

Article

# From Tokenism to Transformation: Relational Guiding Principles for Genuine Co-Design with Young People with Disability Through a Critical Disability Lens

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## Abstract

Co-design is a term commonly used to describe involving people with lived experience in program, policy, and research design and its outcomes. However, the implementation of co-design is inconsistent due to a lack of an agreed-upon definition, framework, and set of principles for application. In this paper, the co-authors, as practising policy advocates and co-designers, aim to develop a set of guiding principles for genuine co-design with children and young people with disability in Australia. The paper first synthesises the existing Australian evidence from youth and disability scholarship, best practice approaches, and case studies of co-design projects recently undertaken where the co-authors are based at Children and Young People with Disability Australia, and then validates this evidence base through collaborative autoethnographic reflections of the co-authors' collective experience in a co-design team. Drawing together themes and insights from this process, we propose four relationally driven guiding principles for genuine co-design that can be applied in Australian as well as international settings: 1. personalised: building trust and safety over time; 2. holistic: embedding co-design across the project lifespan; 3. reflexive: considering and sharing power; and 4. inclusive: prioritising accessibility and diversity. We end with final critical reflections on addressing power relations and ableist structures in genuine co-design with children and young people with disability.

**Keywords:** ableism; Australia; belonging; co-design; collaborative autoethnography; critical disability studies; disability; human rights; identity; principles; young people; youth



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## 1. Introduction

Co-design is a term commonly used to describe a process involving people with lived experience in a program, project, policy, or research design and its outcomes (Lipton et al., 2025a). The qualifier “genuine” is often used to connote that the process has been undertaken in an authentic way that elevates the lived experience voices and perspectives. As stated by Fraser-Barbour et al. (2023, p. 19), “Projects are not co-designed by virtue of being labelled as such; rather they must afford researchers, project members, and other contributors with disability equal places in the process to decide on project and research directions and methods.” Creating project and policy outcomes that are relevant, effective, and sustainable requires meaningful engagement with those who are directly impacted by the issue being addressed. However, in practice, there is a huge variance in co-design

approaches, particularly the extent to which they involve people with lived experience in ways that afford them decision-making power (Lipton et al., 2025a). Some of this variation is due to a lack of theoretical underpinning, with the term originating in the operational context of Scandinavian product design in the 1970s (Lipton et al., 2025a). Moreover, there is strong community scepticism towards the increasing use of the term co-design in government-run consultations that are not deemed to be reflective of lived experience perspectives in their end products (Altman et al., 2025a, 2025b). Its proliferation has led to a watering-down effect, where co-design is perceived as a tokenistic or meaningless term. Emerging monikers such as “faux design” (Butler et al., 2025; Oldman et al., 2025) highlight that the term is being used to legitimise pre-determined outcomes. A key gap is the lack of an agreed-upon set of principles or guidelines that would enable consistent definition, implementation, and evaluation of co-design processes and outcomes (Lipton et al., 2025b).

Co-design with young people—especially when intersectional factors such as disability, culture, or gender are present—is particularly susceptible to these issues (Lipton et al., 2025b). The involvement of children and young people in research has historically been problematic, with parents, caregivers, or teachers used as proxies (Lipton et al., 2025b) and children being treated as commodities for adult use (Spears et al., 2021). This historical disenfranchisement has played into the tokenistic efforts to include children, particularly since their recognition in the United Nations Convention on the Rights of the Child. This is amplified for children and young people with disability, who have often been assumed to lack the agency or capacity to make their own decisions (Bates et al., 2022). Yet in the past twenty years, there has also been increasing recognition of the need to treat children not as objects to be spoken for, but as “subjects-with-voice” (Liddiard et al., 2019), recognising the innate autonomy held by children and young people, including those with disability. In the context of educational co-design, there has been a concerted effort to develop methods, such as cooperative inquiry, that seek to establish an equal partnership between children and adults in the design of technology directed at children (see Guha et al., 2013).

We are thus at a critical juncture where there is an opportunity to progress genuine co-design that centres the rights and autonomy of children and young people with disability. Sensitive to their historical disenfranchisement, in this paper, we seek to disrupt and counter the watering-down effect, or “co-design washing”, occurring in co-design with children and young people with disability. We do so from our standpoint as practising policy advocates at the national representative organisation for children and young people with disability aged 0–25 years, Children and Young People with Disability Australia (CYDA).

It is important to acknowledge upfront the political context in which we write in Australia. Despite institutionalised support for inclusion and rights through robust national and international policy and legal frameworks such as the National Disability Insurance Scheme (since 2013), Australia’s Disability Strategy 2021–2031, a Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability, and being a signatory to the United Nations Conventions on the Rights of the Child and the Rights of Persons with Disability, there is currently a generalised sense of consultation fatigue and distrust in the Australian disability community. This is in large part due to a series of rushed government disability reforms that have paid lip service to the concept of consultation and co-design but have left the disability community feeling unheard (Altman et al., 2025a, 2025b). In this context, advocating for genuinely co-designed research, policy and project design is more important than ever as a resistance against the ableist structures that generally exclude young people with disability (Nind, 2017).

### 1.1. Roadmap of the Paper

Our key contribution is to develop a set of evidence-based, relationally driven guiding principles for co-design. These principles have inductively emerged out of a qualitative methodological approach where we reviewed relevant Australian academic and industry research, best practice models, and case studies, validated by our own collaborative autoethnography (CAE) reflections from a current co-design project with young people with disability. After synthesising this evidence base, we move to a critical discussion through the lens of critical disability studies. This discussion allows for a deeper reflection on relationality by interrogating how to address power imbalance and ableist structures in conducting genuine co-design with children and young people with disability. While our principles are drawn from, and intend to address a gap in, the Australian context, they also include generalisable insights that can be tailored by researchers and practitioners conducting co-design with young people with disability across international settings.

### 1.2. Research Question and Approach

This paper's driving question is as follows: *What does it look like to genuinely co-design with young people with disability in Australia?* To answer this, we draw on the current evidence base to build a set of relationally driven guiding principles for conducting genuine co-design with children and young people with disability in Australia. We present these principles in greater detail in the discussion in Section 3 of this paper; however, in summary, they are as follows:

Principle 1: Personalised approach to foster trust and safety: Build reciprocity, ensure safety through confidentiality and transparency, and provide well-being support.

Principle 2: Holistic approach to the whole project lifespan: Embed co-design across all stages, provide adequate resourcing, and implement a flexible response to co-designer input.

Principle 3: Reflexive approach to power and agency: Undertake reflexive questioning about positionality, and provide opportunities for capacity building, co-research, co-production, and co-creation.

Principle 4: Inclusive approach to accessibility and diversity: Provide accessible materials and formats, include people from diverse backgrounds, recognise intersectionality, use creative and interactive methods, and employ flexible timing and approach.

We call these guiding principles relational because the common denominator and unifying value is relationality. Relational quality is the foundation from which trust is created, reciprocity is enabled, transparency is guaranteed, and well-being and safety are ensured. This requires time, care, and often discomfort—building input throughout a project, examining relational power dynamics through reflexivity, and tailoring the project to the diverse and intersectional strengths and needs of those involved through accessible, inclusive, and flexible methods. Relationality is not an add-on or an afterthought. It is the core defining feature of genuine co-design.

Our rationale for developing principles for genuine co-design is to provide a robust and consistent guide for researchers and practitioners conducting co-design with children and young people with disability. The principles are grounded in evidence identified across academic and industry research, best practice industry models and case studies, and validated by our own collaborative autoethnographic reflections as co-designers in a research project with young people with disability. As such, we apply an approach that is both bottom-up and critical. We prioritise grounded, bottom-up reflections and learnings from researchers of co-design as well as co-design users with lived experience. We do so to promote an authentic co-design process that moves beyond symbolic or paternalistic approaches by valuing co-designer relationships, lived experiences, and strengths. We push these learnings even further by applying a critical disability lens that interrogates ableism

and power. Through this perspective, disability is understood through social and cultural models and not as a deficit of the individual but as stemming from social and structural barriers. This critical approach is important to enable genuine participation for young people with disability based on horizontal relationships and radical accessibility, in which power and responsibility are shared, and processes are responsive to input and needs.

### 1.3. Methodology

This study undertook a two-phase qualitative methodology. In phase 1, we conducted a literature review across Australian academic and industry-based research to establish gaps in the existing body of knowledge and review current best practice models and case studies for co-designing with children and young people with disability. In phase 2, we applied a process of collaborative autoethnography (CAE) to reflect on our own recent experiences of co-design. Framing this in response to the literature, we tested and validated key themes to develop a set of guiding principles for co-design with children and young people with disability.

#### 1.3.1. Phase 1: Synthesising the Evidence Base

Synthesising the existing evidence involved an inductive and iterative stepped process through which we identified theoretical, methodological, and practical gaps in the body of knowledge on co-design with children and young people with disability in Australia.

Step 1: We established an initial set of keywords and inclusion criteria. The inclusion criteria supported the objective to develop a set of evidence-based guiding principles for co-design with children and young people with disability in Australia:

- Research based in Australia.
- Articles published in the past 5 (and up to 10 if particularly relevant) years.
- A focus on co-design methods involving children and/or young people aged 0–25 years with disability.

The keywords were: co-design, disability, children, young people, youth, Australia, peer research, collaborative research, participatory research, universal design, human-centred design, co-production.

The initial search was performed through an academic platform with a comprehensive selection of over 1000 databases, including PubMed, ProQuest, Science Direct, Scopus, and Web of Science. We searched separately for relevant grey literature on Google Scholar and three public platforms (Google, Australian Policy Online, and The Conversation).

Step 2: Due to limited results in the initial search, we added Step 2 to search more broadly for co-design relevant to “youth” and/or “disability”. This widened our search area to include adjacent and relevant fields known for co-design with young people, such as mental health and education and enabled insights from co-design conducted with people with disability more generally (not only young people with disability). With these new inclusions, we performed an additional database search, which increased the number of review articles.

Step 3: We then undertook a detailed hand search of article reference lists and journal article suggestions for additional articles in our topic area, as well as newly discovered concepts that resulted from the first two searches, such as the concept of “faux design”.

Step 4: In addition to reviewing the literature, we drew on our industry knowledge to identify examples of best practice contemporary practical co-design guides and toolkits. For consistency, our inclusion criteria mirrored those used in our literature review (Australia-based, published in the last 5–10 years, and focused on co-design with young people with disability), broadening out to include co-design guides on youth and/or disability. We prioritised examples that “demystified” co-design processes, providing practical definitions,

tools, or steps to conduct co-design. As part of this process, we also selected two case studies from our own organisation, CYDA, that had been externally presented and evaluated to reflect on the whole lifecycle of co-design through drawing on independent insights from the evaluators and co-designers at the conclusion of the projects.

### 1.3.2. Phase 2: Testing and Validating Through Collaborative Autoethnography (CAE)

Collaborative autoethnography (CAE) was selected as a primary method to reflexively bring depth to a topic in which we have firsthand professional and lived experience. While autoethnography is a method of sharing individual and social reflections through personal and reflexive storytelling, CAE involves bringing together two or more autoethnographers to engage in collective reflection of a shared experience (Spies et al., 2021). At the time of writing this article, the co-authors were concurrently co-designers themselves and were part of a research project involving a wider group of five co-designers with intersectional lived experiences. The project's topic is sensitive, thus we intentionally withhold further details to protect the privacy of the co-designers. Co-authors Tess and Shae bring lived experience as parents who are neurodivergent, with Shae also bringing experience as a parent of children with disability. Co-author Madeleine is a young person with disability. We also work together daily as colleagues in a small policy and research team at CYDA. These overlapping roles fostered a trusting rapport (a challenge for this method if not already established), enabling us to engage in the process of making sense of our shared experience through the co-design process.

CAE was intentionally planned for phase 2 to simultaneously provide an opportunity for collaborative testing and for the validation of the evidence found in phase 1. Our CAE discussion was multi-layered, beginning with an overview of the key findings of the literature and then moving on to addressing specific questions about our co-design project. This meant that we carried over general themes from phase 1 to frame how we discussed our experiences of co-design. Doing this collaboratively allowed us to refine our specific experience into wider co-design principles, conducting a reflexive process of inductive theming.

### 1.3.3. Analysis

Qualitative analysis was conducted inductively, identifying broad themes emerging across the literature, best practice models, and case studies. All sources were placed in a table documenting the citation, the inclusion criteria, and a brief annotation. We selected findings that spoke to our aim of identifying principles for co-design, focusing on key learnings and high-level principles. These provided the basis for developing codes that were then refined into broader themes via a process of tallying the most commonly occurring codes and triangulating these across our evidence base. We then tested and validated the key themes collectively through our CAE discussion. We analysed the transcript from the CAE discussion alongside the synthesised themes, translating these into the four relational principles for co-design.

### 1.4. Limitations

We recognise that, as with any research, our contribution is partial and positioned. In particular, we acknowledge the following elements that influence the article's construction and conclusions. First, we have a specific positionality as practising advocates with lived experience. This imbues us with insight, as well as policy and project priorities that direct our focus. Yet, our lived experiences cannot be taken as a proxy to represent all young people with disability. We acknowledge the diversity within disability and recommend further tailored research into the experiences of diverse cohorts. Second, and relatedly, our priorities have directed us to address an evidence gap in the Australian context. While

we have sought to create principles that are broad enough to be globally applicable and tailored to different contexts, they are still grounded in this local specificity. Third, we have chosen a qualitative methodology to provide an iterative and nuanced synthesis, honing and amplifying key evidence. This is akin to a deep dive rather than a comprehensive synthesis that would be achieved by a formalised methodology such as a systematic review or scoping study. Further research is needed to assess the full extent of the relevant literature. Finally, our evidence does not prioritise top-down program-driven approaches, such as universal design. This is a deliberate decision to centre the bottom-up experiences of users and researchers themselves. Further research could integrate the literature on top-down approaches with the bottom-up insights from this article to consider issues such as scalability.

## 2. Synthesising the Evidence Base on Co-Design with Young People with Disability in Australia

This section brings together key current evidence around co-design with young people with disability in Australia, drawing on the youth- and disability-focused scholarship published in the last 5–10 years, best practice co-design approaches, case studies from where we are based at CYDA, and our own collaborative autoethnography (CAE) reflections on being part of a current co-design team.

### 2.1. Literature on Co-Design with Children and Young People with Disability

There is a dearth of scholarship on co-design with children and young people with disability and even less in an Australian context. Analysing Lipton et al.'s (2025a) scoping review of co-design with young people in health and social science research, we identified that only 22 per cent of the reviewed articles were focused on co-design with young people with disability (11 out of 49 articles); of these, only one (Robinson et al., 2023) was Australia-based. Nevertheless, there are key insights to be gleaned from the international literature (see Lipton et al., 2025a, 2025b). First, meaningful and sustained collaboration was more likely to arise from projects that ensured continuity and consistency, such as ongoing funding and dedicated staff. Second, flexibility was important in approach, methods, and timeframes. Specifically for young people with intellectual disability, interactive and experiential modes of engagement were preferred (Kramer et al., 2013). Third, projects needed to be grounded in young people's everyday settings and connected to wider community networks, enabling young people to take on meaningful roles as co-researchers. And finally, it was crucial for researchers to be clear and transparent about the process and methods, to avoid confusion or misunderstanding. The barriers to genuine co-design included limited resources, staff capacity, and logistical challenges such as recruitment. There were also complex effects to be negotiated beyond the co-design process itself, such as when young people with disability felt empowered within the project but still restricted in their personal lives, curtailed by safeguarding in their capacity to be leaders, or experienced negative emotional impacts (Brady & Franklin, 2019). Lipton et al. (2025b) concluded that a standardised model for co-design would create clarity and go some way towards addressing the need for evaluation and upholding ethical standards.

In the Australian context, Robinson et al. (2023) offer key insights on co-design with children and young people with disability. The authors use feminist disability theory to critically reflect on the intersection of youth, disability, and family violence in the Connecting the Dots project, a partnership with Australia's National Research Organisation on Women's Safety. They acknowledge that, "children (with and without disability) understand and experience the world in different ways to adults, and adult proxies cannot always provide a robust account of their experiences and views" (p. 1194). The key strategies to

directly engage with children and young people with disability included the use of flexible, innovative, and creative methods such as drawing, mapping, picture cards, sensory activities, collage activities, and Talking Mats cards. The researchers also recognised and made space for participation at multiple stages of the project, including seeking feedback on the research analysis and findings. They worked to avoid tokenism through incorporating co-researchers in their methodology and closing the loop by including them as co-authors. To support further co-designed research, they note that it will be important to develop and strengthen supported decision-making and child ethics frameworks.

In the context of healthcare service delivery, [Mimmo et al. \(2021\)](#) developed a protocol for conducting co-design with children and young people with intellectual disability. Their model includes employing young people with lived experience of intellectual disability as co-researchers and a focus on mutual capacity building (for co-researchers as well as academics working alongside them). Acknowledging that resource-intensive time constraints could preclude participation, they proposed an adapted and accelerated experience-based co-design including arts-based methods (photo voice and body mapping), video vignettes, and remunerated interactive workshops. Accessibility was considered through the development of Easy Read materials and the inclusion of support persons in workshops.

More recently, [Carey et al. \(2025\)](#) used experience-based co-design in the development of a community cycling program for children and young people with disability. They involved children directly in several stages of the process, including photo elicitation interviews, co-design workshops with creative methods, an advisory group, and evaluation. They also involved parents and adults with disability as co-researchers. While they faced funding and time constraints that limited full involvement and contributed to entrenching power dynamics, they acknowledged these reflexively and worked flexibly to ensure maximum participation, outlining a transparent roadmap of their process and activities that provides a useful co-design blueprint for future research.

Through these examples of co-design projects with children and young people with disability, key ingredients for genuine co-design already begin to emerge. The direct involvement of children and young people with disability is vital, ideally across several stages of the project lifespan. This can be facilitated by building trusting relationships (consistency and continuity) and through flexible and creative methods. It should include transparency around the process and encompass deeper involvement and capacity building by involving young people as co-researchers or co-producers.

Yet while these existing studies provide a useful jumping-off point, in the absence of a robust body of literature specifically examining co-design with children and young people with disability in Australia, we also draw on other relevant scholarship to guide the development of our principles for genuine co-design: (1) co-design with young people more generally and (2) co-design with people with disability more generally (as distinct from children and young people with disability specifically).

### 2.1.1. Youth Co-Design Scholarship

There is a considerable body of Australia-based literature on co-design in the area of youth mental health. An evaluation of a mental health working group of young people with lived experience by [G. Y. Lee et al. \(2023\)](#) found that the gap between research and practice is a translation challenge that can be addressed by including young people across all stages of research. They noted that the limited evaluative work on inclusive research processes is “partly due to lack of transparency from research teams regarding their protocols and because of limited opportunities for long-term collaborations particularly with vulnerable populations” (p. 1713). This mirrors the findings of [Robinson et al. \(2023\)](#)’s seminal work, outlined in Section 2.1, in which they advocate for opportunities for meaningful

participation and feedback at several stages of the co-design process. In their collaborative research with young people aged 12–17 who were caring for a family member in regional Australia, [Fox et al. \(2019\)](#) similarly noted that it was important to make space to challenge the power differential inherent in research relationships through being reflexive, flexible, and responsive.

To ensure that young people with lived experience of residential mental health services were embedded in the research process, [Spies et al. \(2021\)](#) took a novel approach by employing collaborative autoethnography (CAE). They held four workshops with a steering group of young people who shared experiences, wrote down their lived narratives, read each other's contributions, and identified common themes and priorities. These CAE narratives formed the basis of the research findings in which the young people were included as co-authors. Similarly, the creative methods employed by [Hine et al. \(2024\)](#) engaged rural Australian youth experiencing parental mental health challenges in the design of short films to combat mental health stigma. Their key takeaways were the need for thoughtful and proactive planning, time and investment, and reflexivity and transparency around power dynamics. [Suzuki et al. \(2025\)](#) also worked with young people in regional Queensland to co-design justice and health priorities through arts-based methods of applied theatre and through guided workshops and video co-creation. Co-design occurred across five stages of the project, including co-creating and reviewing content. In [Juras et al.'s \(2025\)](#) research on co-designing universal mental health prevention strategies with young people aged 16–24, the young people identified four key values of participation, inclusion, synergy, and process: emphasising the need for the diversity of both older and younger individuals, accessible methods of recruitment and participation, and upholding lived experience knowledge as essential factors in genuine co-design.

A subset of this mental health scholarship focuses specifically on co-design with First Nations young people. Highlighting marginalisation and exclusion from civic processes, this research places emphasis squarely on power in human relationships, systems of oppression, colonisation, cultural bias, and processes of subjectification ([Black et al., 2022](#); [Culbong et al., 2022](#); [Wright et al., 2019](#)). There is recognition that the use of inclusive and decolonising methods can address longstanding power imbalances between First Nations communities and governments, leading to positive and more appropriate outcomes for communities. This is particularly important as a poorly defined use of co-design can entrench and reinforce gender and racial hierarchies and discrimination ([Uchidiuno et al., 2023](#)). An exemplary project is [Carter et al.'s \(2025\)](#) co-designed well-being model for remote young First Nations people in the Fitzroy River, Western Australia. Illustrating the importance of long-term relationships and place-based approaches, the research team built upon a 17-year relationship with the community, enabling deep participation and co-research and involving young people as interviewees and co-designers. Also in Western Australia, [Wright et al. \(2019\)](#) found that a key element during their three-year participatory action research Aboriginal youth mental health project was the development of trusting relationships, built on authenticity, openness, and reciprocity between co-researchers. Discussing the same project, [Culbong et al. \(2022\)](#) advocate for a more nuanced, culturally relevant approach to mental health service provision and support for young people. Developed from a culturally safe co-design process that was held and directed by Elders in partnership with young people and practitioner staff, they propose a model of care framework based on the symbol of a tree—representing strength, growth, trust, culture, and spirit. Another proposal for a co-designed online stepped care platform for the mental health of Aboriginal young people by [Black et al. \(2022\)](#) points to key elements including working with local trusted partners; using culturally appropriate methods, such as yarning circles; establishing governance

structures that share power, such as a youth advisory group; and consulting and reviewing throughout the whole process.

On the adjacent theme of safety, [Dimopoulos et al. \(2024\)](#)'s youth-led investigation revealed the power dynamics that acted as a barrier to children and young people's authentic collaboration in a family violence research project in Victoria, Australia. Young people reflected that coming into a project where "the agenda, research questions and methods were already set gave us no space to share new ideas about how the project could improve family violence services for children and young people" ([Dimopoulos et al., 2024](#), p. 375). The article culminates in three key principles to guide collaborative research: set the research agenda with children and young people and involve them in all aspects of the design; create and hold space and time for children and young people by slowing down and providing flexibility, especially when a trauma informed approach is required; and create accessible spaces that can be shared with peers and decision makers rather than separating children and young people into separate advisory groups.

Other youth-based research has focused on co-design within educational settings. [Spears et al. \(2021\)](#) applied a co-design process based on participatory design of two projects: one developing and testing four online social media marketing campaigns related to online safety, and another exploring early childhood bullying prevention. In both studies, they noted that the process was equally as important as the outputs or outcomes, and that involving them meaningfully, including sharing findings, demonstrated to children and young people that their views and decisions were respected. They found that knowledge should be generated in the spirit of mutual learning, meaning should be co-constructed to form shared understanding, children's involvement in decision making must be treated as a human right, and children must be assumed to have agency and competence. The process of co-constructing meaning enabled children to re-frame concepts to be more impactful to their cohort.

It is clear from the breadth of authorship, variety of methods, level of practical application, and broad agreement on approach that, as a domain, the youth co-design scholarship is well established. There are several key takeaways for developing principles for genuine co-design. First, a defining feature of this work is the deliberate research design that aims to distribute decision-making influence evenly between co-designers across stages, making a case for a whole lifespan approach to co-design. Second, meaningful engagement is shown to arise from embedding relationality practically, through the balance of practical supports—reasonable timelines, adequate resourcing, accessible recruitment and participation pathways—with relational approaches such as mutual learning, closing feedback loops, shared decision-making and authorship. Third, the scholarship focusing on First Nations young people demonstrates the critical importance of considering existing intersectional power dynamics and including place-based and cultural safety approaches in co-design. Finally, youth co-design emerges as a high-impact but high-input approach. It can strengthen research and policy outcomes, but only where researchers commit to transparency; culturally safe, non-tokenistic practices; and long-term partnerships that reinforce young people's agency as a right rather than a courtesy.

### 2.1.2. Disability Co-Design Scholarship

Research and policy using co-design in disability contexts in Australia is increasingly prevalent across sectors, with variations in terminology presenting a challenge to consistent tracking and evaluation. The co-design scholarship focused on the Australian disability community spans healthcare design ([Benz et al., 2024](#); [Cheek et al., 2023](#); [Harrison et al., 2025](#)), technology design ([Aplin et al., 2025](#); [Bircanin et al., 2025](#)), education ([Eghrari et al., 2025](#)), employment ([Fraser-Barbour et al., 2023](#)) and housing ([Watchorn et al., 2024](#)),

to name only a few. [Fraser-Barbour et al. \(2023\)](#) outline some of the key challenges to conducting genuine co-design with people with disability, examining shifts in power both towards and away from people with disability when co-designing a community-based employment project commissioned by the Australian government. Examining the structural and institutional conditions in which the co-design occurred, they point to a concerning trend that this paper seeks to combat: the dilution of genuine co-design and power-sharing due to planning and resourcing constraints, leading to the inclusion of people with disability too late in the process and a lack of time to develop trusted relationships. In their project, which included people with disability in the research team as well as in positions of facilitation and leadership, they found that inclusive managerial practices were crucial to share power and enable the conditions for genuine co-design. They concluded that genuine co-design requires an investment of time and money to involve people with lived experience early in the process, share power, and build trust; and creating cultural safety through “cripping” institutions and research practices to reflect on and address bias. Crip and crippling, terms re-purposed from earlier pejorative use, are now used to describe “any intentional performative intervention that dramatically reveals the taken-for-granted inequities and exclusions that shape the experience of disability” ([Ginsburg & Rapp, 2017](#), p. 82).

For their research on assistive technology (AT) use in Queensland, [Aplin et al. \(2025\)](#) used a participatory action research model incorporating co-design across the whole project lifespan. This included workshops to determine needs assessments for the technology, co-design meetings focused on solutions, and generating a set of recommendations grounded in lived experience. While they implemented a whole lifespan approach, which is an example of best practice, the limitation that was acknowledged was the lack of diversity in the co-design group. There were only two AT users, while the remaining 12 participants were policy and health professionals, thereby replicating power imbalances and the aforementioned lack of authentic involvement of people with lived experience.

[Watchorn et al. \(2024\)](#) included a lived experience researcher to examine the perspectives of stakeholders, including those with lived experience of disability who were involved in projects that co-designed public buildings in the regional Victorian city of Geelong. The findings showed that the participants’ expectations of the co-design process did not align with their experiences, and the authors suggested key principles to address this. Greater clarity around terminology and roles was proposed to rectify the limited opportunities for shared decision-making reported by the participants. The authors suggested their experience likely resulted from the dilution of the term co-design from overuse and the project’s limited consideration of power imbalances. Carefully planning inclusion across the entire lifespan of co-design projects was recommended to ensure more opportunities for genuine decision-making. Finally, including greater diversity in co-designers was suggested to ensure that a range of accessibility needs were represented.

Illustrating how co-design can be applied, [Benz et al. \(2024\)](#) detailed a co-design project for a telepractice service at a disability organisation in Perth. The project included a peer researcher (someone with lived experience of disability) from its inception. The project planning, delivery, and co-design involved experts with and without disability. Particular attention was paid to the “asymmetry of power” between team members. The methods used to address this included balancing the number of lived experience members with staff, enabling lived experience members to decide meeting times, recruiting more marginalised community members, co-facilitation with lived experience researchers, and extensive planning for disability accommodations. Practices such as providing individualised resource packs, response cards with non-verbal communication options, and relationship-building activities were undertaken to ensure the participants felt safe and valued. Although the

project was time and resource-intensive, researchers concluded these were necessary investments to prioritise the well-being of the participants with disability and for genuine co-design to occur.

The disability co-design scholarship shares similarities with the youth co-design scholarship, coming from a starting point of recognising in-built power imbalances. Many key takeaways also align with the youth scholarship, such as the importance of co-design occurring across the whole lifespan of a project, involving people with lived experience early and often, and acknowledging the significant investment needed in building trusted, safe spaces. More so than the youth scholarship, planning for access needs and accommodations was an important feature of the disability co-design projects, and the clarity and transparency established a shared understanding of meanings and concepts. Like the First Nations youth scholarship, there was also a critical approach to reflexively understanding and designing the distribution of power within the projects. Much of the disability co-design literature that was reviewed was frank about the challenges, limitations, and learnings, discussing these transparently to lay the groundwork for what could be done better. A common issue was the lack of diversity amongst co-designers and involving them too late in the process. There was broad agreement that “cripping” institutions and approaches—creating the social, environmental and cultural conditions that centre the perspectives and experiences of people with disability—is critical to ensure the time and resource investment that is required for genuine co-design.

## 2.2. Best Practice Youth and Disability Co-Design Approaches

In the Australian context, this paper has identified potential best practice approaches for co-design that have been recently developed by practitioners in the youth and disability sectors. These approaches are useful in supporting our agenda for developing a set of consistent guiding principles for co-design with children and young people with disability.

Western Sydney University’s Young and Resilient Research Centre produced the *Youth Co-Research Toolkit: Practical Guides and Resources for Researchers* (Third et al., 2023a), which includes the guide, *What is Co-Research* (Third et al., 2023b), directed specifically towards youth researchers, in collaboration with young people at the Centre for Multicultural Youth. The first toolkit is aimed at researchers wanting to engage with young people, and the second at young people to help them navigate co-research experiences. The toolkit offers extensive explanations of power, privilege, and intersectionality, including a reflective section for the reader to consider their own positionality. It offers case studies, practical training, and information about research processes, planning, ethics, and methods. The six principles of co-production listed are: shared decision-making; shared understanding; diverse knowledge and perspectives; reciprocity, mutual benefit and learning; prioritising relationships and trust; and capacity building.

South Australian disability advocacy organisation JFA Purple Orange’s *Guide to Co-Design with People with Disability* (JFA Purple Orange, 2021) is a practical guide targeted to a general audience of anyone who may wish to conduct co-design with people with disability. It starts with a quote from a co-designer that reflects the disability movement’s slogan Nothing about us without us: “co-design is a good example of by us, for us.” It then defines co-design as contra-distinct to consultation: running throughout the whole length of a project and including diverse experiences. It asks the reader to consider why they might use co-design, when it is appropriate, and what the benefits and outcomes might be. It provides tangible and detailed actions for including people with disability in co-design processes, including planning and preparing for co-design, how to run a co-design meeting, and meeting templates. The guide presents nine key principles for co-designing with people with disability: respect, diversity, equality, safety, accessibility,

commitment, authenticity, confidentiality, and acknowledgement. It is unclear if the guide was co-designed.

The University of New South Wales (UNSW)'s Disability Innovation Institute, produced two guides for doing inclusive research (Strnadová et al., 2020, 2022). The 2022 resource is a stepped guide to how to do inclusive research and co-produce knowledge with people with disability. It emphasises changing and challenging traditional asymmetrical research relationships through shared decision-making power. The 2020 guide addresses similar content to the JFA Purple Orange guide, discussing the benefits of co-design, principles, and practical steps, such as how to create (plan, budget, recruit, and pay), conduct (meetings, training, ethics, decisions, and support), and evaluate a co-produced project, and the 2022 addition contains reflective questions for users to encourage them to engage more deeply with the possible pitfalls of co-production (e.g., triggering trauma responses and methods that are not accessible). The six principles for co-production outlined are: power sharing, diversity, flexibility, accessibility, reciprocity, and transparency. The intended audience is academics and researchers, people with disability, and other stakeholders. However, there is more focus on academics as the key audience, encouraging them to be inclusive and reflective. While parts of the guide and its visual illustrations are based on participatory workshops conducted in 2019, it is not clear whether the guide has been co-designed/co-produced.

Disability Advocacy Network Australia (DANA)'s report by Baylous et al. (2025) included a lived experience research team, including people with disability, First Nations people, and young people. The purpose of the report was to consider how disability organisations can be involved in disability research in a meaningful, sustainable way. The team conducted leadership interviews, working groups, and a survey with disability sector representatives to identify and recommend good practice and what was needed for this to be able to happen. The report recommends three key needs centred on mutuality: 1. a two-way learning entailing mutual exchange between researchers and disability organisations, including listening to learn, reflexive practice, and trauma-informed research; 2. co-define, co-design, and co-create through shared decision-making, co-defining the problem, non-ableist forms of expression, and co-facilitation, as well as co-interpreting and co-authoring; and 3. distribution of resources involving fair distribution of time, money, and data, including closing the loop by sharing back with the disability community.

The National Disability Research Partnership's (NDRP) online *Co-Designing Research* hub (NDRP, 2025) features information under headings such as what is co-design, what it is not, why it matters, what skills and experiences should be on your team, what makes co-design work, and what is needed for it to be authentic. The section on what makes co-design work echoes key principles in other resources listed here: start early, build real relationships, be flexible, share power, and focus on real needs. They provide key questions to ask to assess this, including: are people with disability part of the research team or just being consulted? Is decision-making truly shared? Have you built in time for revision and changes, discussion, and relationship building? They also provide case studies and videos. It is not clear whether these have been co-designed.

The best practice youth and disability co-design examples outlined in this section provide a practical understanding of co-design approaches with this cohort. As well as offering tangible methods for co-design, they also address power and systemic oppression through information and practical tools such as reflective exercises on positionality. All list the key principles considered essential to successful co-design, with some emphasising values and others emphasising concrete practices. They converge around relational values and practices such as shared power and decision making, participatory mutual capacity

building, fair and accessible resource distribution, and centring lived experience and perspectives throughout the lifecycle of the project.

### 2.3. Case Studies

In this sub-section, we present two case studies of publicly available co-design projects from where we are based at CYDA. These are the DREAM Employment Network, and The Take Charge of Change project.

#### 2.3.1. DREAM Employment Network and SVA Employment Innovation Lab

The DREAM Employment Network aimed to support young people with disability aged 15–25 years with leadership skills, careers, and build inclusive employer capacity (CYDA, 2023). It ran from September 2023 to September 2024, and was funded by the Australian Government's Department of Social Services Disability Youth Leadership Grant and delivered by CYDA. The co-designed element comprised four co-design groups of employers and young people with disability from across Australia. Planning across three months included: the development of resources, networking events and activities and workshops, consideration of diversity and intersectionality, and employer engagement. The resources on employment and disability were co-designed and targeted towards both employers and young people with disability. The DREAM Network connected with over 224 young people with disability and 299 employers and organisations registered as members with the Network. The governance structure included members of CYDA's Youth Council and nine organisations with an interest in employment for young people with disability. Young people said they felt valued, listened to, and heard in the process (Altman & Hudson, 2025).

One of the co-designed recommendations that came out of the DREAM Employment Network was the development of a youth disability employment lab. After the DREAM Network concluded, this employment lab was created in collaboration with CYDA and Social Ventures Australia (SVA). Funded by the Australian Government's Department of Employment and Workplace Relations, the project ran from August 2024 to August 2025. The lab aimed to facilitate the employment of young people with disability in workplaces through interactive applied learning experiences for participants (employers). Elements included an initial two-day Workshop for employers, ongoing coaching sessions, and two Reconnect sessions with the involvement of "youth consultants" with lived experience of disability, providing real-time feedback and testing to employers.

Although the lab itself was not co-designed, it was responsive to youth feedback, and some of the pilot projects developed by employers "were reshaped based on honest feedback from youth consultants or strategic advice from coaches to avoid short-term placements that risked failure". In doing so, the employment lab built momentum and helped shift persistent barriers to youth employment, with the independent evaluation report finding that "the Lab positively transformed (employers') attitudes toward young people with disability and created a catalyst to develop policies and practices capable of delivering more sustainable win-win outcomes" (Q. Y. Lee et al., 2025).

A key takeaway for the principles of co-design is that there must be an opportunity for adjustment in project planning and activities to ensure that people with lived experience can genuinely shape outcomes. Flexibility and responsiveness must be built into the project design, such as the opportunities for youth consultants to review and test the employer pilots, and time set aside to meaningfully respond and incorporate feedback. This required building trusted relationships between youth consultants and employers over time. Another cornerstone feature is transparency about control over outcomes. While the lab itself was not co-designed, the basis of the idea for the lab was. There were clear

parameters within the lab about the role of people with lived experience (as consultants, not co-designers) and how much decision-making power and influence they could ultimately have over the final pilots.

### 2.3.2. Take Charge of Change Project

The Take Charge of Change (TCC) project is a collection of accessible, co-designed resources to help children and young people with disability and parents and caregivers feel more confident during major life changes, like starting school or moving into employment (CYDA, 2025). Funded by the Australian Government's Department of Social Services and delivered by CYDA, the TCC project involved 40 children and young people with disability, their parents, and caregivers across 24 co-design sessions. Across the project's lifecycle, co-designers were involved from the inception, design and planning of the resources to the production and delivery. The creation of 25 co-designed resources included 15 resources aimed at young people aged 13–25 years, 14 of which are in blog format, a podcast, a life planner, and an additional four resources for parents and caregivers of children with disability, comprising two booklets, a picture story book and a fact sheet. The co-designers shaped the creation of resources using creative mixed methods to produce accessible resources on their chosen topics. For example, the co-designers produced a picture book written by a young person with disability and illustrated by a child with disability. The picture book is made accessible in multiple formats, including a PDF version and a plain text version.

Feedback from co-designers and community members at the project launch webinar was positive, highlighting the increased credibility and trust bestowed through the co-design process (CYDA, 2025). One co-designer shared, "When resources are co-designed, I think they're just instantly more accessible and trustworthy for the audience they are intended for. There is a level of authenticity when people who have lived it are shaping the work." For another co-designer, the process meant that the resources were "more relevant and effective, and they are genuinely meeting the needs of the audience. Lived experience brings a layer of thoughtfulness and depth that you just can't get otherwise".

A key takeaway from the TCC project for the principles of co-design is that although co-design across a project lifecycle may be resource- and time-intensive, it results in more tangible and meaningful outcomes. Both co-designers quoted above emphasise that when done in a trusted way, it genuinely gives space for the input and direction of people with lived experience and that the benefits ripple beyond the lifespan of the project to deliver enduring and positive outcomes for the wider community. These resources are seen to be more relevant, effective, accessible, trustworthy, and thoughtful than resources that have not been co-designed.

## 2.4. Collaborative Autoethnography Reflections

In this section, we as co-authors collectively reflect on our own experiences of being involved in a current co-design project with diverse co-designers with disability, using the method of collaborative autoethnography (CAE). The following CAE reflections have been minimally edited for clarity.

### 2.4.1. Collaborative Autoethnographic (CAE) Debrief Setting

Tess, Shae, and Madeleine are debriefing together in an online meeting in early December 2025. The topic is the first two co-design sessions that have been held for a project they are involved in as co-designers. The debrief is scheduled to draw insights from the co-design experience that are relevant to writing this paper.

#### 2.4.2. Background to the Co-Design Project

Tess, Shae, and Madeleine are among a group of five co-designers in total. They are all wearing two hats for the co-design project—they are co-designers with lived experience and key members of the project support team who have planned the project, as well as being responsible for its outputs. The co-design sessions are facilitated by another colleague with lived experience. A trained safety and well-being officer with lived experience is available in real-time when the sessions are held to assist with any challenging content. There are three co-design sessions being held over a period of six months.

#### 2.4.3. Questions Framing the CAE Debrief

Tess provides the questions in advance for the CAE debrief, specifying that these are to loosely guide the conversation:

1. What have you valued the most about the co-design process?
2. What have you learned from being part of the process?
3. What are the limitations/improvements needed to meet best practice standards?
4. What do you think should be the guiding principles of genuine co-design?

#### 2.4.4. CAE Responses to Question 1: What Have You Valued About the Co-Design Process?

Our collective responses to Question 1 reflect on the elements needed to create a safe space, which include respect within the group but also preparation, boundary setting, and transparency. Tess starts the conversation in response to Question 1.

Tess: "I really valued how quickly a safe space was created, where we felt comfortable to discuss a sensitive topic—and that we're confident to, I wouldn't say challenge each other, but put forward different perspectives and find where the gaps are together. I think that's been a successful part, just creating that space for people to feel authentic."

Shae: "I would add, I've also really appreciated the process, and the transparency around the method, so as a co-designer, you have this awareness that even if your idea doesn't end up being used, it's captured and considered in a systematic way [using online engagement tools, meeting transcript and chat functions]. So that there's sort of this fairness across the board."

Tess: "Yeah, that we're being respectful to people's contribution by ensuring that they have a sense of it's not just going nowhere, it's being absorbed into the final output. I think the reason we have that cohesion in the group is also because we know a bit about each other's experience. So, we can feel like we're all able to meet at the same level. I'm not explaining this very well, not hierarchical, just we can have a conversation about systems and policy level change."

Shae: "We're coming in warm, not cold."

Tess: "Some of that is about the group. And some of that is about the preparation, we've done so much background work preparing people in advance."

Madeleine: "Yeah, one of the things that I have valued is the boundary setting and the work communicating before the sessions. I didn't feel at any point that I had to divulge any personal details to be a part of the co-design process. We could talk more around the system level change and bring our lived experience in but not be siloed into that."

Tess: "I think that's what I was trying to say, which is kind of lived experience expertise. That's just like the foundation for where you're drawing your expertise."

Madeleine: "Also having clear distinct areas of 'this is what you have input into' like 'this is the decision making and what you can impact in this co-design process'".

Shae: "Going back to that idea of the set-up, just seeing how critically important it is to set up the process and be transparent and spend as much time as possible on communicating even when it feels like over-communicating to co-designers about 'this

is what we did last time, this is your role, this is how we will use your information'. So at every stage they trust that their voice, opinions and concerns will be reflected in the final outcome."

#### 2.4.5. CAE Responses to Question 2: What Have You Learned from Being Part of the Process?

The debrief moves fluidly into answering Question 2, focusing on the continuous back-end work, reflexive questioning, and adaptability required:

Madeleine: "Definitely that's something around having the process in place, you do the groundwork to have more in-depth co-design and to relinquish some control around outcomes and the way that other co-designers are inputting. That links into what I've learned from the process is that it's hard, it takes continuous work and reflexivity as you go. So, having a debrief like we're currently doing and really thinking about the way that we're delivering this, but also exactly how we structure things, is all part of the process. And whether it is truly co-design is how open we have been to changing things and accepting input in the decision-making process. It takes time and you need the right people in the back-end, having someone who facilitates from a lived experience lens, and having slides and accessible communication."

Shae: "That's maybe the distinction that we can make, some of those methodological things like having slides and having a chat function, that's access and that's the important layer to accommodate young people with disability and maybe something that doesn't show up in the literature."

Tess: "You've both demonstrated it's such a complicated process and it's not just about the sessions. There's a whole scaffolding. Which is, the reflexivity of the people involved in putting it on—making sure they are operating from best practice, and doing that work in the back-end to be constantly debriefing, learning, and adapting, and taking that spirit into the co-design is really important for it to be genuine and effective. All the things around the actual co-design, and access is part of that as well."

#### 2.4.6. CAE Responses to Question 3: What Are Limitations/Improvements to Meet Best Practice Standards?

Tess continues to highlight systemic barriers to conducting genuine co-design, while Shae reflects on positionality as a way to keep those in focus:

Tess: "I think this is part of why genuine co-design is so difficult, because it doesn't sit well with the contemporary policy landscape that we work within. Or, the political cycle. Nobody has any time and everything is very reactive and everybody is outputs focused. And even us with our knowledge in theory and wanting to do this well, we have to constantly check ourselves because we have multiple competing priorities. I have to check myself and say 'stop trying to predetermine the outcome, stop trying to move to the output, let the process happen.' That is definitely a barrier to it being a widely used practice. But it doesn't mean it shouldn't be something that we're all striving for. It just means that we have to really work at it."

Shae: "And that's where I think that reflexivity is critical because when you lose sight of your own position, then you naturally will start to predetermine outcomes and the transparency gets lost, things get muddled. I wanna tip over into, just knowing that [this article] is focusing on young people, I wanted to add what I call my middle-aged white woman lens. What I've learned [from participating in and analysing co-design] is probably a deeper level of reflexivity. So, understanding my position in a non-profit in Australia with my gender, my ethnicity, skin colour, background. You know, my own ethnography. My story. And then, reading young people's responses [to me in a transcript] and having these revelations about the generation that's coming up and how spectacularly insightful

they are. Young people have this just fantastic way of cutting through and making the point. And I think it's changed me, my position and understanding in the world as a researcher and working in policy. It's also changed my practice, that has been the most profound shift—slowing down and expecting less content, but probably more insight from the outcomes of these co-design sessions with young people."

#### 2.4.7. CAE Responses to Question 4: What Do You Think Should Be the Principles of Genuine Co-Design?

Finally, Madeleine moves to focus on the core principles, emphasising the redistribution of power through co-decision making. All three unpack that this needs to happen iteratively and intentionally, incorporating reflective practices and feedback mechanisms:

Madeleine: "That reflexivity piece is very important because it's the difference between having something predetermined, or the illusion. Having these things that you need to meet or structures in place can mean that there actually is no co-decision making or input. I think that should be one of the core principles is having the power balance and decision-making power to ultimately rest with co-designers and be transparent and clear about what areas they are co-designing. Considering power and how that is shaped not only outside but also in the session. So, thinking about who is more likely to talk more or the make-up of the group is very important."

Tess: "That's such a good summary, Maddy. We've tried to do that in making sure that people who are more involved or have more power, are more towards the end of the speaking order. I think that part of giving people that power for decision-making is also that they have context to actually make the decision because sometimes you can hand people a big topic and say 'what do you want this to look like' and if they don't know what's already been done, or what the systemic levers are, then they can just tell you, 'oh, I want a pig to fly'. And it's like, well we can take that on board, but it's not actually gonna have an impact on decision-making because we can't actually make that happen."

Shae: "That's a risk, because then they're not gonna have any faith in the process. And, it goes into the set-up, having a principled approach. I feel like if we added points throughout the process of reflexively debriefing. Like, 'how has this been uncomfortable for you? How has the process changed you? How are you literally feeling in your body as a co-designer? That could address power throughout. Do you feel like your ideas are being heard?' A kind of feedback loop to deal with power, constantly understanding your own position to deal with power imbalances."

Madeleine: "I completely agree, having multiple avenues of feedback, asking people genuinely how they're finding the process and being open to changing it to fit accessibility and inclusion into the principles."

Shae: "And it needs to be done proactively. So maybe rather than saying 'here's the safety and well-being person', maybe it becomes 'we'll reach out to you following the session and we're going to ask you these questions'."

Tess: "I think it's good we focused on the process in this conversation because we are not only co-designers, but people who also run co-design coming from a research background. This is the invisible labour of co-design that is not really talked about in the public domain. It's a really important contribution, breaking down this black box of what is co-design. Part of why it's not done well is it's not unpacked at this granular level of process."

#### 2.4.8. CAE Debrief Analysis

During this CAE debrief, the co-authors of this paper touch upon several key principles from the youth and disability scholarship, as well as the best practice approaches and case studies. First, we emphasise the importance of building safe and trusted spaces to tackle

sensitive topics collaboratively in a co-design session. Building trust also involved being clear and transparent about when and how input would be incorporated. Second, moving to what we had learned, our conversation breaks down just how much invisible labour must occur in the back-end for these spaces to be genuinely realised, showing how co-design is an ongoing and resource-intensive process. Third, considering the limitations and challenges, we move into a deeper reflection about how much can get in the way of genuine co-design, from multiple priorities to policy timeframes to our own role in power dynamics. Finally, when we think about applying this to principles, we acknowledge that these have to be process-driven and relationship-driven to build in the flexibility to address reflexivity and power. We suggest that this needs to be actively built into co-design through mechanisms such as debriefing, asking critical questions, and leaving space to incorporate and adapt the project to co-designer input. Running through the CAE debrief is a wider acknowledgement that co-design is not easy, but it is worth it—it takes time, care, and constant responsiveness to enact genuinely.

### 3. Discussion: Relational Principles for Genuine Co-Design from a Critical Disability Lens

When examined as a whole, the youth and disability scholarship, best practice approaches, case studies, and CAE reflections are remarkably cohesive in their message for what is needed for genuine co-design. The focus on relationships is paramount—through building trust and providing channels for authentic participation, which involves the redistribution of power and agency. The *how* is also present—through involvement of co-designers throughout the whole project, in safe and accessible ways. Therefore, although there is no universally agreed-upon set of principles for co-design, we see the same ethos showing up across youth and disability scholarship and practice. This affords us the social and professional license to develop a set of guiding principles for genuine co-design with young people with disability.

Principle 1: Personalised approach to foster trust and safety. Take time to build strong, respectful and reciprocal relationships between co-designers. Ensure safety is maintained through confidentiality and providing well-being support. Be transparent about the process and outcomes, such as detailing which decisions are made by whom. Practice consistency and continuity.

Principle 2: Holistic approach to the whole project lifespan. Ensure that co-design is embedded at multiple stages throughout the project via adaptable and well-resourced planning and preparation. Acknowledge from the outset that allowing the project to progress more slowly than is considered “normal” is an important disruption to ableism. Adjust the project iteratively in response to co-designer suggestions and input, and ensure co-designers are aware of these changes.

Principle 3: Reflexive approach to power and agency. Undertake reflexive practice to acknowledge positionality and normativity and provide opportunities to sit within the discomfort this generates. Use power mapping methods across the lifecycle of the project. Create opportunities for upskilling and capacity building across the whole project team and include ways to enable paradigm shifts for those without lived experience. Ensure opportunities for co-research, co-production, and co-creation as outcomes that demonstrate gold-standard co-design.

Principle 4: Inclusive approach to accessibility and diversity. Provide accessible materials and formats, ensure clear communication, and include processes to agree on shared meanings and definitions. Ensure that people from diverse backgrounds and experiences can participate. Utilise creative, experiential, and interactive methods. Be flexible about timing and approach to enable accessibility.

However, more than simply listing principles, we think that it is important to directly reckon with power and normativity by framing these principles through a critical disability lens. Critical disability studies (CDS) enable us to mobilise the concepts of power and oppression in co-design with young people with disability. Contemporary thinking about CDS suggests the theory should foreground disability as a means to interrogate other forms of oppression beyond ableism and harmful normative ideologies (Goodley et al., 2019). This leads us to consider how processes such as medicalisation, adultism, racism, misogyny, classism, trans and queer phobia, interact with disability intersectionally. Centring these processes, not the bodies and minds of those deemed disabled (da Silva et al., 2025; Goodley et al., 2019), in co-design practice means questioning the authenticity of co-design approaches and methods and normative ideas about success, outcomes, and governance.

These questions are particularly pertinent in co-design contexts involving young people with disability, who experience the compounded oppression of being multiply marginalised. As CDS-informed co-designers, our intention should move beyond producing knowledge or outcomes and instead disrupt these normative processes. In a discussion about methods in disability-related scholarship, Minich (2016) argues strongly that our methods must not only aim to produce knowledge, but they should produce “knowledge in support of justice for people with stigmatised bodies and minds” (p. 3). In their recent paper, Daw Srdanovic et al. (2024) demonstrate the depth of their reflexive practice, questioning the ways in which research and scholarship are enacted, including their own methodologies (ethnography) and the paradigms from which they emerge. This leads them to note the failures and limitations of the research environment in which they are operating to absorb some of the key understandings of “crip spaces”. They describe crip spaces as those where bodies and minds are constructed as incompetent for their failure to conform to norms centred on ableness. They argue that such spaces contain a level of reflexiveness, having been forced to exist in the non-accessible, poorly funded margins, meaning they already operate in post-capitalist and post-humanist ways.

When viewing the scholarship and models we have reviewed through the lens of CDS, we critically query whether they collectively go far enough in deeply reflecting upon power and systems change. Some of the scholarship on co-design involving young people and/or people with disability demonstrates deep critical reflection on power dynamics and systems/structures of oppression and marginalisation (Black et al., 2022; Culbong et al., 2022; Fraser-Barbour et al., 2023; Fox et al., 2019; Robinson et al., 2023; Wright et al., 2019). However, while present in spirit, a limitation across the evidence is how critical reflections of power and oppression translate to ongoing practice throughout a co-design project. Given the history of oppression of children and young people and people with disability who have been rendered voiceless due to dominant paternalistic societal attitudes and narratives that infantilise them and reduce their agency (Spears et al., 2021), as well as the ineffective research and project and policy outcomes when those impacted are not included, a comprehensive and critical yet also practically applied approach to power and oppression are necessary for authentic co-design.

What might such an approach look like? This paper suggests three possible interventions. First, we argue that whilst incredibly useful, the scholarship and approaches we reviewed are currently limited by their formats being technocratic, formalised, and constrained by the system in which they operate. Some of the most effective examples we reviewed were more reflective and creative—such as training modules for young researchers, or reflective positionality statements, or scholarship co-written by young people with direct quotes, or visual illustrations. We suggest that within the set of guiding principles we have now established, co-design end products could be more indicative of the

relationships that they take to produce; they are more creative, diverse, and experimental in form and function.

Second, we recommend that co-design planning should incorporate a reflexive approach to power that includes power mapping exercises and debriefing. As an essential first step, all researchers and practitioners need to undertake a deep and thorough examination of their own and their organisation's power in relation to the young people with disability they propose to work with. What biases and norms are operating within people, projects, and institutions? How can these be made transparent and addressed in the project? This process includes normalising discomfort with one's own positionality within power dynamics.

Third, as part of a resistance against ableist structures and systems, we contend that co-design should adhere to a "slow research paradigm." This involves expressly acknowledging that co-design cannot happen effectively within short timeframes and building in time and space for this. Famaye et al. (2025), in the context of developing learning technologies, found that children's involvement was best facilitated by such a "slow research" approach, emphasising trust building, allowing room for learning and exploration, and taking the time to test and apply feedback. Slow research entails front-loading resources to ensure the careful and effective design of activities and outcomes—including adequate time budgeted to ensure that access needs are met; to prepare agendas, documents, slides and other engagement items; and to build capacity and uplift knowledge among co-designers about roles, responsibilities, and expectations to prevent conflict, upskill participants, and demonstrate the value of all members.

We acknowledge that in posing these interventions, they are not easy to implement, and in practice, they present challenges. As we recognised in our CAE reflections, the current fast-paced policy climate does not lend itself to the time and resources needed for genuine co-design. Moreover, in cases where an end product must result in a concrete output that is functional for users or that needs to be policy relevant, creative outputs or outcomes may not be appropriate. In such cases, perhaps those involved need to consider if co-design is the most suited to their aims and objectives—and if not, implement other, less intensive methods of participation, such as consultation, rather than purporting to be using co-design and therefore diluting its genuineness. However, if genuine co-design is the preferred channel of engagement, then we argue that these challenges should not prevent us from putting forward a collective agenda for what we wish it to look like. Without such an agenda, we will simply be stuck in the murky status quo, where half-hearted co-design is undertaken to legitimise predetermined outcomes. Echoing seasoned co-design expert KA from Beyond Sticky Notes (Archer, 2025), we also point out that a reframe may be in order: rather than viewing co-design as a cost-burden, it should be considered a front-loaded investment in an integral movement and set of processes, mindsets, principles, methods and tools. This ultimately saves time and money by getting it right the first time rather than perpetuating endless cycles of reforming and redoing.

#### 4. Conclusions and Future Directions

Synthesising existing scholarship and best practice models with case studies, and testing and validating these through collaborative autoethnography, this paper has sought to develop a set of guiding principles for conducting genuine co-design with children and young people with disability in Australia. As practising policy and research advocates at CYDA, co-design is part of our organisation's ethos. We are involved in co-design with children and young people with disability from several standpoints: as researchers applying for grants, as project support teams planning and preparing co-design, and as co-designers with lived experience ourselves.

Building on this evidence base, we have developed a set of four relational principles that can be applied and used by researchers, policymakers, practitioners, and young people to guide co-design with young people with disability. These principles—1. personalised: building trust and safety over time, 2. holistic: embedding co-design across the project lifespan; 3. reflexive: considering and sharing power; and 4. inclusive: prioritising accessibility and diversity—cover both the process and the intent behind genuine co-design. We hope that these principles can provide some consistency and ensure genuine co-design in the absence of a centralised framework. In the future, we recommend that a co-design framework for young people with disability be developed, with these principles as just one component. Crucially, any such co-design framework must be co-designed with young people with disability themselves.

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## Abbreviations

The following abbreviations are used in this manuscript:

CAE	Collaborative Autoethnography
CDS	Critical Disability Studies
CYDA	Children and Young People with Disability Australia
DANA	Disability Advocacy Network Australia
NDRP	National Disability Research Partnership
UN	United Nations
UNSW	University of New South Wales

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