i>Epilepsy</i>	1	1
<i>Fibromyalgia</i>	2	1
<i>Hemiplegia</i>	1	1
<i>Hypermobility disorder</i>	1	1
<i>Juvenile Rheumatoid Arthritis</i>	1	0
<i>Learning disability</i>	3	2
<i>Mental ill health</i>	1	1
<i>Osteogenesis Imperfecta</i>	1	0
<i>Polymicrogyria</i>	0	0
<i>Post traumatic stress disorder</i>	1	0
<i>Psychosocial disability</i>	1	1
<i>Scoliosis</i>	1	0
<i>Solar urticaria</i>	1	1
Need for communication support indicated on EOI		
Yes	15	11
No	24	10 ^e
Missing	3	0
State/Territory services received		
VIC	20	11
NSW	9	3
QLD	4	3
TAS	2	2

Characteristic	Number expressing interest (<i>n</i> = 42)	Number interviewed (<i>n</i> = 21)
SA	2	2
ACT	1	0
NT	0	0
WA	0	0
<i>Missing</i>	4	0
Metropolitan/Regional services received		
Metro	11	9
Regional	8	3
<i>Missing</i>	23	9

Notes: EOI= expression of interest; number expressing interest includes those who provided contact information.

^a One participant disclosed age as 32 years during the interview, despite EOI screening. The interview data of this individual has been retained.

^b Other identities: from *n*=42: non-metropolitan experience, carer community; from *n* =21: carer community.

^c More than one condition could be selected.

^d Selection of neurodivergent and diagnosis of autism did not completely overlap.

^e One of the 10 people who indicated they did not need communication support on the EOI, indicated they did need support during the screening interview.

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