AutismCRC

Community Forum Guidance:
Engaging with Aboriginal and Torres Strait Islander autistic peoples, autistic individuals with high and complex support needs, and their families/supporters

Final Report

Rachelle Wicks, Emma Hinze, Tara Lewis, Zheng Yen Ng, Libby Groves, Teena Caithness, Taryn Jones, David Trembath

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Rachelle Wicks
Griffith University | The Kids Research Institute Australia

Tara Lewis
Indigenous Allied Health Australia

Libby Groves
Griffith University

Taryn Jones
Griffith University

Emma Hinze
Griffith University

Zheng Yen Ng
Griffith University

Teena Caithness
Griffith University

David Trembath
The Kids Research Institute Australia

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Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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Overview

This guidance document comprises two parts: (1) guidance for engaging with Aboriginal and Torres Strait Islander autistic people and their families/supporters, and (2) guidance for engaging with autistic people with high and complex support needs, and their families/supporters. It was developed to provide practical, community informed guidance for engaging with these groups within the autistic and autism communities in ways that authentically reflect their diverse voices. Its overarching aim is to build existing knowledge and capabilities to support deep, respectful engagement with members of the autistic and autism communities who are underrepresented in research and practice development activities.

The document was developed in response to recommendations from previous Autism CRC projects, which highlighted a clear need for greater accessibility and inclusion in consultations involving marginalised groups within the autistic and autism communities. In particular, it recognises that autistic people with high and complex support needs, Aboriginal and Torres Strait Islander peoples, and their families/supporters face significant barriers to engagement given traditional engagement approaches are often inaccessible and inappropriate because they do not foster the long-term relationship building, authentic partnerships, and sense of safety necessary for respectful, ongoing collaboration. As a result, these perspectives, preferences, and needs are too often excluded from the design and implementation of practice tools, resources, and processes, perpetuating marginalisation and inequity.

The document is designed to complement, rather than replace, the existing Autism CRC Participatory and Inclusive Autism Research Practice Guides. It provides additional, tailored guidance for engaging with autistic people with high and complex support needs, Aboriginal and Torres Strait Islander autistic people, and their families/supporters.

To develop the guidance document, information was gathered through multiple research and consultation activities: environmental scans of literature on best practice in co-production with each identified group; interviews with representatives of key community and professional organisations; yarning sessions with Aboriginal and Torres Strait Islander autistic people and parents of autistic children; and individual engagements with autistic people with high and complex support needs and with parents of autistic individuals with high and complex support needs. The yarning sessions and individual engagements followed an iterative process of information sharing, analysis, and checking for understanding and accuracy, with a feedback loop approach led by convenors with lived experience who held pre-existing relationships with participants in their respective groups.

A broad cross-section of stakeholders contributed their perspectives. Input regarding individuals with high and complex support needs included the voices of three parents of autistic adolescents with high and complex support needs and two autistic adults with multiple co-occurring conditions requiring high and complex support. The yarning sessions involved engagement with four parents of autistic children and one autistic adult, all of whom are Aboriginal or Torres Strait Islanders. Organisational perspectives were gathered from nine community organisation representatives, 20 professional organisation representatives, and one autism research society representative. Of these organisational inputs, six were specific to autistic individuals with high and complex support needs, two were specific to Aboriginal and Torres Strait Islander peoples, and one related to culturally and linguistically diverse communities.

Collectively, these efforts ground the guidance document in both evidence and lived experience, with a consistent emphasis on respectful, long-term engagement that centres safety, partnership, and the authentic inclusion of those who are too often left out of decision-making and practice design.

1. Guidance for engaging with Aboriginal and Torres Strait Islander peoples

1.1 Introduction

This section brings together evidence, ethics, and lived experience to support respectful engagement with Aboriginal and Torres Strait Islander peoples, including families of autistic children. It was developed in partnership with Indigenous Allied Health Australia and led by Tara Lewis, an Iman woman with connections to Taroom Country. The term “Aboriginal and Torres Strait Islander” is used, rather than “First Nations”, to respect the language preference of Aboriginal and Torres Strait Islander communities.

The guidance is intended to be used to inform any community engagement and research activities that involve Aboriginal and Torres Strait Islander peoples, including autistic people and their families/supporters. It establishes baseline expectations for culturally responsive, respectful, ethical, and inclusive engagement and encourages consistent application across contexts.
It begins by acknowledging the history of harm created through research conducted on, rather than with, Aboriginal and Torres Strait Islander peoples. For too long, research has extracted knowledge, reinforced deficit narratives, and dismissed cultural authority. Repairing this relationship requires more than inclusion or consultation; it calls for a fundamental shift in how research and practice are conceived, governed, and enacted.

The guidance primarily reflects the stories shared by individuals from the autistic and autism communities through yarning that provide practical knowledge and experience. It was also informed by an environmental scan of research literature (see *Supporting Information* for more details), and representatives of key community and professional organisations working with Aboriginal and Torres Strait Islander autistic peoples and their families/supporters. By including research evidence and professional perspectives with the lived experiences of community members, the guidance both reflects and builds upon previously identified principles by grounding them in their stories. Its purpose is to support consultation and co-production processes that are respectful, inclusive, realistic, and specifically focused on Aboriginal and Torres Strait Islander autistic peoples.

Ultimately, this work is an act of restoration. It is about bringing research, practice, and community back into right relationship, and ensuring that future generations inherit systems that uphold dignity, cultural strength, and self-determination.

1.1.1 Research, power and harm

For many Aboriginal and Torres Strait Islander peoples, research has not been a neutral or ethical process and instead has served the colonial interests rather than community wellbeing. Historically, research was conducted on Aboriginal and Torres Strait Islander peoples, positioning Aboriginal and Torres Strait Islander Peoples as subjects to be studied in relation to whiteness rather than recognising the strengths of culture, identity, and languages. Knowledge was extracted, interpreted through Western worldviews, and used to categorise, control, and pathologize communities, which has left deep mistrust. Aboriginal and Torres Strait Islander peoples were too often treated as subjects of curiosity, their voices silenced and their ways of knowing dismissed.

In health and disability research, this harm has been compounded by deficit framings that position Aboriginal and Torres Strait Islander children and families as lacking or broken. Research has often failed to recognise that difference is not deficit, and that communication, learning, and connection are shaped by culture, Country, kinship, and language. For autistic Aboriginal and Torres Strait Islander children, this has meant being measured against Western norms and described through clinical language that erases relational and cultural strengths.

The enduring harm of these research practices is still felt today. Many families remain cautious about engaging in research or services that claim to help but instead perpetuate judgment, tokenism, and extraction. Repairing this relationship requires truth-telling about the role of research in colonisation, acknowledgement of intergenerational trauma, and a commitment to shifting power. For researchers, this means moving away from a position of authority and control and toward humility, accountability, and service. The researcher's role is not to extract data, interpret participants, or translate their cultural worlds into Western frameworks, but to hold space responsibly, listen deeply, and honour the knowledge shared.

In practice, this requires sitting in relationship rather than sitting above the community. It involves recognising that Indigenous families are not "subjects," but sovereign knowledge-holders with expertise in autism, culture, kinship, and survival. The researcher has a responsibility to protect story, not own it; to understand knowledge within context, not strip it of meaning; and to be prepared to change their own assumptions, methods, and timelines in response to what participants share.

Accountability also means recognising that harm is not only created through what researchers do, but through what they fail to do - when stories are reduced to deficits, when findings are presented for institutional benefit, or when communities are left without outcomes, reciprocity, or continued relationship. Ethical practice cannot be performative or procedural; it is a lived commitment to transparency, respect, and returning benefit to the communities who have entrusted their knowledge to the research process.

To move forward, research must become a practice of restoration, one that honours Aboriginal and Torres Strait Islander sovereignty, privileges community knowledge, and restores balance through respectful relationships and accountability to Country and people.

1.2 Guiding principles

A principles-based approach to working with Aboriginal and Torres Strait Islander peoples means grounding engagement in core values such as respect, cultural safety, reciprocity, and self-determination rather than imposing rigid processes based on Western priorities. This approach is important because it allows for flexibility to respond to diverse cultural contexts, supports genuine partnerships, and ensures decisions are guided by integrity and transparency. Prioritising shared principles founded on the views of Aboriginal and Torres Strait Islander peoples contributes to building trust and fosters meaningful, long-term relationships that honour community voices, knowledge, and culture.

The principles outlined below originate from a systematic review conducted by Butler et al. (2022) and subsequent work by Anderson et al. (2023), identified through an environmental scan of research related to co-design and co-production with Aboriginal and Torres Strait Islander peoples. The systematic review by Butler et al. (2022) identified six interrelated key themes that were then refined by Anderson et al. (2023) into principles for effective co-design in health with Aboriginal and Torres Strait Islander Peoples: (1) Aboriginal and Torres Strait Islander leadership, (2) culturally grounded approaches, (3) respect, (4) community benefit, (5) inclusive partnerships, and (6) evidence-based decision-making (refined to transparency and evaluation; see Appendix 1 for details). Together, these principles establish a foundation for ethical and transformative engagement that moves beyond consultation toward shared governance, mutual respect, and community-driven outcomes.

The principles emphasise that co-design must be Aboriginal and Torres Strait Islander-led at every stage, from defining priorities to implementation and with governance structures that uphold self-determination and community control. Culturally grounded approaches ensure that projects are shaped by Aboriginal and Torres Strait Islander worldviews, knowledges, and languages, addressing the continuing impacts of colonisation through decolonising and strengths-based methodologies. Respect is enacted through culturally safe practice, flexibility, and time for genuine relationship-building. The principles also call for clear community benefit, not just institutional gain, and for partnerships that are inclusive, reciprocal, and sustained over time. Evaluation and decision-making must draw on Aboriginal and Torres Strait Islander voices to ensure cultural rigour and accountability and transparency in all aspects of the co-design project is essential.

The six principles outlined above were also collectively reflected in the responses provided by organisation representatives from across health, community, and education sectors when asked for their perspectives on what methods are helpful and/or unhelpful when it comes to community consultation with Aboriginal and Torres Strait Islander peoples (see below). Further details about the organisation consultation can be found in the Supporting Information document.

1. Aboriginal and Torres Strait Islander leadership

Authentic leadership begins with ensuring that consultation is community-led rather than externally imposed. It must originate from or be endorsed by the community to guarantee safety and relevance. Elders and respected community members should be involved from the outset, with cultural authority and protocols guiding the process. They highlighted that representation matters: Aboriginal and Torres Strait Islander professionals and other community members should hold leadership roles within consultation teams, bringing genuine cultural authority and lived experience. Leadership also means committing to power-sharing and sustainability by embedding cultural

governance, employing Aboriginal and Torres Strait Islander people as paid team members, and planning for continuity beyond project timelines. Steering committees and advisory panels with equal voting rights, co-designed with communities, are effective models. This principle is captured in the ethos of “Nothing about us without us,” ensuring Aboriginal and Torres Strait Islander voices lead every stage from conception to evaluation.

2. Culturally grounded approach

A culturally grounded approach requires deep understanding of cultural and historical context and respect for cultural protocols. Engagement methods should reflect cultural practices, such as yarning circles and storytelling, which create safe spaces for open dialogue and relational engagement. Face-to-face interactions, particularly on Country, are essential for building trust. Communication must be simple, visual, and, where possible, translated into Aboriginal languages. Concepts like “disability” may differ from Western perceptions, so clarity and cultural sensitivity are vital. This approach demands continuous cultural competency and self-reflection from non-Indigenous participants, avoiding tokenistic or hierarchical methods that “do to” communities rather than “be with” them.

3. Respect

Respect underpins every aspect of engagement. It involves valuing the expertise, experience, and time of Aboriginal and Torres Strait Islander people by providing remuneration and practical supports such as transport assistance and childcare. Building trust requires time, continuity, and reciprocity; quick, transactional consultations undermine this foundation. Transparency about obligations, such as mandatory reporting, is essential for creating genuinely safe spaces. Disrespect is signalled by ignoring cultural protocols or failing to follow through on commitments, so processes must be flexible and responsive to community needs.

4. Benefit to community

Co-design projects must deliver tangible benefits that matter to communities, not just meet external agendas. Asking “Whose priority is this?” helps avoid tokenism and ensures that engagement serves community interests. Communities have expressed fatigue with being over-researched without seeing outcomes, so projects should focus on strengths and aspirations rather than deficits. Planning for continuity beyond project timelines is critical to avoid abrupt endings when funding ceases. Ultimately, engagement should create sustainable, meaningful outcomes valued by the community.

5. Inclusive partnerships and relationships

Effective co-design relies on genuine partnerships built on trust and cultural respect. Collaboration with Aboriginal Community Controlled Organisations, such as NACCHO, IAHA, and First Peoples Disability Network, is considered best practice. Inclusive partnerships involve establishing steering committees and advisory panels with equal voting rights and co-designing research projects with communities. Successful engagement is a relationship, not a checklist; it requires deep listening and walking alongside communities. Processes should adapt to community preferences, avoiding large impersonal forums that silence quieter voices.

6. Transparency and evaluation

Transparency must be embedded throughout the co-design process. This includes clear communication about obligations and formal accountability mechanisms such as advisory panels and steering committees. Cultural governance and co-design principles should guide planning and implementation. Evaluation should value lived experience as evidence alongside scientific data, using agreed performance indicators to maintain accountability to the community. Longer lead times, stable structures, consistent personnel, and remuneration are essential for sustaining trust and ensuring transparency.

1.3 Principle-based best practices

Anderson et al. (2023) also developed a practical framework that translates the six principles in 27 best practice actions for co-design with Aboriginal and Torres Strait Islander peoples (see Appendix 1 for details). Using an Indigenist methodology and collaborative yarning, their framework shows how these principles are enacted through relationships, governance, and process rather than applied as static steps.

Anderson et al. (2023) emphasise that effective co-design begins with Aboriginal and Torres Strait Islander leadership and cultural governance, where Aboriginal and Torres Strait Islander authority shapes decision-making from conception to evaluation. Culturally grounded practice is reflected through the use of language, story, and relational protocols that ensure cultural safety and authenticity. Respect is demonstrated through time, reciprocity, and consistent presence, while benefit to community is achieved through tangible outcomes, shared ownership, and sustainability beyond project timelines. Inclusive partnerships rely on trust and shared accountability, and transparency and evaluation ensure continuous reflection, learning, and responsiveness to community priorities.

The frameworks by Butler et al. (2022) and Anderson et al. (2023) are powerfully echoed in our own yarns with Aboriginal and Torres Strait Islander families of autistic children. Families spoke about the importance of empathy and care, of being listened to and treated with understanding, and of recognising their children's and communities' strengths. They described engagement as relational and grounded in Country, kinship, and culture, and called for professionals and researchers to relinquish power, confront racism, and design services with communities, not for them. Taken together, the principles articulated by Butler et al. (2022) and Anderson et al. (2023), alongside the lived experiences from families, highlight that genuine co-design is not a checklist of actions but a way of being. It is lived through relationships that embody integrity, accountability, and cultural respect. The recommendations for engagement that follow weave together national evidence and community voice to define what culturally responsive, strengths-based, and relational practice looks like in supporting Aboriginal and Torres Strait Islander families of autistic children.

1.4 Community-based recommendations for engagement

Based on yarning sessions with Aboriginal and Torres Strait Islander families and community members, engagement must reflect deep cultural integrity and relational accountability.
The following recommendations translate these community insights and knowledges into guiding practices that align with the overarching principles of inclusive engagement, respect, cultural grounding, Aboriginal and Torres Strait Islander leadership, community benefit, transparency, and evaluation.

1.4.1 Empathy and care

Families spoke about the importance of being met with genuine empathy, care, and understanding. Professionals and researchers must listen without judgement, create space for emotion, and approach families with compassion for the complex experiences they navigate, particularly in systems that have historically devalued Aboriginal and Torres Strait Islander knowledges, cultural strengths, identity, and ways of connecting. Families described the emotional labour of navigating these systems, often without support:

> "I feel like I didn't have anyone to talk to... it was exhausting."

Empathy is not just emotional awareness; it is an active practice of listening, believing, and holding space for families whose daily experiences are shaped by exclusion and misunderstanding.
For Aboriginal and Torres Strait Islander families of autistic children, empathy becomes a cultural practice of care: showing up with humility, recognising exhaustion, and validating struggle without pathologising it. Families described empathy as the moment they felt seen, when a practitioner's tone softened or when someone asked about their wellbeing. One parent captured the fear of judgment that makes empathy essential:

> "You're scared of saying the wrong thing and being judged."

Empathy also meant being understood without needing to explain cultural or family context, and knowing when professionals needed to step in, advocate, or protect families from harm. As one parent shared:

> "She had my back."

This kind of advocacy and shared responsibility made families feel supported rather than alone.

In research and service settings, embedding empathy means prioritising human connection over clinical process. It means slowing down, allowing time for story, and recognising that listening itself is an act of healing. One parent reminded us of the emotional and practical labour involved in even showing up:

> "It takes so much effort to even get to an appointment."

1.4.2 Strength-based approaches

Families called for professionals and researchers to engage with them and their children through a strength-based lens which recognises creativity, connection, and cultural identity rather than focusing on deficits. They described how transformative it felt when professionals centred what their children could do, who they were, and what they brought to their family and community.

One parent shared the relief of finally receiving communication that affirmed her child rather than pathologizing him:

> "Taking that strength-based approach was everything my mother's heart needed to read... because I know my son, I know he's got ADHD and autism, but seeing something that reflected his strengths instead of just the problems - that meant everything."

Another parent reflected on the broader strengths held across community and spoke about how their children are clever in their own way and how people often talk about what they can't do, but they don't see how strong they are, how much they teach us.

A strength-based approach to engagement means seeing Aboriginal and Torres Strait Islander children and families as capable, creative, relational, and culturally grounded. For many participants, strengths were visible in their children's humour, curiosity, kindness, or unique ways of relating to the world. Families rejected engagement that framed their children as "behind," "non-compliant," or "lacking," and instead emphasised cultural and relational strengths with strong kinship ties, adaptability, resilience, and joy.

Strength is also collective. Families spoke about drawing strength from community, Country, and culture. Recognising and building on these collective strengths is not an "add-on" to engagement; it is central to how safe, respectful, and culturally grounded relationships are formed. Strength-based engagement restores dignity and cultural continuity for families navigating systems that often overlook or misunderstand Aboriginal and Torres Strait Islander ways of being, knowing, and raising children.

1.4.3 Relationships and relational accountability

Relationships were repeatedly described as the core of culturally grounded practice. Trust is built through consistency, presence, and ongoing reciprocity. For participants, relationships were not a preliminary step to "get to the real work", they were the real work. Families spoke about the importance of professionals and researchers genuinely trying to connect not only with their child, but with parents, carers, and kin. Meaningful engagement meant being relatable, taking time to understand family context, and recognising that wellbeing, decision-making, and cultural knowledge sit within the whole family, not just the individual child. One participant explained the emotional and practical load that families carry:

> "It takes so much effort to even get to an appointment... you've got to be able to yarn about what's going on, otherwise it's not worth going."

One parent described how a trusted relationship with the Aboriginal Education Officer made the difference between her child engaging or shutting down:

> "He has been fundamental, going down once a day just to see how he's going... see if he needs to have a movement break... go sit in the yarning circle... then he's fully settled."

Engagement succeeds when it honours the time it takes to build trust, when professionals follow up, and when communication continues even after formal projects end. Relational accountability means understanding that families are not data points or service users; they are people, knowledge holders, and collaborators in the wellbeing of their children.

Families valued researchers and professionals who stood alongside them through conflict, advocacy, and exhaustion, those who "had their back." This kind of allyship requires courage and humility. Relational accountability also extends to researchers and institutions: being answerable to families, ensuring reciprocity, and maintaining transparency in how knowledge is shared and used.

1.4.4 Respect for our ways

Families emphasised that genuine engagement must respect Aboriginal and Torres Strait Islander ways of communicating, connecting, knowing and being, all of which are deeply connected to Country. Respect extends far beyond cultural awareness; it requires recognising how culture, place, kinship, and identity shape interactions, behaviours, meanings, and healing, and engaging with families in ways that align with, rather than disrupt, these relationships.

As participants shared:

> "You've got to listen to how people yarn, not interrupt, not rush. The silence tells you something too."

> "It's aligned with our ways... so having more respect for our ways is so important to not place those Western normative expectations on our jarjums."

Families also described how disrespect often shows up through stigma, stereotypes, and racism, when Aboriginal children's strengths, communication styles, humour, and sensory needs are pathologized or misunderstood. Respect, in the context of genuine, proper engagement, means actively challenging these harmful assumptions, seeing children, families and communities in their strengths and identities rather than through deficit-based or racialised interpretations, and recognising the protective role that culture, kinship, and Country play in children's wellbeing.

> "And especially those protective measures for our people... I think we've seen, even with the recent protests, that racism is still running rampant. I just don't understand how people can grow up like that."

Families described how Aboriginal and Torres Strait Islander ways of receiving and sharing knowledge are embedded in story, movement, humour, cultural practice, and deep listening. These ways are relational and embodied, yet they are often misread within research and service systems as disengagement or non-compliance. Respecting Aboriginal and Torres Strait Islander epistemologies means allowing knowledge to be expressed through culture, through connection, and through relational practices shaped by families and children. One parent spoke about how cultural activities created the conditions for her son to connect, participate, and make sense of the world:

> "The Aboriginal activities are exactly what his sensory system needs… movement, dance, art — stuff that's really good for him."

These ways of engaging are deeply tied to Country and to the relational worlds that our families live within. In every yarn, families spoke about the grounding, healing, and regulating power that comes from being on Country and in culturally aligned environments. This was not just about children's wellbeing in isolation, it was about how services and researchers show up, where they choose to meet Aboriginal and Torres Strait Islander peoples, and whether those environments respect identity, movement, sensory needs, and cultural connection.

Families described how being outside, creating art, dancing, and engaging in Aboriginal activities supported calm, identity, and regulation because these practices align with who our children are and how our communities make sense of the world. For Aboriginal and Torres Strait Islander peoples, engagement happens most meaningfully in spaces that honour culture, not in clinical rooms that disconnect people from their relational supports.

One parent explained it powerfully:

> "Environments are disabling…. but environments are also healing."

Respecting Country also means respecting cultural authority. Families emphasised that Elders, knowledge holders, and leaders guide relational protocols, communication norms, and the right ways to approach care and engagement in research. Meaningful engagement with Aboriginal and Torres Strait Islander peoples requires honouring these Aboriginal and Torres Strait Islander governance processes, rather than imposing Western timelines, tools, or expectations.

> "We shouldn't keep knowledge in one little package. We should be talking together, because Elders and families share that knowledge across the whole community."

Recognising Country as an active participant reframes engagement entirely: Country carries knowledge, memory, and spirit that enable healing and guide the relational work of research. When professionals create opportunities for mob to reconnect through art, language, movement, yarning, story, and outdoor play, they are not simply delivering a service, they are engaging in ways that support holistic wellbeing, where identity, environment, community, and health are inseparable.

1.4.5 Community design and Aboriginal and Torres Strait Islander leadership

Families emphasised that meaningful engagement with mob must be led by Aboriginal and Torres Strait Islander peoples themselves. Research and services cannot be effective when designed outside community, or when families are only invited in at the end to "give feedback." Genuine engagement begins with Aboriginal and Torres Strait Islander leadership and accountability back to community.

As participants shared:

> "You can't make something for us without us — it won't work."

> "If it affects a community, then that community deserves a voice."

Families described leadership as relational, grounded in community knowledge systems, and carried collectively through Elders, parents, young people, and cultural leaders. Aboriginal and Torres Strait Islander leadership is not symbolic — it shapes how spaces are created, how decisions are made, and how projects remain accountable to mob.

One participant explained this responsibility clearly:

> "Involving and collaborating with community to better create environments and spaces that incorporate our ways of doing, being, becoming."

This means engagement must be guided by cultural ways of knowing, being, and doing from the outset and not retrofitted later. Community-led design centres lived experience and cultural authority as the starting point, ensuring that processes reflect the relational practices, values, and aspirations of families.

Families also raised the question of responsibility and power in systems that continue to fail mob:

> "Is it up to them to lead that, or is it up to community to say, 'you need to fix that?'"

This reflects a broader truth: engagement is not neutral. Systems hold responsibility to relinquish power, remove barriers, and make space for Aboriginal and Torres Strait Islander leadership, not expect communities to shoulder the labour alone.

Aboriginal and Torres Strait Islander leadership in engagement is therefore governance. It means embedding Aboriginal and Torres Strait Islander voices across planning, decision-making, implementation, and evaluation. When Aboriginal and Torres Strait Islander peoples lead, projects become more culturally aligned, respectful, and sustainable, and the outcomes benefit the whole community, not just the system.

1.4.6 Relinquishing power and overcoming racism

Families were clear that meaningful engagement cannot occur in systems that continue to reproduce racism, stigma, and professional power imbalances. Engagement, they emphasised, is shaped not only by what professionals do, but also by how power circulates in education, health, disability, and research settings, and by who is allowed to lead.

Participants shared the exhaustion of navigating systems that misinterpret, judge, or silence them.

> "I feel like I didn't have anyone to talk to… it was exhausting. And when I did, I didn't always feel safe. You're scared of saying the wrong thing and being judged."

This emotional labour is intensified by structural racism, where Aboriginal children's behaviours, sensory needs, and communication styles are often misunderstood, and where families are left to carry the burden of advocacy on their own.

Families stressed that respectful engagement requires shifting power, not merely offering support. They described the need for systems to stop acting 'on' communities and to start working in genuine partnership, in ways that transfer authority, decision-making, and accountability.

> "They need to stop talking about helping us and start working with us. That's what real change looks like."

Aboriginal and Torres Strait Islander leadership emerged as a central part of this shift. Families emphasised that engagement becomes genuine only when Aboriginal and Torres Strait Islander people lead the thinking, shape the decisions, and guide the governance.

> "There needs to be that voice, and not just leadership, but the ability to have that leadership."

Relinquishing power requires institutions to embed anti-racism, cultural authority, and Aboriginal and Torres Strait Islander governance at every level. This includes how decisions are made, how programs are evaluated, and how engagement unfolds on the ground. It also means creating culturally safe and responsive environments where families can speak openly without fear, and where their expertise is recognised as essential rather than supplementary.

Together, these insights and lived experiences show that engagement is not simply a matter of good communication or inclusive practice. It is a redistribution of power and a commitment to dismantling racism. Families reminded us that genuine partnership begins with listening, believing, and acting on community authority. Structural change becomes possible when systems recognise that Aboriginal and Torres Strait Islander families are not passive recipients of services, but knowledge holders, leaders, and rights-holders who must shape every stage of the work.

1.4.7 Guidance for Culturally Safe Engagement: Cultural Responsiveness in Action

Cultural responsiveness is the foundation of cultural safety. Indigenous Allied Health Australia's Cultural Responsiveness Framework (2019) is a key resource that provides a practical, action-based approach to cultural safety that focuses on Aboriginal and Torres Strait Islander peoples.
It is built around the three core principles of Being, Knowing, and Doing, which guide what people who engage with Aboriginal and Torres Strait Islander people need to learn, how they need to act, and what steps to take to be culturally responsive. This approach combines knowledge (knowing), self-awareness and behaviour (being), and practical action (doing). It is about how we engage with people and put what we learn into practice.

Drawing on the guidance in the Framework (2019), engagement with Aboriginal and Torres Strait Islander peoples must reflect the core capabilities of self-awareness, inclusive engagement, and responsibility and accountability. For further information about the Framework and guidance for engaging with Aboriginal and Torres Strait Islander peoples, please refer to the Indigenous Allied Health Australia website (https://iaha.com.au/workforce-support/training-and-development/cultural-responsiveness-in-action-training/).

Self-awareness

Continually develop self-knowledge, including understanding of personal/organisational beliefs, assumptions, values, perceptions, attitudes and expectations, and how they impact relationships with Aboriginal and Torres Strait Islander peoples.

Knowing:

- understand your own assumptions, biases and pre-conceived ideas
- understand reflective practice and strength-based approaches.

Being:

- be open to continuous improvement and life-long learning
- be self-motivated, self-directed and self-evaluating.

Doing:

- challenge own assumptions, biases and preconceived ideas
- acknowledge own skill and knowledge in being culturally responsive.

Inclusive engagement

Honour Aboriginal and Torres Strait Islander self-determination with opportunities to lead, participate and engage in meaningful and supportive ways.

Knowing:

- understand the local communication and communication leadership protocols
- understand self-determination principles and nation building processes
- understand the importance and role of narrative and stories in developing relationships.

Being:

- be respectful of silences and actively listen
- be flexible and approachable and open to feedback.

Doing:

- build networks in Aboriginal and Torres Strait Islander communities
- learn from Aboriginal and Torres Strait Islander people in how to effectively engage
- collaborate with Aboriginal and Torres Strait Islander organisations and communities
- maintain respectful and honest relationships.

Responsibility and accountability

Take responsibility for renewing Aboriginal and Torres Strait Islander health, monitor outcomes and progress and reports to Aboriginal and Torres Strait Islander peoples.

Knowing:

- understand determinants of health and impact on Aboriginal and Torres Strait Islander peoples
- understand the importance of including Aboriginal and Torres Strait Islander concepts of cultural, social, emotional and economic wellbeing in criteria for monitoring and reporting
- understand social justice and human rights principles.

Being:

- be clear and realistic about your own contribution to addressing inequalities and the renewal process
- appreciate Aboriginal and Torres Strait Islander concepts of cultural, social, emotional and economic wellbeing and ways of maximising outcomes.

Doing:

- set targets and work in partnership with Aboriginal and Torres Strait Islander individuals, families, communities and organisations
- include cultural responsiveness goals in engaging and planning processes
- measure and update progress meaningfully to Aboriginal and Torres Strait Islander individuals, families, communities and organisations as an ongoing process.

1.5 Conclusion

Frameworks such as those articulated by Butler et al. (2022), Anderson et al. (2023) and Indigenous Allied Health Australia (2019) remind us that co-design and co-production are not simply methodological choices, but ethical relationships grounded in Aboriginal and Torres Strait Islander leadership, cultural integrity, respect, community benefit, self-awareness, inclusivity, and accountability. These principles are brought to life through the voices of families in our yarns, who described what meaningful engagement feels like when it is done properly. Families spoke about empathy and care; strength-based approaches; trust built over time; respect for culture and Country; the importance of Indigenous leadership; and the need to confront racism and relinquish power so that communities can determine what is best for their children, families and communities.

Together, these learnings affirm that culturally responsive engagement practices cannot be reduced to procedures, checklists, or policy statements. It must be lived through relationships of reciprocity, honesty, and care, and through a commitment to honouring Aboriginal and Torres Strait Islander sovereignty, knowledge, and relational ways of being. When practitioners and researchers listen deeply, embed Indigenous governance, and ground their work in respect for Country and community, systems of care begin to shift. They become environments that are not only safe, but healing, and not only inclusive, but just.

2. Guidance for engaging with autistic people with high and complex support needs and their families/supporters

2.1 Introduction

This section of the document was developed to support meaningful and ethical engagement with autistic people who require high and complex supports, along with their families and supporters. Throughout this section, the term “high and complex support needs” is used in accordance with terminology currently adopted in research and government, with the following definition applied within the project.

> Autistic individuals with high or complex support needs are those who require substantial assistance with self-care and other activities of daily living on a consistent basis across life contexts (e.g., require 24/7 care and supervision due to health, mental health, behavioural, cognitive and/or communication challenges) and are likely to have significant needs that require management within the community by families, carers, and/or disability support services.

This group includes autistic people who experience very high and ongoing support requirements across multiple areas of daily life. These needs are typically lifelong and may include the following characteristics (Commonwealth of Australia, Department of Social Services, 2024).

a) Adaptive functioning*:* Requires 24-hour access to an adult who can provide care if concerns arise, cannot be safely left alone, and needs continuous support to complete basic daily activities.
b) Daily living and personal care: Requires significant person-to-person assistance with daily living skills and personal care.
c) Communication: Experiences complex communication challenges, which may include being non-verbal, minimally verbal, or having expressive communication that is not consistently understood without support.
d) Safety and monitoring*:* Requires constant or frequent monitoring due to safety concerns such as self-injurious behaviours, pica, or absconding.
e) Permanence: Support needs are ongoing and typically lifelong.
f) Adaptive behaviour*:* Has substantial difficulties with everyday adaptive skills, including understanding and using information, relating to other people, and managing practical daily living tasks (e.g., self-care).

2.1.1 Terminology, language and representation

Clear, shared definitions are important for ensuring that engagement with autistic people requiring high and complex supports is inclusive, accurate, and respectful. They help identify who is represented, what supports are needed, and how participation should occur. Without a shared understanding, communication and behaviour may be misinterpreted as resistance or disengagement, eligibility decisions become inconsistent, and consultation processes risk excluding those with the greatest support needs. Agreed terminology also supports fair access to services and funding, helps design accessible engagement methods (for example, Easy Read materials, visual supports, and home-based consultation), and promotes language that recognises autonomy, identity, and dignity. Clear definitions further distinguish between autistic people who are part of this group and those who are not and help to clarify that autistic people who do not require high and complex supports can speak in support of, but not in place of, autistic people in this group.

There is currently no nationally agreed terminology in Australia to describe autistic people who experience profound and pervasive adaptive and functional challenges and require high and complex levels of support. Internationally, comparable groups are often referred to as autistic people with profound and multiple learning disabilities (for example, in the United Kingdom; National Health Service [NHS], 2025; PMLD Link, 2017) or those with profound autism (for example, in recent consensus work in the United States; Hughes et al., 2023; Lord et al., 2022).
As such, the term "high and complex support needs" used within the project includes autistic people who experience multiple and profound disabilities and require continuous, multi-domain support, sometimes in the absence of co-occurring intellectual or physical disability.

Autistic people in this group are largely underrepresented in research, consultation, and policy processes (Commonwealth of Australia, Department of Social Services, 2024; Commonwealth of Australia, Department of Health and Aged Care, 2025; den Houting, 2021; Gibbs et al., 2024; Karavolos et al., 2024). Engagement is often logistically, cognitively, and emotionally complex.
As a result, decisions about their lives are frequently informed by people who do not share their experiences, rather than by their own perspectives and those of the people who know them best (den Houting, 2021; Jivray et al., 2014; Nicolaidis, 2012).

However, autistic people requiring high and complex supports often show strong abilities for connection, curiosity, and participation when engagement is organised around their interests and communication strengths (Courchesne et al., 2020). Many value being recognised and included as contributors and enjoy opportunities to take part in shared activities and decision-making.
When facilitators and supporters pay close attention to their communication and preferences, build on deep and focused interests, and allow time for familiarity, autistic people in this group can meaningfully participate in joint activities, express choices, and influence the direction of work in ways that are observable and understandable. Their participation helps clarify what makes environments workable, what contributes to distress, and which changes are most likely to improve daily life.

2.1.2 Family and organisation perspectives on terminology

Families and organisational representatives described the group using several overlapping terms, such as referring to their family members or service users as *autistic people with multiple and profound disabilities*, as *having very high and complex support needs*, or as having *profound autism*. They felt that the generic term *high and complex supports* did not adequately express the intensity and 24-hour nature of daily support requirements. Autistic people in this group were described as having minimal or no functional speech, needing continuous or near continuous supervision, and being unable to be safely left alone. Consequently, families saw themselves not only as caregivers but also as advocates, coordinators, and protectors, and reported that engagement that overlooks these responsibilities and risks felt disconnected from reality.

Organisations and families reported that many feel excluded from mainstream autism discourse, which they perceived as often focusing on autistic people who are more independent, do not have an intellectual disability, and/or can speak fluently. Parents and carers described feeling judged for using terms such as profound autism and experiencing language policing that invalidates how they communicate the extent of their autistic family member's disabilities and support needs. They noted that these terms are often necessary in clinical, emergency, and service contexts to signal serious risk and support needs, and that being asked to modify their language without recognition of their family member's circumstances contributed to cynicism, mistrust, and a sense that their realities were unwelcome in community, clinical, and policy conversations.

2.1.3 Purpose and scope of this guidance

This guidance combines practical knowledge from autistic adults who require high and complex supports, parents of autistic young people advocating on their behalf, and key community and professional organisations working closely with this group. It is also informed by an environmental scan of the literature on co-production and engagement across disability and autism, undertaken because there is very little published guidance that focuses specifically on autistic people who require high and complex supports (see *Supporting Information* for more details). By integrating disability-focused and autism-focused co-production evidence with lived and practice-based knowledge, the guidance adapts existing principles to the realities of this group. Its purpose is to support consultation and co-production processes that are respectful, inclusive, realistic, and specifically focused on autistic people with very high and complex support needs, rather than assuming that guidance designed for the broader autistic population is sufficient.

In this section, the term "this group" refers to autistic people who require high and complex supports and their families and supporters. This includes autistic people who may have multiple and profound disabilities, who require continuous or near continuous assistance with personal, behavioural, and health-related needs, and who are unable to live independently. The guidance is intended for use in community engagement and research activities that involve autistic people who require high and complex supports and their families/supporters. It establishes baseline expectations for ethical and inclusive engagement and encourages consistent application across contexts. While approaches will need to be adapted to individual circumstances and projects, the underlying principles of accessibility, respect, and representation should be upheld in all cases.

2.1.4 Previous family and organisation consultation experiences

Families and organisations also described the cumulative emotional toll of providing intensive care in high-risk situations involving their loved one. Parents and supporters reported experiences suggestive of trauma, such as long-term hypervigilance, repeated crises, witnessing severe self-injury and medical emergencies, and very limited opportunities for rest or privacy. These conditions influence how, when, and to what extent families can participate in consultations or co-production activities. For many, engagement is an additional burden layered on top of already overwhelming responsibilities, and their capacity to participate fluctuates with the immediate safety and care needs of their autistic family member. In practice, engagement with autistic people in this group is closely linked to engagement with those who support them in daily life.

> "You do not have that person without their family."

Practical care demands were a significant barrier to participation. Attending events or meetings in person was often impossible due to supervision needs, limited respite, and transportation challenges. Families considered low-barrier options such as live streaming, recordings, and flexible arrangements that allow parents and supporters to take turns attending as essential and stressed the importance of consultations that align with existing routines and supports.

Families and organisations emphasised that engagement is most effective when it is clear, specific, and directly relevant to improving the daily lives and support needs of autistic people in this group, and to sustaining those who support them. Examples included navigating the National Disability Insurance Scheme (NDIS) and other service systems, managing safety and behavioural crises, planning for housing and support that promotes quality of life, and preparing for ageing and future care arrangements. Conversely, they were frustrated by forums focused primarily on abstract debate or highly emotive personal stories when these did not also create space to address issues such as severe self-injury, medical complexity, or the demands of ongoing supervision. When consultations were structured in this way, families felt that both their autistic family member's experiences and the realities of multiple and profound disabilities were overlooked, and that discussions did not address the questions they were trying to resolve in supporting their autistic family member to have a safer and more enjoyable life.

Families were often described as exhausted, yet they still participate because they want to improve outcomes for their autistic family members and contribute to systemic change. They were wary of one-off consultations that extract information without providing feedback, support, or visible follow-through, and they wanted to see tangible results rather than being consulted and then forgotten.

Participants preferred consultation environments that are safe, trauma-informed, culturally respectful, and explicitly welcoming of families of autistic people with multiple and profound disabilities. They wanted to "tell it how it is", including through real life examples or videos that show how their autistic family member experiences daily life, distress, and support needs, to build genuine understanding rather than sanitised narratives. They identified financial compensation, childcare, and flexible scheduling as basic conditions for participation, not incentives. Overall, feedback indicated that engagement with this group must be respectful and practically focused. Families carry significant responsibility and expertise, so their knowledge is central to understanding what meaningful and ethical engagement looks like for autistic people who require high and complex supports. Meaningful engagement, therefore, requires avoiding large, generic forums that feel unsafe or irrelevant, prioritising flexible, low-barrier participation, and recognising family input as

essential and legitimate, particularly when the autistic person cannot participate directly or independently.

2.1.5 Co-production in this guidance

Co-production is a widely used approach that allows people to work together in partnership with service providers and other stakeholders in health and social care, community, education, research, and policy and practice contexts (Albert et al., 2023; Bandola-Gill et al., 2023; MacLachlan et al., 2024; Masterson et al., 2022; Porter, 2012; Social Care Institute for Excellence, 2022;). In this document, *co-production* is used as an umbrella term that includes consultation, co-design, and other participatory methods. The intent is to encourage collaboration at all stages, from identifying priorities to developing outcomes, while recognising the practical limits that may exist when engaging with autistic people who require high and complex support.

2.1.6 Clarifying involvement and influence

In this guidance, "involvement" and "influence" are intentionally distinguished so that participation by autistic people requiring high and complex supports and their families/supporters is meaningful rather than tokenistic.

Influence refers to having a genuine role in shaping decisions, priorities, and outcomes. This includes providing input that may lead to changes in project goals, questions, methods, materials, or interpretations, or sharing or delegating decision-making power in agreed areas. Influence also requires that autistic people and families/supporters can see how their contributions have affected results, even when not all suggestions are adopted.

Tokenistic participation occurs when autistic people and families/supporters are asked to be involved but have little or no real influence. Examples include requesting stories or feedback that are not genuinely considered, inviting people to meetings without accessible information or real decision-making opportunities, or using their presence to claim co-design or co-production without sharing power.

To reduce the risk of tokenism, each role within a project should have a clearly defined level of involvement and influence. Not every autistic person, family member, or supporter will participate in every stage or decision. However, when they do participate, the potential influence of their role should be clear, realistic, and respected in practice, with transparent explanations given when limits are reached.

2.1.7 Method and future development

This guidance was developed through in-depth engagement with a small group of autistic adults who require high and complex supports, parents of autistic young people with high and complex support needs, adults advocating on their behalf, and representatives from key community and professional organisations. The development process drew on an extensive literature review and on key national documents, including the National Autism Strategy 2025-2031 (Commonwealth of Australia, Department of Social Services, 2024), the National Roadmap to Improve the Health and Mental Health of Autistic People 2025–2035 (Commonwealth of Australia, Department of Health and Aged Care, 2025), Autism CRC's Participatory and Inclusive Autism Research Practice Guides (den Houting, 2021), and the Parents and Carers of Autistic People Focus Group Report (Karovolos

et al., 2024). Working closely with a small participant group allowed the project team to spend time that is necessary for building trust, accommodating communication and access needs, and adapting the process in response to recruitment and engagement difficulties; these experiences reflect the broader barriers to involving this group and directly informed the engagement strategies outlined in this guidance.

While this guidance is grounded in a focused set of voices and experiences, the principles and approaches are intended to be transferable and to provide a foundation for future work. Further consultation with autistic people requiring high and complex supports, their families and supporters, and service providers can build on this foundation as a starting point, refine the guidance for different contexts, and extend it to additional communities and settings.

2.2 Guiding principles

Co-production with autistic people with high and complex support needs and their families/supporters should be founded upon the following knowledge and guided by the following Foundation and Principles:

Knowledge as the foundation for ethical and respectful engagement

Authentic engagement with autistic people requiring high and complex supports begins with knowledge. Knowledge of their experiences, communication styles and support contexts, developed in partnership with autistic people, their families and trusted supporters, provides the basis for ethical, respectful and meaningful practice. This shared understanding enables authentic connection and more inclusive, responsive decision-making. Recognising that this knowledge develops over time, through continual learning, attention to context, and ongoing relationships, helps maintain accuracy in interpretation and action, and supports accountability and respect across the course of engagement.

Principle 1: Inclusive and respectful representation

Inclusive co-production means that autistic people with high and complex support needs, and their families/supporters, are at the centre of engagement and decision-making. Other autistic people and allies who are not directly involved in the person's daily support can play an important role in advocating for this group, but they cannot speak on their behalf or replace their direct participation or the involvement of those who know them well. Respectful representation involves using language and processes that recognise diversity in communication, culture, and identity, and that avoid limiting engagement only to those who can participate in conventional ways.

Principle 2: Rights, autonomy and safety

Co-production must uphold the rights, dignity, and autonomy of autistic people requiring high and complex supports, and protect them from psychological, physical, and relational harm. Ethical reflexivity is needed throughout the process to ensure that participation remains voluntary, safe, and aligned with each person's preferences and goals.

Principle 3: Relationships and trust

Effective engagement with autistic people who require high and complex supports relies on relationships that build trust, emotional safety, and familiarity over time, providing a foundation for authentic communication and participation throughout the project.

Principle 4: Accessibility and flexibility

Accessible co-production designs participation so that autistic people with high and complex support needs and their families/supporters can engage in ways that fit their sensory, communication, cognitive, emotional, and physical needs. Flexibility in timing, format, environment, and roles is essential to respond to changes in capacity and context over time, and to ensure that involvement remains feasible, meaningful and sustainable.

Principle 5: Power sharing and collective ownership

Power sharing requires explicit attention to how influence and decision-making operate, and a deliberate commitment to redistribute them so that autistic people and the people they trust can shape priorities, processes, and outcomes. Collective ownership means that decisions are not made about an autistic person without meaningful involvement from them and, where relevant, from families, support workers, and trusted advocates.

Principle 6: Valuing expertise and mutual benefit

Valuing expertise and mutual benefit in co-production means recognising lived experience, family knowledge, practice wisdom, and professional expertise as equally important forms of knowledge. Further, making roles and expectations explicit and ensuring that all contributors receive recognition, support, and opportunities to build confidence and skills so that participation is mutually beneficial rather than extractive.

Principle 7: Transparency and accountability

Effective co-production is grounded in transparent communication about aims, processes, limits, and decision-making, together with clear accountability for how contributions from autistic people, families and supporters can and will inform outcomes.

2.3 Principle-based Best Practices

A principle-based approach to co-production with autistic people with high and complex support needs and their families/supporters involves the following actions.

Knowledge as the foundation for ethical and respectful engagement

In practice, this means:

- Develop specific knowledge about autism and high and complex support needs, including communication differences, sensory processing, co-occurring conditions, learning profiles, and emotion regulation, with particular focus on co-occurring intellectual disability and high dependence on formal supports and services.
- Understanding each autistic person's daily life and support network, including family, supporters, cultural background, and practical limitations, and applying this knowledge to create meaningful and respectful ways for them to participate.
- Treating the knowledge of autistic individuals and family members/supporters as key sources for understanding priorities, communication, and safety, and using what they share to challenge assumptions, refine interpretations, and adapt plans.
- Preparing beforehand instead of relying solely on "on the floor" learning, including developing a practical understanding of relevant service systems (such as NDIS, mental health pathways, eligibility criteria, and common barriers), so that discussions are based on actual constraints and opportunities.

- Engaging in ongoing, reflective learning by viewing knowledge as provisional, leveraging feedback and supervision to spot knowledge gaps or misunderstandings, and making visible adjustments in planning, communication, and decision-making throughout the project.

Practical strategies for applying this principle in recruitment, preparation, and early engagement are further detailed in Stage 2 and 3 of the Recommendations for Engagement chapter.

Principle 1: Inclusive and respectful representation

In practice, this means:

- Making roles and advocacy boundaries explicit, including being clear that autistic people who do not require high and complex supports, and other allies who are not directly involved in the person's daily support, can speak in support of this group but are not proxies for their perspectives or for the perspectives of the families and supporters who know them well.
- Actively engaging autistic people with very high and complex support needs who rarely receive invitations, by recruiting through accessible, community-based networks and treating proactive outreach as core work rather than an optional extra.
- Including relational and supported forms of participation as legitimate, recognising that supporters, family members, and workers directly involved in daily care can provide valid representational input when direct participation is not possible, while ensuring that decisions remain grounded in the autistic person's preferences, rights, and best interests.
- Designing processes that prevent de facto exclusion, for example, by allowing slower processing, shorter or more frequent contacts, alternative communication methods, and additional practical supports, so that participation is not limited to those who can manage standard formats.
- Treating all communication methods as valid for autistic people who need high and complex supports, including speech, AAC, behaviour, and relational cues, and reflecting personal preferences in facilitation, feedback, and documentation of contributions.
- Using respectful, transparent, and responsive language, including recognising that terminology preferences may differ, avoiding deficit focused or homogenising terminology, and, where possible, adjusting language to reflect how autistic people who need high and complex supports and their families describe themselves, while being transparent about why and when differing preferences cannot all be accommodated.
- Ensuring that representations reflect lived realities by prioritising topics identified by autistic people and families, and by involving them in checking whether summaries and messages accurately convey their experiences and perspectives.

Recruitment strategies, representation practices, and multi-perspective approaches are further developed in Stage 1 and Stages 2–4 of the *Recommendations for engagement* section.

Principle 2: Rights, autonomy, and safety

In practice, this means:

- Embedding a rights-based and trauma-informed foundation that explicitly prioritises autonomy, dignity, and safety, and that views previous negative experiences with services as common rather than exceptional.
- Support informed, voluntary, and ongoing consent through accessible information, regular checks that people want to continue, and clear assurances that pausing or withdrawing is okay and will not affect supports or future opportunities.
- Preventing psychological and physical harm by identifying likely risks (such as sensory overload, interpersonal triggers, trauma cues, abuse or neglect risks) and modifying locations, formats, pacing, and communication in advance to ensure the process does not cause harm.
- Using trusted supporters and supported communication methods that extend, rather than replace, the autistic person's agency, including recognising non-speaking, behavioural, and bodily communication as valid and verifying interpretations whenever possible.
- Creating safe feedback channels that enable autistic people and supporters to raise concerns, disagree, or critique processes without fear of criticism, exclusion, or missing out on opportunities, and responding to this feedback promptly and with clear visible change (where required).
- Balancing safety with autonomy by collaborating with autistic people and trusted supporters to determine what feels safe enough, which risks are acceptable, and what safeguards are preferred, rather than defaulting to restrictive or paternalistic practices.

Practical safety planning, consent processes, and exit options that operationalise this principle are outlined in Stage 2 and Stage 4 of the *Recommendations for engagement* section.

Principle 3: Relationships and trust

In practice, this means:

- Spend time building rapport and familiarity before seeking formal input, including repeated, low-pressure contact so autistic people and supporters can become comfortable with people, places, and routines.
- Providing consistent, predictable contact and communication through stable roles, clear expectations, and reliable follow-through on commitments, including clearly explaining any changes in personnel, plans, or timelines.
- Communicating in ways that feel natural and supportive for autistic people, including supported or co-constructed communication, non-speaking and embodied communication, and preferred modes such as visual, audio, written, or AAC-based communication.
- Fostering balanced and inclusive discussion by observing group dynamics, providing diverse ways for participation both within and outside meetings, and preventing subtle exclusion or dominance by certain voices.
- Fostering confidence, recognition, and continuity by acknowledging contributions, providing tangible recognition when appropriate, and, where possible, maintaining relationships across related projects so trust does not need to be rebuilt from scratch each time.

- Continuously reflect on how your communication style, assumptions, expectations, and positional power influence trust and participation, and adapt your approach when it restricts agency or safety.

Practical methods for initial contact, establishing rapport, and maintaining ongoing relationships are outlined in Stage 3 and Stage 4 of the *Recommendations for engagement* section.

Principle 4: Accessibility and flexibility

In practice, this means:

- Designing accessibility into projects from the start by including accessibility needs in budgets, timelines, staffing, and technology choices, rather than treating them as optional adjustments.
- Providing accessible preparatory information and consent processes in various formats, using plain language and multimodal supports that match autistic people's and supporters' communication needs/preferences, and allowing time for processing and decision-making.
- Offering multiple, flexible participation options (for example, in person, online, synchronous, asynchronous, low-tech, written, visual, recorded) so autistic people and supporters can select those that suit their regulation, communication, and support needs.
- Supporting diverse and supported communication by aligning tools and formats with each person's strengths, treating AAC, assisted, and relational communication as equal to spoken and written language, and recognising gestures, behaviours, and autonomic cues as meaningful.
- Adapting environments, contexts, and practical supports to reduce barriers, including meeting in familiar settings where appropriate, providing sensory supports and regulation options, and addressing practical barriers such as transport, respite, and scheduling.
- Resourcing, training, and regularly reviewing accessibility over time, including staff training in respectful, autism-informed communication that recognises diverse communication styles, and incorporating feedback mechanisms to adapt supports as needs evolve.

Concrete strategies for formats, environments, pacing, and practical supports are detailed in Stage 2 and Stage 4 of the *Recommendations for engagement* section.

Principle 5: Power sharing and collective ownership

In practice, this means:

- Making decision roles and influence clear by explicitly defining who makes which decisions, what input is sought from autistic people and supporters, and how different forms of expertise will shape outcomes, using accessible visual or written summaries.
- Develop shared decision-making and leadership frameworks that enable autistic people and trusted supporters to take the lead or share leadership roles where desired, with suitable support, mentoring, and flexibility in roles.
- Actively reviewing and addressing power imbalances by examining whose voices influence decisions, which perspectives are absent, and how professional roles and organisational authority may dominate, then adjusting facilitation and decision pathways accordingly.
- Recognising when you hold power and practising letting it go by intentionally creating space for autistic people and supporters to set priorities, question assumptions, and influence

methods and interpretations, all while balancing safety requirements with respect for autonomy.

- Prioritising autistic needs by using structured feedback and reflection ensures that topics and decisions reflect autistic and family priorities. Providing clear reasons when proposals cannot be adopted and offering alternative options where possible.
- Linking recognition and feedback to shared ownership by making visible how contributions have altered language, plans, and decisions, and by providing appropriate recognition according to agreed roles and contributions.

Specific tools for mapping influence, managing disagreements, and recording minority views are provided in Stage 1, Stage 4 and Stage 5 of the *Recommendations for engagement* section.

Principle 6: Valuing expertise and mutual benefit

In practice, this means:

- Making roles and all forms of expertise clear by identifying who is involved, including autistic people, families, support workers, and other supporters, and explaining how lived, relational, practice, and professional knowledge will each contribute to decisions.
- Recognising lived, relational, and professional knowledge as essential and complementary, especially for autistic people whose communication may be limited, emerging, or supported, and ensuring that supporter knowledge is used to uphold the autistic person's perspective rather than replace it.
- Involving families and trusted supporters as valid representatives when direct participation isn't possible, with clear expectations that representation reflects the person's expressed wishes and best interests, and that direct or supported participation is used whenever feasible.
- Providing fair, flexible, and visible recognition through payment, authorship, co-presentation, accreditation, certificates, written acknowledgements, or other forms of credit that align with people's roles and preferences, including for families and supporters whose contributions have often been overlooked.
- Building capability and confidence for meaningful contribution by providing mentoring, orientation, and scaffolded learning opportunities, and by adjusting expectations to suit each person's strengths, interests, and support needs over time.
- Ensuring reciprocity and continuity across projects so that autistic people and supporters benefit clearly from their involvement, and so that relationships and learning are not repeatedly restarted without considering past contributions.

Detailed guidance on team composition, co-facilitation, payment and recognition, and support for co-researchers and advisers is provided in Stage 2 and Stage 6 of the *Recommendations for engagement* section.

Principle 7: Transparency and accountability

In practice, this means:

- Establish clear communication expectations from the start about the information participants will receive, including how often, through which channels, and at what level of detail, using accessible formats and timing.
- Making roles, decision pathways, and constraints clear so autistic people, families, and supporters can easily see who makes decisions, how their input will be used, and which elements are negotiable or limited by policy, ethics, or legislation.
- Communicating openly and consistently, including when plans change, by providing regular, accurate updates about progress, next steps, and emerging constraints, and explaining shifts in clear, specific language.
- Making feedback and influence visible by demonstrating how contributions have shaped priorities, wording, methods, or decisions, and by offering clear, respectful reasons when suggestions have not or cannot be adopted.
- Recognising contributions clearly and appropriately through transparent processes for payment, authorship, acknowledgements, certificates, or personalised feedback, with criteria and timelines explained beforehand and revisited as needed.
- Providing procedural and administrative clarity, including details about payments, documentation, response times, scheduling, cancellations, and rescheduling, so that practical processes themselves demonstrate accountable practice.
- Using mutual reflection to monitor and strengthen transparency, inviting autistic people, families, supporters, and researchers to comment on where processes feel unclear, symbolic, or extractive, and using this feedback to refine communication and decision-making practices.

Specific closure, “closing the loop”, and documentation practices that operationalise this principle are detailed in Stage 4 and Stage 6 of the *Recommendations for engagement* section.

2.4 Recommendations for engagement

The following sections set out detailed recommendations, explanations, rationales, and implementation options organised into six key engagement stages. These stages follow the typical sequence of an engagement process, from initial planning through to follow-up and review. They are intended as a practical guide that can be adapted to different contexts, with each step highlighting specific considerations for engaging autistic people who require high and complex supports and their families/supporters. A quick guide summary is included in Appendix 3.

Stage 1. Define the purpose and plan

This stage applies when an engagement activity is first being considered. It includes clarifying the purpose and rationale, examining feasibility and risks, deciding whether engagement is appropriate, and identifying potential communities or participants. This step precedes any formal preparation or contact with autistic people and families.

Foundational commitments to participation

- Start from the assumption that autistic people requiring high and complex supports can meaningfully participate in engagement when it is accessible, inviting, and adequately supported, rather than presuming disinterest or incapacity.
- Intentionally invite people with lived experience, including autistic people requiring high and complex supports and their families/supporters, from the earliest stages of planning, rather than waiting until decisions are already made.
- Position autistic people requiring high and complex supports and their families as core contributors whose perspectives are necessary, not as “too hard to include” or optional additions to broader consultation.
- Design engagement so their participation is feasible and meaningful, not merely symbolic or a box-ticking exercise, even when this requires more time and resources than typical stakeholder processes.
- Make it clear that participation at any level is voluntary. Autistic people and families can choose whether and how to be involved, and saying no or changing their level of involvement does not reduce the value of their contributions.

> “It's so heterogeneous that it needs to be acknowledged that there's very different groups with different needs.” (Family member)

> “At the outset in the planning stages of community consultation, it is very important I think at that beginning stage to particularly think about that group are very diverse individuals as well… not an homogeneous group and to think about and to have very clear plans about how to engage them and include them in a consultation.” (Organisation representative)

Clarifying purpose, involvement, and influence

This step focuses on defining why engagement is occurring, which decisions are open to change, and how autistic people requiring high and complex supports and their families/supporters will participate in, and influence, those decisions.

- Define the purpose of the engagement, specify which decisions are genuinely open to change, and identify where autistic people requiring high and complex supports and their families/supporters will be involved and where they will influence decisions. Record this in plain language and share it with them at the outset.
- Decide the level of participation you can commit to for each activity (for example, Inform, Consult, Involve, Collaborate, Empower or Co-Lead), and make explicit what this means for the involvement and influence of autistic people requiring high and complex supports and their families/supporters.
- Record the planned level of participation in plain language and explain to autistic people and families what involvement is expected, what influence they will have, where decisions will be made, what is out of scope, and what the activity is mainly for (for example, to share information, gather views, work together on design, or support shared decision making).
- For each engagement activity, identify its primary level of participation and ensure expectations, time commitments, and decision-making processes are consistent with that level of involvement and with the agreed influence of autistic people and families.
- Use a recognised participation framework or continuum (for example, the IAP2 Spectrum of Public Participation, a ladder of participation, or an Inform → Consult → Involve → Collaborate → Empower continuum) to check that planned activities match the intended level of influence and the practical form of involvement.
- Plan from the outset to review the level of participation over time and, where feasible and wanted by autistic people and families, increase opportunities for stronger participation and greater influence, for example, moving from Consult to Collaborate or Empower or Co-lead.

> "It's important to get started. Start at the best level you can achieve right now. Aspire, don't settle. Even if you can't do substantive co-design research right now, the 'bare minimum' level is a good place to start and will build the skills and knowledge you need to do substantive codesign research." (Organisation representative)

Selecting an engagement approach and governance to match goals

This step focuses on choosing an engagement approach and governance structure that can realistically support the agreed level of participation and influence for autistic people requiring high and complex supports.

- Acknowledge that engaging autistic people requiring high and complex supports typically involves greater time, cost, and coordination than standard engagement, and plan for this from the outset as a core project requirement rather than an optional extra.
- Select a participatory approach that aligns with the engagement goals, available resources, and intended level of participation and influence (for example, community-based participatory research, stakeholder engagement, emancipatory research), and document why this approach is appropriate for autistic people requiring high and complex supports and their families.

- Discuss and document with autistic people with high and complex supports, their families, and partner organisations the type of involvement and influence they can expect overall, for example, advisory input, co-design, or shared governance, and seek agreement on the preferred approach.
- Design governance structures, roles, meeting formats, communication channels, and resourcing that genuinely support the agreed level of partnership, including time, budget, accessibility adjustments, and clear decision-making authority that explicitly incorporates the perspectives of autistic people requiring high and complex supports and those who know them well.

Identifying participants, partners, and roles

This step involves deciding whose perspectives are essential, what roles are needed, and how to invite people into those roles in ways that are voluntary, sustainable, and share power fairly.

- Identify which perspectives must be represented for the project to succeed, placing autistic people requiring high and complex supports and their families/supporters at the centre, and including service providers and relevant community organisations where they add needed expertise.

> "When it's relevant, "community members" can also refer to supporters of autistic people, like their family members and friends, service providers, educators, policy makers, and other relevant people or organisations." (Environmental Scan)

- Map the types of lived experience that are crucial for the specific project aims, such as particular support needs, regional or remote living, cultural background, communication profiles, or care roles.
- Clarify the core roles required for the project from the start, such as autistic co-lead, convener, family adviser, cultural adviser, lived experience researcher, organisational partner, and administrative support, and specify where each role has input, involvement, or decision-making influence.
- When inviting autistic people and their families into roles, emphasise that participation and leadership are voluntary, that they can decline or step back at any time, and that taking on a smaller role does not reduce their standing in the project.
- Work with autistic people requiring high and complex supports and their families/supporters to agree on roles and time commitments that are realistic and sustainable for them, and that align with shared long-term goals.
- Where possible, plan for a balance between autistic community leaders and other autistic people, so that influence is not concentrated only among those who are most resourced or vocal.
- When inviting additional contributors, for example, service providers, policy staff, or researchers, confirm their willingness to share power with autistic people requiring high and complex supports and their families/supporters, to listen to and act on their perspectives, and to support these perspectives to remain central in planning and decision making.
- Where resources allow, consider where additional training, mentoring, or paired roles may be needed so that autistic people requiring high and complex supports and their families/supporters are supported to participate in leadership and decision making.

- Check that the proposed mix of roles and autistic people requiring high and complex supports and their families/supporters is feasible within available resources and constraints over time and adjust the engagement approach early if it cannot be sustained.

Stage 2. Facilitator, knowledge and skills

Effective facilitation is crucial to safety, inclusion, and genuine power-sharing. Conveners and co-facilitators need skills in active listening, managing group dynamics, and responding to distress across all stages of engagement. They also require a deep understanding of autism, co-occurring conditions, and the specific needs of autistic people who require high and complex supports, including how these needs shape participation for families and supporters.

Clarifying roles and expectations

This step ensures that everyone understands who is in which role and how the session will run.

- Make it clear at the start of each session who is facilitating, who is part of the project team (for example, researchers or coordinators), and who is attending as a participant, family member, supporter, or organisational representative.
- For online sessions, ask people to use screen names that show how they are participating (for example, “Alex – family”, “Jordan – service provider”, “Lee – autistic participant”).
- Explain who is responsible for timekeeping, note-taking, wellbeing checks, and follow-up, so participants know what to expect and how to ask for help or clarification.

Active listening and assuming competence

This step focuses on listening in ways that respect autistic people and families as knowledgeable contributors, even when communication is complex or mediated.

- Ask open, clear questions and allow time for responses without rushing, rephrasing repeatedly, or filling silences.
- Listen carefully to what is said and to what is difficult to say, paying particular attention to family context, daily demands, and any constraints that shape what people feel able to share.
- Assume competence in autistic people and families, even when communication is limited or mediated, and avoid talking about people as if they are not present.

Managing power dynamics and turn-taking

This step focuses on creating space for a range of voices, rather than letting the most confident or resourced dominate.

- Plan a communication order or turn-taking structure for group sessions so that no single person or group dominates the discussion.
- Notice when some voices are consistently louder, more confident, or more familiar with professional or advocacy language, and actively make space for others, including autistic people requiring high and complex supports and their families/supporters.
- Intervene respectfully if people are being spoken over, dismissed, or sidelined, and restate that all perspectives are valued and needed for the work to be accurate and useful.

Ensuring everyone can contribute

This step recognises that group consultations can unintentionally exclude autistic people requiring high and complex supports and some families/supporters and builds in alternative ways to participate.

- Recognise that group formats can disadvantage autistic people and families who have slower processing speed, high anxiety, or minimal/no spoken communication, and plan from the outset to adjust for this.
- Provide multiple ways to contribute, such as spoken responses, chat, written input, symbols, visual tools, or a follow up one to one conversation, and explain these options clearly.
- Build in pauses after questions, avoid rapid topic changes, and allow time for regulation and communication so people are not forced to respond under pressure.
- Check periodically whose perspectives have been heard and whose may still be missing. Invite those who have not had the opportunity to share to contribute in low-pressure ways (for example, individual follow-up, written reflections, or supported conversations).

Responding to distress or discomfort

This step ensures that facilitators notice and respond safely when participation becomes distressing or overwhelming.

- Be attentive to possible signs of distress, overload, or withdrawal, especially when there are noticeable changes from a person's usual way of participating (for example, becoming much less engaged or much more agitated than is typical for them).
  Check in using agreed signals and, where appropriate, seek guidance from families and supporters about how this person usually shows discomfort.
- When you notice possible signs of distress or overload, use the agreed exit or break options in a way that does not single the person out. In a group setting, this might include pausing the discussion for everyone, calling a short general break, or moving briefly to a less demanding activity, so that the autistic person and their supporters can step away, regulate, or leave if needed without additional attention being drawn to them.
- After the session, follow up with anyone who appeared distressed to check their wellbeing, clarify any misunderstandings, and adjust future engagement plans and supports.

> "They didn't use a communication order, and they allowed certain people to dominate the conversation, and there were two women in the group who were from the CALD community, and they didn't get as big a say you know, they were spoken over a lot. So the facilitation, they weren't really aware of power." (Organisation representative)

Supporting bodily signals, sensory experience, and emotional expression

This step emphasises practical tools and observation to support autistic people in communicating bodily sensations, sensory experiences, and emotions, particularly when interoception (awareness of internal body signals), alexithymia (difficulties recognising and expressing emotions), or communication differences make this hard to describe directly.

- Recognise that for many autistic people requiring high and complex supports, bodily discomfort, sensory overload, or emotional distress may first appear as changes in behaviour, movement, or participation rather than verbal reports. Treat these changes as meaningful signals that require interpretation.
- Wherever possible, ask families and supporters what signs they recognise for experiences such as pain, fatigue, sensory overload, anxiety, or low mood, and what usually helps. Use this information to guide interpretation and responses during sessions.
- Use visual tools to connect bodily sensations, sensory experiences, and emotions. For example, body maps or cards that indicate locations and qualities of sensations (such as tight, hot, heavy, buzzing) paired with simple feeling words or icons.
- Introduce these tools gradually and in a clear way. Demonstrate how to use them ("My stomach feels tight; I might put this card here") and encourage the autistic person to show what works for them, without pressuring them to label complex emotions.
- Use tools during planning and engagement to help the person express discomfort, stress, or pain in ways that can be acted upon. For example, using a body map or symbol card to indicate "head hurts", "too noisy", or "need break", and then adjusting activities, timing, or environment accordingly.
- Pay attention to sensory and movement cues when using these tools, such as changes in posture, pacing, vocalisation, or self-stimulatory behaviours, and consider these as part of how the person communicates their feelings.
- When a person cannot reliably use visual or symbolic tools, depend more on structured observation in familiar settings, along with input from families and supporters, to understand what tends to increase distress, what calms or regulates them, and how this should shape engagement.

> "The timing of when you actually consult can be quite, it can be quite tricky and I think it's really important to understand that on particular days you know, functional needs may be different depending on what the mood state might be like and how you how you then kind of adapt and adjust your communication style to suit the particular consultation with that family is really important." (Organisation representative)

Stage 3. Preparation for engagement

Put in place the supports, materials, and structures needed to begin engagement with autistic people requiring high and complex supports and their families/supporters in ways that are safe, accessible, and respectful.

Assigning a convener (primary contact person)

Ensure there is a consistent, autism-informed primary contact who coordinates communication, supports accessibility, and maintains relationships with autistic people requiring high and complex supports, along with their families and supporters.

- Identify and appoint a convener as the single, consistent point of contact, and decide whether a secondary support contact is needed, depending on participant needs and workload.
- Ensure the convener understands their role, scope, and responsibilities and meets the facilitation capabilities.
- Involve the convener in co-designing and reviewing accessible materials used across the project, including preview information, consent and payment documents, and session resources, so they are familiar with the content and able to support autistic people requiring high and complex supports and their families/supporters to use it.
- Wherever possible, appoint a convener who has lived experience of autism or caring, or pair the convener with an autistic or family co-facilitator, with appropriate support and boundaries for these roles. Where this is not yet possible, ensure the convener works closely with autistic people requiring high and complex supports and their families/supporters, actively seeks feedback, and shows evidence of learning from their expertise over time.

Sharing about yourself and building reciprocity

Support more equal, trusting relationships by encouraging project team members to share appropriate, bounded information about themselves first, so autistic people requiring high and complex supports and their families are not the only ones disclosing personal experiences to people they do not yet know.

- Plan for project team members to share simple, human information about themselves, for example, their name, role, a few interests, and something about why the project matters to them, rather than presenting only as professionals or experts.
- Use preview materials (photos, brief descriptions, or very short videos) to introduce project team members so that autistic people and families know who they will meet and can start to form a sense of familiarity before the first session.
- Treat early conversations as relationship building, not purely as data collection or consultation. Make space for autistic people and families to ask questions about you and the project and respond openly within agreed boundaries.
- Aim for a sense of mutual exchange in which autistic people and families are not the only ones being asked to disclose personal experiences. Sharing appropriate aspects of your own story signals respect, reduces power differences, and can make it easier for people to contribute in ways that feel safe.

Example**:** Before starting formal consultation, a project convener shares a short photo-based introduction about themselves, including their role, their love of cooking, and photos of their garden. In early online meetings, they spend a few minutes talking with the autistic person and family about shared interests, such as local weather and favourite animals, and invite the autistic person to ask questions about them. This reciprocal sharing helps the autistic person feel more comfortable and turns later conversations about services and supports into a continuation of an existing relationship rather than a one-off, transactional interview.

> "You know, you don't have to give, you know, really detailed information about yourself, but sharing stories about who you are as a person as well and where you've come from is really important to develop that trust with families." (Organisation representative)

Safety, participation demands, and exit options

Prioritise psychological and physical safety, reduce participation demands, and make it easy for autistic people and families to pause, leave, or change their participation without feeling pressured or exposed.

Planning for psychological and physical safety

- Prioritise psychological and physical safety as a core objective of the engagement.
- Allocate time and repeated contact for relationship building so involvement is not one-off or tokenistic.
- Identify people who know the autistic person well and involve them in planning and introductions, where consent is given.
- Gather information on the autistic person's communication methods, sensory needs, triggers, and supports that help them feel safe and settled, and plan the environment and pacing accordingly. Ask each autistic person and supporter how they prefer to describe themselves.
- Develop a brief safety plan for visible acute distress or medical events, for example, seizures, sudden self-injury, or panic. Specify who will notice and respond in the moment, how to pause or stop the activity, and when to seek additional help.
- With consent, obtain an emergency contact and preferred response plan for each autistic person, including any existing seizure protocols, behaviour support plans, or crisis plans, and follow these before using generic emergency procedures.
- Agree with autistic people and families how facilitators will respond if they become seriously worried about someone's safety, for example contacting a nominated clinician, crisis line, or emergency service, and be explicit about any legal or organisational duty of care.
- Distinguish between behaviour that signals discomfort or rising distress and behaviour that indicates imminent risk and choose responses that first reduce demands and support regulation, rather than automatically escalating to external services.

Emotional labour and structured support for autistic co-researchers and family advisers

- Recognise that autistic co-researchers and family advisers often carry heavy emotional load, especially when work involves repeated exposure to distressing stories, systemic barriers, or their own lived experiences. Treat their psychological safety as a core project responsibility.

- Provide consistent opportunities for debriefing and reflection throughout the project's duration, not just after crises. This could include regular one-on-one check-ins, small group debriefs, or written reflection options separate from task-focused meetings.
- Set sensible boundaries on emotional workload, such as a cap on the number of concurrent high-intensity projects, limits on hours per week spent on highly emotive tasks, or clear expectations that people can say “this is enough for now” without facing penalties.
- Make supervisors and mentors explicitly responsible for monitoring workload, stress, and access needs for autistic co-researchers and family advisers, and for responding by adjusting deadlines, redistributing tasks, or modifying roles when needed.
- Offer practical adjustments for participation that respect autistic communication and regulation needs, such as flexible camera use, permission to move during online meetings, the option to contribute in writing or asynchronously instead of only in live discussion, and clear advance agendas with time estimates.
- Ensure that access to psychological support or employee assistance services is clearly explained, and budget for independent support where appropriate, so autistic co-researchers and family advisers are not left to absorb emotional labour alone.

Supporting variable communication and participation

- Expect that communication and participation will vary with environment, familiarity, and demand, and treat these shifts as routine, not as a lack of interest.
- Plan for situational mutism or temporary communication shutdowns, and treat these as indicators of overload or anxiety, not disengagement or opposition.
- Build flexibility into pacing, environment, and activity, for example, using short breaks, movement opportunities, snacks or drinks, shorter sessions, changing settings, or switching to alternative modes of involvement.

Safety information, housekeeping, and exit options in groups

- This subsection applies to group-based activities such as focus groups, advisory groups, co-design workshops, and project meetings, where autistic people and families may need low-demand ways to pause or leave without drawing attention to themselves.
- At the start of the engagement, explain in plain language what will happen if facilitators become seriously concerned about someone’s safety, including any situations where they may need to contact emergency services or a nominated support person, so that this is understood in advance rather than introduced during a crisis.
- Provide this information in preview materials and in one-to-one or small pre-engagement meetings so group time is not dominated by housekeeping.
- Establish clear, low-demand ways for people to indicate they need a break or to leave, for example:
- a private message to the convener in chat or by text
- an agreed signal, card, or emoji that means “I need to step away”.
- Make it explicit that participants can turn cameras off, mute, or leave the session at any time without needing to explain or justify this.
- Plan standard breaks into all sessions and state these in advance, for example, “we meet for 60 minutes with a short break at the halfway point”.

- Agree with facilitators that they will not call on or question someone who has stepped away, turned their camera off, or used an agreed exit signal and that any follow-up will be gentle, optional, and focused on support.
- Where possible, cover administrative information such as consent, payments, reimbursement, and housekeeping in separate brief pre-meetings or one-to-one contact so that main group sessions can focus on participation rather than logistics.

> "Making sure everybody was on the same page, making sure everybody felt safe, making sure everybody knew that at any time they could contact the health and safety person if they, you know, were struggling in some way, and we have now implemented as standard breaks as well." (Organisation representative)

Balancing protection and participation

- Autistic people requiring high and complex supports are often described by professionals, services, or ethics processes as "too vulnerable" or "too risky" for direct engagement. This group can be at increased risk of distress, trauma, anxiety, and depression, and some autistic people may already be closer to the threshold for mental health difficulties than peers who do not have comparable support needs. This vulnerability warrants careful planning and monitoring but does not in itself justify excluding them from engagement.
- While safety is essential, overprotection can also cause harm by removing opportunities for agency, relationship building, and influence. A person-affirming approach treats autistic people as rights holders whose perspectives are necessary for ethical decision making and recognises that participation can be structured in different ways, including observation in familiar settings and supported proxy input from people who know them well.
- Wherever possible, use supported decision-making approaches that provide information in accessible formats, allow additional time and support for choice, and help autistic people express assent, uncertainty, or refusal in their own ways. Work with families and supporters to identify when participation feels safe enough, what signs of emerging distress look like for that person, and what should trigger stopping or changing the activity.
- Ethics and safety planning should distinguish clearly between discomfort, emotional difficulty, and actual risk of harm. Plans should aim to reduce avoidable distress through preparation, pacing, and support, rather than excluding autistic people requiring high and complex supports from engagement altogether. When seeking ethics approval, document how inclusion will be managed safely, including the roles of families/supporters, so that the default is thoughtful participation rather than automatic exclusion.
- If families or services feel that any form of direct engagement, including brief observation in familiar settings, is not acceptable, this should prompt careful discussion rather than automatic exclusion. Explore whether there are ways to participate that feel safe enough, such as very short, well supported observations or co-observed sessions, and be transparent about how the absence of any direct engagement limits whose experiences can be represented. Where only proxy input is possible, document this clearly and consider what additional steps are needed in future work to include autistic people in this group more directly.

Planning for endings, grief, and closure

Planning for endings recognises that autistic people and families may experience the end of an engagement as a loss, and puts in place clear, predictable closure processes.

> "We're also mindful like you know there's nothing worse than being part of something and then suddenly that's the end, like we realise that's one of the issues with research." (Organisation representative)

- Acknowledge from the outset that the engagement has a beginning and an end and explain in plain language how long the project will run, what will happen when it finishes, and what will and will not continue. Repeat this information at key points, for example, when new blocks of sessions start, so it becomes familiar rather than sudden.
- Use calendars and visual schedules to show upcoming sessions, breaks, and the final meeting, and encourage families to mark these dates in their own calendars. Visual schedules can reassure people about what is coming next, even when they already remember dates.
- During the last few contacts, state clearly that the project is ending because the planned work is finished, not because of anything the autistic person or family did or did not do. Be prepared to repeat this reassurance several times in simple, concrete language.
- Develop explicit closure plans, including how you will say goodbye, how you will explain the end of the project to the autistic person, and what information or support will be provided after the last formal session. Co-design this explanation with family/supporters so that wording and timing fit the person's understanding and rehearse it in advance where helpful.
- Provide concrete completion artefacts, such as certificates of participation, simple letters, or visual stories that summarise what the person contributed and what was achieved, to support understanding of finishing and to recognise their involvement. Encourage families to keep these where the autistic person can see or revisit them if they ask about the project later.
- Where resources allow, schedule planned post-project check-ins several months after completion, for example, a brief phone call, online meeting, or written update, to signal continued regard, answer any questions, and provide a sense of closure. Budget for these touchpoints from the outset so they are not lost when timelines or funding become tight and make it clear that families can decline check-ins if they prefer not to continue contact.

Example**:** An autistic young adult who required high and complex supports took part in a short research project and enjoyed regular contact with the team. When the project ended, she repeatedly asked: "What did I do?" and "Will they remember me?", believing the researchers had left because she had done something wrong. The family and team gave the same simple explanation many times, that the project had finished because the planned work was complete and not because of anything she had done and offered brief follow-up contacts. Over time, this repetition and planned check-ins reduced her distress, illustrating how endings can be experienced as personal rejection and why clear closure, repeated reassurance, and limited follow-up matter.

> "Just have touch points that the kids and the participants can put in their calendars. [Individual] loves calendars and [individual] marks off days." (Family member)

Accessible communication and information

This step is to make project information understandable and usable for autistic people requiring high and complex supports and their families/supporters by using multiple formats, layered detail, and predictable, respectful framing.

Core communication standards

- Use plain, clear language in all spoken and written communication. Avoid jargon, acronyms, idioms, metaphors, sarcasm, and indirect hints, and keep sentences short with one main idea at a time.
- When speaking, use a slower pace than you would in typical meetings, pause often, allow extended processing time before expecting a response, and clearly signal when you have finished a question or explanation, so the autistic person knows it is their turn to think or respond.
- Be prepared to wait in silence for longer than feels usual, without adding extra information, repeating the question rapidly, or moving on to a new topic. Treat silence as thinking and processing time, not as a problem to be fixed, and allow the autistic person to set the pace of the interaction wherever possible.
- Expect to repeat or rephrase information several times and treat this as part of matching your communication to the autistic person's communication abilities and processing needs, rather than assuming they can work with typical pace and complexity.
- Check understanding using specific questions or supported choices rather than general questions such as "Do you understand?". Many autistic people requiring high and complex supports may say "yes" by default in formal or group settings, including when they feel unsure or when saying "no" feels unsafe (for example, because "no" has often been treated as wrong or unacceptable, not an acceptable response). For example:
  - For people who can answer short questions verbally or via AAC, use prompts such as "What will happen next?" or "Which of these is right for you?"
  - For people who use pointing, eye gaze, or limited speech, offer response cards, pictures, or objects to choose between, rather than relying on spoken yes/no.
  - Where yes/no questions are used, follow them with a simple choice or demonstration, for example, "Show me which one you mean" or "This one or this one?", so understanding does not depend on a single "yes"

> "'Cause it takes a lot of me to process things, and sometimes it could take us a little bit longer, and sometimes we need to get it explained to us in a different way so we can understand it. [It] could take a few times as well and those sort of things." (Autistic individual)

General formatting and layout standards

- Provide all key materials in at least two formats, for example, written plain language plus visuals, or audio plus a short visual summary, so people can choose what works best for them.
- Where possible, also offer Easy Read versions of key documents and short audio or video overviews for families/supporters who prefer concise information or have limited time or energy for reading.
- Segment longer content into short sections and present key information in more than one format, for example, brief text plus images plus short audio, to reduce fatigue and cognitive strain.
- Avoid dense blocks of text. Use headings, white space, bullet points, and short paragraphs so information is easier to scan and revisit.
- Use layouts that are easier for many autistic people to follow, for example a clear left-to-right or top-to-bottom flow, numbered steps or single direction arrows, and minimal visual clutter. Avoid crowded diagrams or arrows pointing in multiple directions.
- Keep videos and webinars brief wherever possible, for example videos of around two to four minutes and webinars of about twenty to thirty minutes, with clear narration and simple captions.
- Ensure all digital materials are compatible with assistive technologies, such as screen readers and AAC interfaces, and check that links, buttons, and downloads are straightforward to access.
- Use clear narration and simple captions in videos, and minimise text per page or slide, ideally one or two short sentences.
- Where you use visual slides, keep each slide focused on a single idea, with minimal text and a clear heading.
- Consider bright, colourful, high contrast layouts for people who find this motivating, but be ready to reduce visual intensity if it becomes overwhelming. Aim for visually engaging rather than visually busy.
- Check with autistic people requiring high and complex supports and their families/supporters, which formats and layouts are workable for them, and adjust if a chosen format is not working in practice.

Formats for autistic people requiring high and complex supports

This subsection focuses on formats used directly with the autistic person, distinct from materials prepared primarily for families and supporters.

Do not assume that Easy Read alone will be accessible. Many autistic people requiring high and complex supports cannot reliably use written text even in simplified form.

In consultation with the autistic person and their family/supporters, match communication methods to the autistic person's communication abilities, cognitive profile, and developmental level, and prioritise non-text-based formats when written or video materials are not usable. Common options include:

- Symbols or photos that the person can point to, select, or look at, including simple choice cards linked to the topic being discussed.

- Key words or response options supported by visuals or AAC systems so that the person can choose between alternatives related to the engagement activity.
- Very simple visual stories, picture sequences, or other non-text-based explanations that draw on the autistic person's own interests, for example, dinosaurs, specific characters, music, animals, or photography, and are tailored to their communication strengths.
- Supporter-mediated communication, where a trusted person helps interpret and relay messages in ways that respect the autistic person's preferences and autonomy.
- Where the autistic person cannot reliably use any of these or other response formats, planned observation in familiar settings, with informed consent, is used as a primary source of information about what supports work, what causes distress, and what improves participation.

When using visual stories, picture sequences, symbols, or other non-text-based explanations, create or adapt materials specifically for the autistic person rather than relying only on generic templates. Aim for images, wording, and pacing that reflect their communication abilities and familiar contexts and check with family/supporters that the materials make sense and feel respectful.

> "Videos – Keeping them short is great. Clear voices, simple captions and simple use of language…Easy read summaries – The types that usually work best for [child] are large, bright, colourful pictures accompanied by a sentence or two. Clear simple language works best in terms of [child's] comprehension. With more complicated language, [child]'s attention would be focussed on decoding the words rather than on comprehension of the full sentence." (Family member)

Formats for parents and supporters

- Do not assume that parents or supporters can easily read long documents, process complex information, or find time to review detailed materials. Many are managing high caring demands, fatigue, their own health or mental health needs, and in some cases, their own disability or neurodivergence.
- Ask parents and supporters what types and lengths of information are workable for them, for example, full documents, short summaries, audio, video, or a brief phone call, and be prepared to adjust if their capacity changes over time.
- Offer at least two options for key information, for example:
  - Full, plain language documents for parents or supporters who want detailed information and have the time and energy to read it
  - Easy Read documents, short audio recordings, or brief video overviews for parents or supporters who prefer concise information or who have limited time, energy, or reading stamina.
- Keep written materials for parents as clear and focused as possible, with explicit headings, short sections, and clear statements of what they are being asked to do, so that they can quickly identify what is essential and what can be read later.
- When parents or supporters are contributing as proxies for an autistic person who cannot participate directly, make it clear which questions are about the autistic person's experiences, needs, and preferences, and which questions (if any) are about the parent's or supporter's own circumstances. Avoid using tools that only ask about the parent or supporter when the purpose of the activity is to understand the autistic person.

- Where both perspectives are relevant, design surveys or interviews so that parents and supporters can clearly indicate when they are responding on behalf of the autistic person and when they are describing their own experiences as carers. Use separate items, answer fields, or sections for each perspective to reduce ambiguity.
- Treat proxy reports from parents and supporters as a central source of information for autistic people who require high and complex supports, while recognising that these reports are shaped by the parent's or supporter's vantage point and should be interpreted alongside other available information about the autistic person.

> "We would usually read the full, actual reports when they are available… infographics – they provide a quick summary and help memory. We do join/ or watch the occasional webinar on topics or speakers of particular interest, often the Q&A is disappointing, or the key questions of interest seem to be avoided, especially the curly ones related to severe and profound autism! The chats can be quite good." (Family member)

Language, interpreting, and translation support

- Identify any language and communication access needs early, including Auslan, spoken language interpreters, and translation of key materials into community languages.
- Treat interpreter and translation costs as core project costs rather than optional extras and include them in the Stage 1 budgeting for engagement with autistic people requiring high and complex supports.
- Ensure interpreters and translated materials are briefed on the language and core concepts used in the project, including how autism and support needs are described, so that key ideas are conveyed accurately and respectfully.

Preview information and predictable routines

- Provide brief preview materials to introduce the project and what will happen, such as accessible flyers, very short videos, or visual stories.
- Send preview materials before first contact, giving families time to review them together in their own way and prepare questions or concerns.
- Include photos and short, plain language descriptions of each project team member so the autistic person and family know who they will meet, what their role is, and a little about them as a person, for example, "I am Alex. I am a researcher. I like gardening and photography, and I will help run the meetings."
- Where project team members are comfortable, offer a very short video introduction so that autistic people and families can see and hear the person before meeting them. These videos should focus on simple information about who the person is, what they do in the project, and one or two interests or everyday details, not just formal titles.
- Create a simple visual sequence of the engagement process using photos or screenshots rather than text only, for example, a picture of the computer or meeting room, an example slide or question screen, and an image showing how people will join the conversation.
- Use these images as a step-by-step visual schedule, for example, "first we sign in", "then we say hello", "then we talk", "then we finish", keeping wording minimal for autistic people who prefer not to read detailed explanations.
- When using images, select imagery that conveys warmth, support, and shared participation, and avoid pictures that portray autistic people as isolated or deficit-focused. Ensure any

images involving autistic people and families are used with consent and are respectful to them.

- Keep preview videos very short and simple, for example, a simple greeting and one or two sentences about what the person does, and only use video if you are confident, as it will not feel overwhelming for the autistic person.
- Check with the family and, where possible, with the autistic person, whether the preview materials are helpful or feel like too much, and adjust by shortening, simplifying, or changing format rather than adding more detail.

> "Preview materials of the research project in visual or simplified format. For example, a fun colourful flyer which clearly shows the autistic child/adult with a family member's hand on their shoulder (to reinforce that they are being supported in this) talking with researchers. That sort of thing would make [child] comfortable and would reinforce the notion of a collective approach." (Family member)

Accessible rating and feedback tools

Adapting rating scales and feedback tools so autistic people requiring high and complex supports can express preferences and views without being overwhelmed.

- Use very short rating tools with only two or three options, for example, "yes / unsure / no" or "helps / sometimes / not helpful", rather than long scales. Fewer options reduce cognitive load and make it easier to respond.
- Provide visually supported options, such as simple faces, colour strips, thermometers, or clear icons instead of, or alongside, words. Keep the visuals consistent within a project so that meanings do not keep changing.
- Avoid large numbers of choices or complex scales, such as 5–10 point ratings, as these are rarely usable for autistic people requiring high and complex supports and often create confusion and fatigue.
- Allow the autistic person to respond in different ways, for example, by pointing, choosing a card, looking at a symbol, or using assistive communication, with support from a trusted person if needed.
- When designing rating tools, work with families and supporters to identify a small number of likely response options and to create a simple "something else" option, for example, a blank card, extra symbol, or space for a short note, so that the person is not forced into a choice that does not fit.
- Recognise that some autistic people requiring high and complex supports will not be able to use rating tools at all. In these situations, prioritise supported conversation, where possible, and structured observation in familiar settings as the main sources of feedback, and treat ratings, if used, as supplementary rather than primary data.
- Identify and prepare simple visual tools that can help autistic people describe bodily sensations, sensory experiences, and emotions, particularly when interoception or alexithymia are present. For example, body maps, feeling cards, or symbol sets that families already use.

Participation formats, timing, and creative methods

Offer multiple ways to participate, match formats and timing to people's energy and routines, and use creative methods that support autistic people who do not use, or prefer not to use, spoken or written language.

Flexible formats and accessibility

- Plan to offer multiple modes of participation, for example, in person, online, phone, written, and asynchronous options, recognising that many autistic people requiring high and complex supports will only be able to engage meaningfully in familiar in-person settings.
- Prioritise in-person engagement in the autistic person's usual environments, for example, their home, school, day program, or a familiar local park, rather than expecting them to attend clinics, universities, or unfamiliar offices. Treat travel by the project team as a core access requirement, not an optional extra.
- Select venues that are physically accessible and consider sensory factors such as noise, lighting, smells, room temperature, and the availability of space to move, lie down, or step outside.
- Ensure online platforms used for families and supporters have basic accessibility features, for example, captions, chat, and low bandwidth options, and be explicit that cameras can be off and people can contribute by chat, audio only, or written follow-up.
- For participants in regional and remote areas, plan for connectivity barriers by offering alternatives such as phone-based participation, low-bandwidth platforms, sending materials in advance, or arranging local in-person visits where feasible.
- Recognise that rigid consultation formats are often unsuitable for autistic people requiring high and complex supports and their families, who may experience fatigue, time pressure, and fluctuating capacity. Build in flexibility so that sessions can be shortened, rescheduled, or shifted to a different format.
- Offer multiple ways to contribute, for example, short surveys, voice-to-text messages, video or audio recordings, drawings, comic strips, other visual narratives, and asynchronous interviews.

Allow in-the-moment or diary style recordings so families can share experiences when events occur, for example, short notes, photos, or voice memos captured on a phone, rather than relying only on recall in scheduled sessions.

> I'd think about it from like a multimedia kind of perspective, how can you have lots of different ways to capture their insights... Flexibility of modalities and flexibility of time and then support... can someone just be made available to just sit with certain folks and get them through that... could it be their support worker or a family member that gets briefed and supports the person through that process?" (Organisation representative)

> "To help with reach, so you know with regional and remote kind of areas being able to kind of use resources that are going to be engaging for them, and it may be one to one consultation within a regional setting rather than telehealth if needed or small groups." (Organisation representative)

Timing, pacing, and energy

- Schedule engagement activities at times that fit the autistic person's optimal engagement periods and the family's routines, for example, avoiding school pick up, mealtimes, medication times, or key caring tasks, and always offer an alternative time if the proposed slot is not workable.
- Expect that capacity will fluctuate. Build default options for shorter sessions, rescheduling, and "finish later" plans, rather than treating changes as exceptions.
- Structure meetings to allow extended processing time, predictable pauses, and, where helpful, multiple shorter sessions or small breakout conversations, with clear follow-up opportunities for additional input.
- Ask the autistic person and/or family which modes feel safest and are most workable for them and build in the possibility of changing mode as needs or circumstances shift, for example, moving from video to phone, or from group to one-to-one.
- Select engagement methods that balance what autistic people and families say is workable for them with the aims and practical requirements of the project. Where there is tension, name it and problem-solve together, rather than defaulting to what is easiest for the project team.

> "Principles and tools for engagement could include… ensuring flexibility to account for differences and fluctuations in ability to participate" (Environmental scan)

Example**:** A researcher arranged several short visits with an autistic adolescent who required high and complex supports before asking any research questions. Early sessions focused on talking about the weather, which was a deep interest for her, and on building predictable routines around each visit. As familiarity and trust developed, she began to offer more spontaneous comments. She could take part in a simple consultation activity with support from her family and a trusted support worker. Between visits, the researcher shared photos of local storms, so the young person could see and talk about the weather in the researcher's area, reinforcing the relationship in a way that was not purely transactional.

Group methods and size

- Choose engagement formats that suit the project and participants, such as small workshops, focus groups, surveys, or co-design sessions, and avoid assuming that every activity needs a group format.
- Use smaller, topic-focused groups wherever possible, as these usually produce clearer, more relevant feedback and are less demanding for autistic people requiring high and complex supports and their families/supporters.
- Avoid large mixed groups, especially where there are strong power differences or highly emotive topics, when these are likely to become overwhelming, emotionally charged, or to drift away from the focus.
- Include visual supports in group sessions where they help understanding, for example, a simple agenda, a visual timer, or one key question in plain language. Keep slides uncluttered, use visuals as light prompts rather than the main focus, and check with autistic people and families whether these supports are helpful or distracting.

- Where an autistic person requiring high and complex supports is present in a group setting, ensure there is a clear role for them, appropriate communication support, and explicit permission to come and go, move around, or sit apart while still being included.

> "Maybe could ask you in like a group of five could ask, say like does [individual's name] have anything want to say or something like that? Possibly. I think that works well when I've been in those sort of things." (Autistic individual)

Creative and arts-based participation

- Plan from the outset for arts, play, or story-based methods for autistic people who do not use, or prefer not to use, spoken or written language. Treat these as core participation methods, not addons.
- Use activities such as drawing, colouring, making comics, selecting images, photography, music-based tasks, or simple play scenarios to help people show their experiences in concrete ways.
- Build stories and activities around the person's own interests, for example, dinosaurs, specific characters, music, animals, or particular places, and use these as the frame for questions and discussion.
- Use tools such as simple videos with captions and limited text, AI-generated or other images, or digital storyboards to co-create short narratives, then check back whether these stories fit the person's experience.
- Provide scaffolded prompts during story-based activities, for example, choices between two options or structured "finish the sentence" supports, rather than relying on open-ended questions only.
- Pay close attention to movement based and sensory cues during these tasks, such as drawing pressure, pacing, music choice, changes in facial expression, or shifts in activity. Use this information, together with family input, to better understand comfort, stress, and preferences, especially for non-speaking autistic people.
- Where appropriate, use simple games or gamified activities to support participation and learning, for example, board games or card games about rights, choice, feelings, or everyday situations.
- Ensure game-based activities are optional, fun-focused, and matched to the person's age, interests, and emotional readiness.
- Avoid gamified formats when discussing highly sensitive or traumatic topics, or where play elements could feel dismissive or trivialising of people's experiences.
- Where possible, co-design or adapt activities with autistic people requiring high and complex supports and their families so that imagery, pace, and tasks feel safe, respectful, and engaging.

> "Team members may be reassured there is no requirement to make eye-contact or contribute through speech - they could contribute via writing, drawing, or using technology." (Environmental scan)

Conversational style and use of questions

This subsection builds on the core communication standards by focusing on how conversations and sessions are structured.

- Favour question-led, conversational discussions or shared activities over slide-heavy, presenter-driven formats wherever this works for the autistic person and family. Treat engagement as a conversation you are invited into, rather than a presentation to be delivered.
- Be cautious about using slide decks as the main structure for online or group sessions. For many autistic people requiring high and complex supports and their families, long or visually busy slide sequences feel formal, tiring, and more demanding to join in. Often, a simple spoken agenda and a few key prompts are more workable.
- Use slides or written prompts only as light supports, for example, a single question, key phrase, or image, rather than as the main focus of the session. Where possible, keep slides off screen for most of the conversation and bring them up briefly only when they genuinely help.
- Allow the conversation to unfold in a "yarning" style where appropriate, following the autistic person's and family's lead and interests, then use follow-up questions to clarify or deepen understanding. Keep the facilitator's role focused on gently holding the topic and summarising, rather than steering tightly through a pre-set slide sequence
- Where someone communicates mainly through actions, gestures, or brief phrases, treat their actions and interests as part of the conversation, and use gentle, simple questions alongside observation, rather than pressing for extended verbal answers.
- Check with participants at the start and over time whether they want more visible written questions, a clearer agenda, or fewer visual elements and a more free-flowing conversation, and adjust the format accordingly. Make it explicit that it is acceptable to ask for "fewer slides and more talking together" if that feels easier.

Example**:** In one online consultation, the facilitation team originally planned to use a slide deck with written questions and an agenda visible throughout. Parents of autistic adolescents requiring high and complex supports reported that this felt formal and tiring, and autistic participants were largely silent. In later sessions, the facilitator kept the slides closed, used a very simple spoken outline ("first we say hello, then we talk about what is working, then we finish"), and brought questions in verbally, returning to people's comments and interests as they emerged. Families reported that this conversational style felt more relaxed and respectful, and autistic young people contributed more spontaneously through speech, AAC, and gestures, despite the absence of visible slides.

Working with family and trusted supporters

Involve family members and trusted supporters in ways that assist communication and participation while protecting and amplifying the autistic person's own perspective and preferences.

Deciding whether and how supporters are involved

- Recognise that for many autistic people requiring high and complex supports, meaningful participation will only be possible if family members or trusted supporters are actively involved. Treat their presence as expected and welcome, not as an optional extra.

- Where possible, ask the autistic person who they would like involved, in what ways, and at which points in the process. Use accessible formats, such as simple choices, visual options, or supporter-mediated conversation, to explore these preferences.
- When the autistic person cannot reliably indicate preferences about supporter involvement, work with families/supporters to identify who is trusted and safe and review these arrangements over time rather than assuming they are fixed.
- Plan structured opportunities for both the autistic person and their parent or supporter to contribute, including time together and, where appropriate, time separately. This allows supporters to share contextual information without speaking over the autistic person and enables the autistic person to express views that might feel difficult to share with family.
- Plan how the autistic person's own preferences and views will be checked and confirmed in accessible ways, so that supporter reports are complemented, not treated as the only source of information.

> "So I think being quite open to first and foremost, including them directly, so needing to hear from people with high and complex needs with autism directly. But also, being open to that it might not be possible, and that it might have to occur via family supports advocates, peak bodies that have a really deep, deep understanding of the lived experience of people with autism" (Organisation representative)

> "Communication support from family or supporter is a right, not a 'bonus'" (Family member)

Clarifying roles and valuing expertise

- Name explicitly that family members and trusted supporters bring specialist knowledge and lived expertise built over years of supporting the autistic person in everyday contexts. Treat this as essential expertise for understanding what works, what causes distress, and what enables participation.
- Clarify that supporters participate as communication partners and contextual informants whose insights complement, rather than replace, the autistic person's perspective. Make it clear that the aim is to combine the autistic person's own views, when available, with family and supporter knowledge.
- Offer flexible participation modes for supporters, including written input, brief phone or online conversations, or assisted/mediated contributions, so they can participate in ways that are workable within caring demands, fatigue, and their own health or disability.
- Make it clear that family and trusted supporters are invited, not required, and that their level and type of involvement can change over time if this better fits the autistic person's preferences or the family's capacity. Revisit roles periodically rather than assuming the initial arrangement is optimal.
- When differences arise between what supporters say and what the autistic person expresses, treat this as a signal to slow down, seek clarification in accessible ways, and explore context.

> "I understand a parent's voice cannot replace that of their child, but the parents intuitive, relational expertise and ability to articulate on behalf of [child] should be respected." (Family member)

Recruitment strategies

Reach autistic people requiring high and complex supports and their families/supporters through channels and messages that are accessible, trusted, and realistic for their time, energy, and technology access.

- Recognise that traditional methods, such as generic surveys, newsletters, open expressions of interest, and broad social media posts, are often ineffective for reaching autistic people requiring high and complex supports and their families. Many do not have the time, energy, or digital access to respond to general calls.
- Do not rely solely on email or mainstream social media to reach potential participants, especially those who have limited digital access, high caring demands, or little time for online engagement. Treat these as supplementary channels, not primary strategies.
- Use creative, community-based recruitment such as QR codes or flyers in clinics, waiting rooms, schools, respite and day programs, disability services, GP practices, and community centres, so that information appears in places families already attend.
- Use accessible online platforms for outreach, including social media pages and newsletters of trusted services and community organisations, and ensure posts are compatible with assistive technologies such as screen readers. Use simple, plain language and clear headings so that key information is visible at a glance.
- Work through trusted intermediaries wherever possible. Engage community leaders, peer networks, service coordinators, support coordinators, therapists, and advocacy organisations to share information directly with families who may not respond to mainstream channels. Invite their feedback on wording, timing, and format so recruitment messages feel relevant, respectful, and realistic for the families they support.
- Allow for slower, relationship-based recruitment rather than expecting rapid responses to a single call-out. Provide sufficient time between initial contact and any decision point so that families can think, ask questions, and discuss participation in the context of their existing demands.
- Make recruitment information clear about practical supports and recognition, for example, transport, timing flexibility, support people, and payment, so that families can judge from the outset whether participation is genuinely workable for them.

> "We found it helpful to promote our consultations via social media – in groups that are likely to have people with higher/complex support needs families involved" (Organisation representative)

Recruitment balance and research fatigue

- Avoid relying on the same small group of autistic people requiring high and complex supports and families across multiple projects or cycles.
- Where people have been heavily involved in previous consultations or co-production work, offer them the option of a "rest period" before inviting them again.

- Work with community organisations and networks to broaden the pool of potential contributors, including people who are less visible in online or advocacy spaces.
- When families decline because they are at capacity, record this as an indicator of research and consultation load rather than as lack of interest.

Organisational recruitment infrastructure

- In the longer term, effective engagement with autistic people requiring high and complex supports is likely to need organisational infrastructure, not just project-by-project outreach.
- Peak bodies, large services, or research consortia could consider developing a dedicated advisory network or register of autistic people requiring high and complex supports and their families/supporters, with clear eligibility criteria, consent processes, and governance.
- Governance arrangements should be co-designed with autistic people and families so that such networks provide mutual benefit: reliable and appropriate recruitment pathways for projects, and access to information, peer connection, and opportunities to influence systems for participants.
- Safeguards structures are needed to prevent over-use of the same people, ensure alignment with people's preferences and capacity over time, and avoid the inclusion of participants whose support needs sit outside the intended focus of the group.

Working with ethics committees

- When seeking ethics approval, project teams should explicitly describe both the supports that will be in place for autistic people requiring high and complex supports and the harms of excluding their perspectives. Ethics deliberations often focus on immediate risk to participants, but an ethical stance also includes the longer-term risk of designing services and policies without input from those most impacted. Applications should emphasise supported decision making, consent processes tailored to communication needs, and clear safety plans, so that committees can see that risk is being managed rather than avoided through blanket exclusion.

Positive, person-affirming invitations

Frames invitations so that autistic people requiring high and complex supports and their families/supporters are approached as valued experts whose experiences and insights are central.

- Explain participation in ways that affirm identity and agency, for example, "This is your chance to teach us about you and what works for you" or "We would like to learn from your experiences so we can improve how services support autistic people and families." Address both the autistic person and their family/supporters, not only the parent or only the service.
- Emphasise that all experiences are welcome, including things that are hard or painful, as well as things that work well. Make it clear that there is no expectation to be "grateful" or to present only positive stories.
- Avoid deficit-based, or problem-focused language when inviting people to take part, for example, language that frames autistic people as burdens, risks, or case examples. Instead, use language that focuses on rights, preferences, supports, and changes people would like to see.
- Be honest about what is and is not up for discussion. Briefly restate the purpose, scope, and limits of the activity in the invitation itself, in plain language, so that families know what the

engagement is for, what is out of scope, and what kind of influence they can realistically expect.

- Do not ask for ideas, stories, or feedback that you know you cannot use. If there are fixed elements that cannot change, state this clearly and explain why, so that people are not invited to invest emotional labour in areas where their input cannot be acted on.
- Make it clear that participation is voluntary, that people can say no, pause, or change their level of involvement at any time, and that declining or stepping back will not affect their access to services or the value placed on their views. State explicitly that choosing not to participate will not disadvantage them.
- Where possible, invite interest rather than immediate commitment. For example, offer an option to receive more information, have a brief phone call, or attend a short introductory session before deciding whether to take part, so that families can make informed decisions without feeling pressured.

Team composition and co-facilitation

Embed lived experience and power sharing in facilitation by including autistic people and families/supporters in co-facilitation roles, with clear expectations and appropriate preparation, support, and recognition.

- Include, wherever possible, autistic and/or family lived experience researchers or advisers as co-facilitators, with experience that is relevant to autistic people requiring high and complex supports rather than only “general” autism experience. Align their roles with the levels of participation and influence described in Stage 1.
- Where possible, pair professional or academic facilitators with autistic or family co-facilitators rather than relying on a single lived experience person. Make it explicit that lived-experience co-facilitators are contributing their own perspectives and knowledge, not speaking for all autistic people or all families.
- Clarify roles, decision-making processes, and boundaries between academic staff and lived experience co-facilitators so that responsibilities, authority, and limits are explicit. Document who leads on which tasks, how disagreements will be resolved, and how lived experience input will shape final decisions and outputs.
- Ensure lived experience co-facilitators receive appropriate preparation, including orientation to the project, accessible versions of internal documents (for example, role descriptions, ethics summaries, payment information), and, where needed, training or mentoring in facilitation skills, group processes, and managing sensitive topics.
- Provide ongoing support, debriefing, and access to supervision or peer support for lived experience co-facilitators. Recognise the emotional labour involved in hearing and sharing difficult experiences, and plan time for recovery and reflection as part of the role, not as an optional extra.
- Plan for any access, communication, or sensory supports that co-facilitators require, for example, flexible timing, remote or hybrid participation options, assistive technologies, interpreters, adjusted environments, or support people. Treat these supports as standard parts of the role.
- Treat payment and recognition for lived experience co-facilitators as core project costs. Provide appropriate remuneration that covers preparation, meetings, travel, follow-up, and

debriefing, and use agreed forms of acknowledgement such as co-authorship, named acknowledgements, or formal role titles where this is acceptable to them.
- Regularly review team dynamics to ensure that autistic and family co-facilitators are involved in setting agendas, framing questions, and interpreting findings, rather than being confined to "sharing stories" or purely relational roles. Adjust facilitation practices if their influence is drifting away from what was committed to in Stage 1.

> "Someone that has a lived experience on like the co-author list but actually participating in the conducting of the research and whether it is that we have interviewers that identify as autistic themselves and can conduct the interview." (Organisation representative)

Practical supports and participation costs

Treat engagement with autistic people requiring high and complex supports as a core project cost by budgeting for payment, supports, and reasonable expenses so participation is not financially or practically punitive.

- Build in additional time and budget for engagement with autistic people requiring high and complex supports and their families/supporters, including travel time, shorter or repeated sessions, and preparation and follow-up with families and supporters.
- Plan and budget for practical supports needed for participation, including transport, accessible venues, support people, childcare or respite, and refreshments that are compatible with sensory and dietary needs.
- Offer reimbursement and, where possible, arrange transport and coverage of reasonable supporter and childcare/respite costs when these are barriers to participation, and state this clearly in invitations and information materials.
- Provide an honorarium, sitting fee, or voucher that recognises the time, planning effort, and expertise contributed by autistic people and families, and use agreed forms of acknowledgement such as certificates of participation or named acknowledgements. Recognise and appreciate contributions in whatever form and amount people can offer, rather than valuing input only when it matches pre-set expectations.

> "So, I mean there are basic things like we will pay for time. You know we will make sure that there's and they're usually gift vouchers, but we try to make sure that... at least time is covered. Now some people, for them that's not that much of a driver... we've done things like covering babysitting or... we've done presentations at conferences together and so that's an opportunity... some people find that really great." (Organisation representative)

Shared communication and decision-making processes

Translate participation and influence commitments from Stage 1 into concrete practices by setting up clear, accessible ways to communicate, share information, make decisions, and respond to concerns.

- Start by being explicit about the purpose and limits of involvement. Clarify what is genuinely open to influence, what has already been decided, and how autistic people requiring high and complex supports and their families/supporters will see their input reflected in decisions.

Do not ask for ideas or feedback that you do not intend to use, as this is likely to feel tokenistic and erode trust.

> "Genuine consultation and proper consideration of input before decisions are made. Being willing to change course and content when good input challenges and highlights the issues with the initial propositions." (Family member)

- Co-design simple collaboration guidelines with autistic people requiring high and complex supports and their families/supporters. Cover communication channels, expected response times, how concerns are raised, and how feedback will be responded to and reported back.
- Agree on a clear decision-making process, for example, consensus where possible, with a documented backup process if agreement cannot be reached and specify who has authority for which kinds of decisions. Make sure this is written in plain language and shared with all partners.
- Individually ask each autistic person requiring high and complex supports and their families/supporters about access and accommodation needs, including timing, format, sensory and cognitive supports. Summarise these (with consent), share them with relevant facilitators, and revisit them regularly, especially when circumstances change.
- Where accommodations or preferences appear to conflict, name this openly, problem-solve together and record the agreed compromise so it can be reviewed later. Emphasise that competing access needs are a design problem, not a problem with any person or group.
- Select meeting formats that match the group's access needs and roles, for example, a mix of in-person, teleconference, videoconference, and text-based chat, and allow people to use the format that works best for them where possible.
- Present concepts, documents, and choices using accessible language and formats so autistic people requiring high and complex supports and their families/supporters can make informed decisions. Allow extra time in meetings for reading, processing, and clarification, and be prepared to defer decisions when more time is needed.

On needing time to make decisions:

> "Then after the meeting, you might think, 'oh, I want to say that.' And you can then say this is what I wanted to say. Or you could say, 'look, I don't want to make a decision now, but I want to have more thoughts.'" (Autistic individual)

- Provide key materials before meetings in the formats people have requested, and clearly indicate which sections require decisions or feedback, what kind of response is needed, and by when.
- Use a consistent, structured format for group emails, for example:
  - Purpose
  - Actions requested
  - Deadlines or timeframes
  - Payment or reimbursement information (if relevant)
  - Additional details or attachments.
- During meetings, use active facilitation that includes a clear agenda, time to settle in and catch up, explicit cues when moving between topics, and an agreed process for handling digressions or sensitive issues. Make sure there is time for autistic people requiring high and

complex supports and their families/supporters to raise their own topics, not only respond to pre-set questions.
- Regularly reflect as a team on whose voices are shaping decisions, who is quiet or missing, and how academic and community power are operating. Adjust facilitation, roles, or processes to rebalance power when needed, for example, by changing formats, adding one-to-one follow-up, or inviting specific feedback from quieter participants.
- When collaboration difficulties arise, treat them as signals that the process or supports need adjustment, rather than problems located in autistic people requiring high and complex supports or their families/supporters. Review expectations, formats, and supports, and make changes that reduce strain and increase genuine influence.

Stage 4. Initiation and early engagement

Put preparation work into practice through first contact and early meetings, so that autistic people requiring high and complex supports and their families/supporters can get to know the team, understand the engagement, and begin building safe, trusting relationships.

Early contact and trust building

- Offer one-to-one introductory conversations before any group or formal engagement.
- Provide an initial short meeting (around 10–15 minutes) to outline the purpose, who will be involved, and what to expect, and adjust length and format to the person's communication, sensory, and processing needs.
- Use the convener as the main person the autistic person or family meets first, with optional involvement of one additional support person.
- Allow lead time between the introductory contact and the first formal session, so families can process information, discuss it together, and prepare.
- Build in brief social time before or after sessions so people can arrive, settle, and connect without pressure to perform.
- Use clear name badges and introductions so people know who is present and how they are involved.
- Recognise that trust for autistic people requiring high and complex supports and their families typically develops through repeated, predictable, low-demand contact rather than single interactions.
- Meet each person in ways that fit their physical, emotional, and cognitive needs, and treat feeling safe, respected, and personally known as a precondition for engagement rather than an optional extra.

> "Planning to include [people with high and complex support needs] is really important. And that might require… quite a long lead in time because… it will require I think more of a trust and relationship building." (Organisation representative)

> "It might be important to first connect with, let's say, a caregiver or a parent who knows the person. And well ahead of the contact with a person to really help them understand who this person is, what their interests are? What do they like? What do they not like? How do they generally prefer to communicate?" (Organisation representative)

> “The importance of time and building some sort of relationship that it can't just be like a one-off or tokenistic, that it's important and often very helpful to get to know the person, either through somebody else, you know, who knows the person quite well” (Organisation representative)

Shared humanity and respectful presence

- Use approachable, everyday clothing where appropriate to reduce perceived power differences.
- Allow the autistic person or family to see something about you as a person, such as a personal object, workspace, or core interest, when they show interest.
- Offer brief, participant-led moments of connection or diversion within clear time limits and boundaries.
- Engage in two-way conversations rather than one-sided questioning and respond as a person as well as a professional.
- Focus on human connection, not just tasks, by listening carefully and responding with warmth and respect.
- Treat people’s stories as personal and sensitive and handle them with care and confidentiality.
- Use formats that support safety and connection, such as yarning, side by side conversations, and informal check-ins.
- Avoid interactions that feel extractive or purely transactional by ensuring people receive information, support, or other meaningful benefits in return for their time and expertise.
- Keep all such activities consent-based, clearly explained, and bounded to maintain psychological and psychosocial safety and focus.

> “It's... sometimes about [helping] people feel confident that you're holding their story gently, that you're going to listen to what they say and that you're going to hold things... in a respectful kind of manner.” (Organisation representative)

Creating every day, comfortable settings

- Treat in-person engagement as something that usually happens in the autistic person’s own environments, rather than in university, clinic, or office settings. Where it is safe and workable, plan to meet at home or in another familiar, low-stress place of their choosing.
- Recognise that travel to institutional settings can be a major barrier for autistic people requiring high and complex supports and their families, due to fatigue, transport logistics, distress in unfamiliar places, and the need to manage equipment, routines, and behaviours in public.
- Co-design the setting with the autistic person and their family/supporters so they can communicate and regulate at their best, for example, choosing a quiet room at home, a familiar community venue, or a local playground rather than a formal meeting room.
- With consent, spend some time in flexible observation or everyday interaction in these familiar settings, particularly for autistic people who communicate mainly through movement, behaviour, or non-spoken means, so you can see how they regulate and participate in their own environment.

- Use familiar, low-pressure contexts when helpful, for example, a shared online morning tea where each person has their usual drink or snack, to create a sense of being together, support orientation to time, and provide a gentle transition into task-focused discussion.
- Allow everyday conversation and shared routines to support trust, rather than keeping all contact highly formal, while still maintaining clear boundaries, timeframes, and consent.

> "A good facilitator: Seeks advice on what setting would work best for the person to ensure a meaningful engagement and a willingness to be flexible. For example, going for a walk with them." (Environmental scan)

Stage 5. Ongoing engagement and across stage approach

This step is to support autistic people requiring high and complex supports and their families/supporters to stay involved across sessions and stages, keep communication clear, accessible, culturally and trauma-informed, and adapt the process as needs and circumstances change. Not all projects will have a lengthy ongoing stage, but many of these practices still apply wherever contact continues over time.

Co-production with autistic people requiring high and complex supports needs to follow a trauma-informed approach that prioritises safety, choice, collaboration, empowerment and trustworthiness in all phases of the work.

> "Co-production requires the consideration of a trauma informed approach to research which prioritises the principles of safety, choice, collaboration, empowerment, and trustworthiness in all phases of co-production." (Environmental scan)

Keeping people informed over time

Ensure that autistic people and families/supporters know what is happening, how their input is used, and what will happen next, including any changes to plans.

- Provide regular, accessible updates on what has happened since the last contact, how feedback has been considered, and what is planned next. This can be through short emails, texts, visual summaries, or brief phone calls.
- After key sessions, send a short, plain language summary of what was discussed and any agreed actions, and who is doing what, so that families do not have to rely on memory alone.
- Clearly signal any changes to timing, format, or focus of upcoming sessions, and check that these changes are workable for the autistic person with high and complex support needs and their family/supporters.
- When roles, timelines, or expectations change in a significant way, record these changes clearly and share them in accessible formats so that everyone understands what has changed and why.
- Reiterate at appropriate points what the engagement is aiming to achieve, what kinds of decisions are being made, and how autistic people and families are shaping those decisions.
- Keep a brief record, in accessible language, that links key changes in the project or process to specific input from autistic people and families, so that transparency about influence is maintained.

> "Send minutes from each meeting to all participants, in their preferred format. Send updates to the co-design group throughout the project, demonstrating how their input has been used." (Environmental scan)

Flexible participation and continuity

Maintain participation without penalising people for health, fatigue, caring responsibilities, crises, or service changes.

- Expect that health, fatigue, crises, and service changes will affect participation for autistic people requiring high and complex supports and their families, and treat these as routine conditions to plan around.
- Revisit participation arrangements made in earlier stages to check they still fit the autistic person's and family's energy, routines and capacity, and adjust as needed.
- Offer alternatives when people cannot attend a scheduled session, for example, one-to-one follow-up, asynchronous voice or video messages, written or pictorial notes, or brief check-ins, so that participation is not lost because of illness, fatigue or caring demands.
- For group activities, provide clear options to attend some sessions and not others, to join for shorter segments, or to participate in different ways, without pressure to commit to every meeting.
- Be flexible about rescheduling and missed sessions and avoid framing these as lack of interest or commitment, particularly where families are managing multiple appointments and crises.
- When needs change, offer to pause, scale back, or modify participation rather than withdrawing opportunities altogether, and agree on how and when to revisit involvement.
- Remind autistic people and families periodically that they can change their level of involvement, pause, or step back, and clarify what this will look like in practice, including how they can re-engage later if they wish.

Supporting regulation, safety and trauma-informed practice

Maintain psychological, sensory and relational safety, and use trauma-informed principles throughout sessions.

- Integrate regular breaks, snacks, and opportunities for movement into sessions to support regulation and sustained participation, including options to step away from the screen or change position without drawing attention.
- Normalise regulatory supports such as stimming, use of sensory tools, lying down, or camera off as acceptable ways to participate, provided the autistic person is safe.
- In group sessions, briefly explain at the outset that people can move, take breaks, and adjust their participation level without needing to justify this, so that these options are available to everyone.
- In one-to-one sessions, co-create simple signals for when the autistic person needs a pause, a change of topic, or to finish the session, and respond to these consistently.
- When sessions involve difficult or distressing topics, allow time before ending to check how the autistic person is feeling, respond to any residual distress, and then shift to a predictable, positive, or interest based topic (for example a favourite activity, character, or upcoming

enjoyable event), so the session finishes with a sense of safety and competence rather than with distress.

- Monitor psychological and relational safety throughout the engagement, not only at the start or during crises. Watch for signs that communication is becoming difficult or that overload is emerging, such as situational mutism, temporary shutdowns, withdrawal, or sudden increases in arousal. Respond by reducing demands, slowing the pace, offering breaks, or changing the format.
- Where safety, behaviour support, or crisis plans already exist, follow these during ongoing engagement. Adjust expectations and participation demands so that involvement does not increase risk for the autistic person or their family/support.
- At the start of new phases or formats, briefly remind people of exit options, complaint pathways, and wellbeing contacts, so that pausing, leaving, or seeking external support is clearly available throughout.
- Attend to cultural safety as part of trauma-informed practice, including offering choice in facilitators where possible, checking for culturally appropriate language, and being responsive to community norms and obligations.

Staying responsive and adapting supports

Use what is learned over time to refine communication, methods and supports, and to evaluate and adjust the co-production process itself.

- Build, across contacts, a working understanding of how the autistic person shows interest, consent, uncertainty, and refusal, and use this understanding to adjust how information and choices are presented.
- Use what you learn about the person's sensory needs, energy patterns, and communication style to adjust timing, breaks, formats, and participation demands across sessions, including for families/supporters.
- Regularly revisit and refine the communication, support, and environmental plans developed in earlier stages from this learning, and summarise any changes in plain language so everyone is clear about what will happen next.
- Use brief check-ins at the end of sessions to ask what worked, what was hard, and what should be different next time, using the accessible rating and feedback tools already developed with autistic people and families.
- Reflect back, in simple language, what you think you heard from autistic people and families and invite corrections, for example, "My understanding is that X felt too fast and Y was helpful. Have I got that right?"
- In longer projects, schedule occasional sessions that focus specifically on how the involvement and influence process is going, separate from the project topic, and use this feedback to adjust methods, roles, and expectations.
- At key points in the project, invite autistic people and family/supporters to review plain language summaries or emerging interpretations, and check that these reflect what they intended to communicate.
- Be prepared to change methods, materials, timing, or group structures in response to feedback or emerging needs, and document these changes in accessible language that is shared back with participants.

> “Things can go wrong… so be prepared to reflect and make changes. Be prepared to assess how well things are going and make changes if needed. Don’t be afraid to stop or change if things are no longer working” (Environmental scan)

> “A continuous evaluation process, with opportunities to check-in with study participants in a fluid and individualized way throughout the codesign process.” (Environmental scan)

> “The team made me feel like my input was heard by relaying everything back and recognising any frustrations. They demonstrated their understanding by providing me with an example or adapting some aspect, so it became more appropriate.” (Environmental scan)

Balancing perspective and tracking contributions

This step is to ensure that both autistic people and their supporters are heard, that power imbalances are recognised, and that involvement and influence are both transparent and meaningful.

- Throughout the process, ensure both the autistic person and their supporters have protected time and space to speak and be heard in ways that work for them, including alternative or augmentative communication.
- When one perspective is consistently dominating decisions or discussion, notice this explicitly, adjust facilitation to rebalance contributions, and record differences in perspective respectfully where they affect choices about supports, priorities, or next steps.
- When perspectives differ, focus discussion on what will best support the autistic person’s wellbeing, autonomy, and rights, and record how this conclusion was reached, including points of agreement and disagreement.
- Record contributions and decisions in simple, accessible ways that link specific changes or decisions to participants’ input, so that people can see how their involvement has shaped the work.
- Make it clear that not every autistic person or family will be involved at every stage of a project. Different roles can carry different levels of decision power by agreement. Document these expectations openly so that levels of involvement and influence are transparent rather than assumed.
- Establish an agreed process for situations where autistic advisers or family partners strongly disagree with the project team, for example documenting the disagreement, revisiting assumptions together, and, where appropriate, including a brief statement of differing views or a minority report in internal records or public outputs.

> “Effective and quality co-design includes the following key elements for all participants to: Be acknowledged for their contribution or have transparency around why their ideas were or were not taken on board.” (Organisation representative)

Respectful and inclusive communication across stages

Maintain communication that is accessible, rights based, and inclusive of autistic people with very high and complex support needs, recognising diverse communication styles and support needs at every stage of engagement.

- Use the agreed accessible formats and supports at every stage of the engagement, not only in introductory materials or formal meetings, for example, visual supports, Easy Read, interpreters, augmentative communication, or pre-recorded options.
- Check periodically that communication is still matched to the cognitive and communication profiles of both the autistic person and their supporters, including vocabulary level, sentence length, processing time, and the amount of information given at one time, and adjust where needed.
- Co-design terminology and language early with autistic people requiring high and complex supports and their families/supporters, and remain open to revising terminology as the project develops and as participants' preferences change.
- Avoid imposing a single correct label where multiple terms are used in the community. When choices are made about terms, name this explicitly and explain which term is used in a particular document and why.
- Ensure language does not erase autistic people with very high and complex support needs. Name disability and support needs clearly while avoiding deficit-based or dehumanising phrasing.
- Recognise that autism can be experienced both as an identity and as a disability and reflect both perspectives where appropriate, so that participants who identify with either or both positions are represented.
- Use language that is clear, respectful, and autism informed in all written and spoken communication, recognising strengths and interests while also naming support needs, barriers, and required adjustments.

Stage 6. Closure and follow through

Honour commitments, provide predictable endings, and ensure autistic people requiring high and complex supports and their families can see how their input has shaped decisions and outcomes. This stage also covers transition planning when engagement activities move into a new phase.

Closing the loop on decisions and outcomes

- Show in clear, specific ways how autistic people and families' contributions influenced decisions, documents, or actions. Use accessible examples such as before/after excerpts, tracked changes with brief explanations, or short summaries structured as "You told us X, so we changed Y.
- Explain respectfully where ideas could not be implemented and why, in plain language. Treat non-adopted suggestions as important data, not as material to be quietly discarded, and record the reasons so that decisions can be revisited later if contexts change.
- Link closure activities with the "Planning for endings, grief, and closure" processes developed earlier, so messages about finishing are consistent, predictable, and sensitive to possible grief or self-blame.

> "Keep people interested and engaged. Keep people with lived experience regularly informed about the outcomes of their work and show they are being heard and respected. This can help sustain motivation and engagement. It's not co-production if people are asked for their views and then hear nothing more about what happened." (Organisation representative)

Recognition, acknowledgement, and ongoing benefit

- Thank autistic people requiring high and complex supports and their families/supporters explicitly for their time, expertise, emotional labour, and flexibility. Use language that recognises them as partners and knowledge holders rather than as "cases", "examples", or "subjects".
- Provide brief, accessible summaries of findings or outcomes to all contributors, highlighting where their input made a difference. Use formats that match their communication preferences, for example, Easy Read summaries, short audio or video overviews, or visual one-page infographics.
- Aim for participants to gain something meaningful and positive from the engagement, not only that they provided input, for example increased confidence, useful information, or a sense of contribution.
- Offer forms of recognition that are meaningful, age appropriate, and consented to, such as certificates, letters of appreciation, named roles, brief contribution statements, or co-authorship and acknowledgements where appropriate. Clarify in advance whether and how people wish to be named.
- In longer projects, recognise contributions at agreed milestones as well as at final completion, for example interim certificates, update letters, or small appreciation events, so that appreciation and feedback are ongoing rather than confined to the end.
- Ask the autistic person and their family what types of recognition feel comfortable and useful, and avoid approaches that feel childish, tokenistic, or inconsistent with how they see themselves.
- When preparing certificates, letters, or emails of thanks, include one or two plain language lines about what the person helped with, for example "You helped us understand what makes meetings work better for your family", so that recognition feels specific rather than generic.
- Where appropriate, and consistent with ethics and authorship guidelines, offer formal recognition in project outputs, for example co-authorship, listed Advisory Group membership, or named acknowledgements in reports, guidance documents, and research papers, aligned with the person's level of contribution and preferences.
- Where it fits the project scope, provide optional, low-demand opportunities for social connection or ongoing benefit, such as informal group time, low-demand online hangouts, introductions to peer networks, or access to relevant resources. Make it clear that these are invitations, not expectations.
- For longer programs or iterative projects, briefly outline any future opportunities to stay involved or to hear about subsequent phases, so endings do not feel like a complete cut-off unless they need to be.

> "Recognise people's contributions. If people are putting their time, effort and valuable experience into making a service better, they should be recognised for it. This might be a payment, which may be essential for some people because without it, they couldn't afford to take part. For others a sense of achievement, or a simple thank you is enough." (Environmental scan)

Co-designed dissemination and representation

- Involve autistic people and families in deciding how findings are shared with different audiences, including which formats (for example, Easy Read, web pages, videos, webinars, community meetings), which audiences (for example, families, services, policymakers), and which channels feel most relevant and respectful.
- Provide draft versions of key community-facing outputs in accessible formats so contributors can check how they are represented, for example, Easy Read summaries, short videos with captions, or draft web content, and invite feedback on accuracy and tone before public release.
- Pay particular attention to how autistic people requiring high and complex supports and their families are portrayed. It is important to describe the realities of distress, risk, and intensive daily care when these are central to understanding support needs. At the same time, portrayals should protect the autistic person's dignity and privacy, and avoid framing their experiences as spectacle, shock, or pity.
- When families and supporters share their experiences, make it clear whose perspective is being described (for example, the autistic person as understood by the family, the family's own experience, or both). Where the autistic person's preferences are known, incorporate them; where they are not, explain how their current and future dignity are being protected, including for autistic children who will later become adults.
- Ensure that dissemination plans are realistic within project resources, but make visible the steps that have been taken to share findings back to the communities that contributed.

> "Co-production can broaden the places and ways in which research is shared. Research activities in this phase include developing outputs to communicate research findings to diverse audiences. Co-production activities include identifying the audiences and deciding the best ways and formats to use to communicate the findings." (Environmental scan)

Structured closure and support for co-researchers and advisers

- Recognise that autistic co-researchers, autistic co-facilitators, and family advisers may carry significant emotional load across a project, especially when work involves repeated exposure to distressing material or systemic barriers. Treat structured closure and debriefing as part of the research design, not as an optional extra.
- Plan closure processes for lived experience team members that include:
  - a dedicated debrief or reflection meeting focused on how the work has affected them
  - opportunities to identify ongoing support needs or follow-up conversations
  - explicit acknowledgement of emotional labour and any grief or loss associated with ending the project.

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Appendix 1: Principles and associated best practice points for co-production with Aboriginal and Torres Strait Islands peoples

1. Aboriginal and Torres Strait Islander leadership

Authentic and appropriate Aboriginal and Torres Strait Islander leadership must be embedded within the co-design approach. The nature and function of this leadership must be determined with the community and should reflect the community's structure and interests. Aboriginal and Torres Strait Islander leadership needs to begin during the conception stages of the project and extend beyond the completion of the project.

In practice, **Aboriginal and Torres Strait Islander leadership** means:

- Aboriginal and Torres Strait Islander leadership directs all levels and components of the project.
- Priorities and processes are determined by Aboriginal and Torres Strait Islander communities.
- Capabilities that support Aboriginal and Torres Strait Islander leadership are nurtured and strengthened.
- Governance structures are determined by the community and reflect community interests.
- Appropriate cultural and community approvals are obtained.

2. Culturally grounded approach

The strength and diversity of Aboriginal and Torres Strait Islander culture must be reflected in the co-design project and approach. A continuous process of striving for cultural competency and self-reflection by non-Indigenous people involved in the project is essential.

In practice, a **culturally grounded approach** means:

- Continuous striving for cultural competency is reflected in the processes.
- Diversity among Aboriginal and Torres Strait Islander Australians and cultures is acknowledged and responded to by the project.
- Aboriginal and Torres Strait Islander worldview underpins all components of the project.
- Strengths of Aboriginal and Torres Strait Islander cultures, knowledges and peoples are recognised and applied throughout the project.
- Continuing impacts of colonisation are acknowledged and mitigated.

3. Respect

The expertise, experience and time of Aboriginal and Torres Strait Islander people and organisations must be respected and recompensed to ensure equity for all involved in the co-design process. Approaches must incorporate flexibility and must be familiar and engaging for Aboriginal and Torres Strait Islander Australians to feel comfortable and welcome to lead and participate in the process.

In practice, **respect** means:

- Expectations of Aboriginal and Torres Strait Islander people and organisations are fair and reasonable.
- Provision of remuneration to Aboriginal and Torres Strait Islander people and organisations equitably compensates their time and knowledge.
- Adequate time and resources are provisioned to successfully complete the project objectives.
- Flexible and iterative processes are embedded and facilitated.
- Culturally appropriate language, branding and design is used throughout the process.

4. Benefit to community

Co-design projects must aim to serve Aboriginal and Torres Strait Islander Australians and communities above all else. The project conception, design, processes and outcomes must provide timely, tangible and sustainable benefits that are valued by the community.

In practice, **benefit to the community** means:

- The community sets the agenda for the project or contribute to these.
- The outcomes of the project offer tangible and sustainable benefits that are valued by the community.
- Aboriginal and Torres Strait Islander people and communities own the data and the knowledge resulting from the project.
- Capabilities valued and prioritised by Aboriginal and Torres Strait Islander people are fostered and strengthened.

5. Inclusive partnerships/relationships

Fostering and maintaining equitable and collaborative relationships between all participants is central in driving effective co-design projects. Establishing appropriate communication channels and conflict resolution processes, formulated by and with community, that maintains trust and supports authentic partnerships is imperative.

In practice, **inclusive partnerships/relationships** mean:

- Sustained collaboration that fosters two-way learning is developed and maintained.
- Self-determination of Aboriginal and Torres Strait Islander Australians is supported by the project.
- Achieving equity for Aboriginal and Torres Strait Islander Australians is prioritised.
- Regular and sustained culturally appropriate communication channels are maintained.
- Conflict resolution protocols are formalised to manage disagreement.

6. Transparency and evaluation

Transparency in all aspects of the co-design project is essential. Accountability to Aboriginal and Torres Strait Islander leaders must be formalised and embedded into co-design projects. Embedding monitoring and evaluation throughout the co-design process using agreed performance indicators that facilitate transparency and accountability to community is essential.

In practice, **transparency and evaluation** mean:

- Transparency in decision making and benefits to stakeholders is ensured to enable accountability.
- Monitoring and evaluation processes are built into the project.
- Project outcomes are not pre-determined and are authentically co-designed.

Appendix 2: Principles and associated best practice points developed from the environmental scan related to co-production with individuals with high and complex support needs

Power-Sharing and Equity

Co-production should actively rebalance power. Autistic people with high and complex support needs, and, where relevant, their families and supporters, should be supported to have meaningful influence at every stage where appropriate. While roles and levels of decision-making power may vary, efforts should be made to ensure that no decisions are made without those directly involved.

When someone cannot self-advocate, respectful family advocacy can support or amplify their preferences and rights. This means recognising the expertise (that comes from lived experience and daily connection) of those who support non-speaking or highly supported people, while ensuring all contributions are resourced, respected, and part of shared decision-making. Family input does not replace autistic voice but can help uphold it when direct input is not possible.

In practice, power-sharing and equity means:

- Creating structures for shared decision-making
- Recognising and addressing power imbalances across roles and institutions
- Supporting different ways and levels of participation
- Including family and supporter input when needed
- Valuing all contributions equally, regardless of role or title
- Sharing ownership of knowledge and decisions
- Reviewing how power is held and used over time
- Avoiding tokenism by ensuring real influence

Accessibility and Flexibility

Co-production should be accessible and flexible at every stage to ensure that autistic people with high and complex support needs, and, where relevant, their families and supporters, can engage in ways that work for them.

This includes both universal and individual access, flexibility in timing and format, and the proactive removal of barriers. Accessibility should be ongoing and responsive, adapting to changing needs and contexts over time. Families who advocate on behalf of those unable to contribute directly should also be supported to participate meaningfully.

In practice, accessibility and flexibility mean:

- Offering multiple modes of engagement
- Ensuring environmental, sensory, and communication accessibility
- Being flexible with timing, format, and input
- Meeting people where they are (e.g., informal or online options)
- Proactively identifying and removing barriers
- Allocating time, funding, and support to enable access
- Supporting family or supporter input where appropriate
- Adapting strategies to reflect changing capacities and needs

Recognition, Reciprocity, and Capacity-Building

Co-production should respect and value all contributions, including lived and relational expertise. Autistic people with high and complex support needs, and, where relevant, their families and supporters, should be genuine partners and/or contributors, not token participants. This includes fair recognition, shared learning, and support to build capacity over time.

Families who advocate for those unable to contribute directly should have their role acknowledged as valid and meaningful. Building capacity requires adapting to diverse communication styles, learning needs, and abilities, with training and support that facilitate active participation.

Reciprocity means everyone contributes, and everyone benefits

In practice, recognition, reciprocity, and capacity-building means:

- Valuing all types of knowledge: personal experiences, insights from relationships, and practical skills.
- Recognising when families advocate for autistic people who can't do this for themselves.
- Offering flexible ways to acknowledge contributions, like payment, credit for writing, or formal recognition.
- Providing training and support that fits different needs.
- Helping people grow in confidence and ability over time.
- Making sure everyone learns from each other and reflects together.
- Avoiding taking information without giving back – all input must lead to action.
- Helping people continue to grow and lead even after the project ends.

Diversity, Inclusion, and Authentic Voice

Co-production should, as much as possible, ensure that all relevant perspectives, identities, and lived experiences are present, valued, and empowered to contribute meaningfully. Inclusion is not passive, it requires intentional actions to involve those who are often excluded, including autistic people with high and complex support needs and, where relevant, their families and supporters.

All contributions should be treated with respect, and all forms of knowledge, academic, community-based, and lived, valued equally. Authentic voice should be supported through accessible, alternative, or supported communication. Intersectionality should be recognised, particularly for autistic people with intellectual disability and/or multiple additional diagnoses, whose perspectives and support needs may differ.

In practice, diversity, inclusion, and authentic voice means:

- Proactively seeking diverse participants
- Respecting all communication styles
- Creating safe, inclusive spaces for contribution
- Supporting family or relational advocacy where needed
- Addressing intersectionality and diverse experiences
- Avoiding tokenism by integrating feedback into decisions
- Explaining when input is not used and why

Respect, Trust, and Safety

Co-production should be built on mutual respect, emotional and physical safety, and genuine trust. Autistic people with high and complex support needs, and, where relevant, their families and supporters, should feel welcome, valued, and safe to participate without fear of harm, exclusion, or retaliation.

This includes recognising trauma, creating consistent and supportive relationships, and consulting before decisions are made. Safety should be actively maintained and not assumed. Families who advocate for those unable to participate directly must also feel safe, heard, and respected.

In practice, respect, trust, and safety means:

- Valuing all forms of expertise and contribution
- Promoting psychological and cultural safety
- Recognising and responding to trauma and past harm
- Prioritising consistency, trust, and relationship-building
- Designing inclusive, non-retaliatory feedback processes
- Co-creating safer and braver spaces over time
- Consulting before, not after, decisions are made
- Supporting family members who advocate on others' behalf

Transparency and Accountability

Co-production should ensure that everyone shares a clear understanding of the project's purpose, goals, roles, and expected outcomes. Communication should be open and ongoing, with all contributions acknowledged and discussed. Transparency includes recognising differing forms of expertise and ensuring decisions are made and shared fairly.

Accountability means closing the loop, explaining how feedback is used, what happens next, and why some suggestions may not be taken up. It also means building in time for reflection and shared oversight across the project.

Both transparency and accountability are essential in building trust and relationships over time (and will increase the chances of future participation).

In practice, transparency and accountability mean:

- Clearly sharing goals, roles, scope, and processes
- Communicating openly and honestly throughout
- Recognising different types of knowledge and assumptions
- Explaining how input is used or, if not, why
- Including time for collective reflection and feedback
- Ensuring all voices are heard and credited appropriately

Collective Action, Relationships, and Wellbeing

Co-production should intentionally support positive relationships, shared purpose, and environments that promote wellbeing. Autistic people with high and complex support needs, and those who support them, should feel safe, included, and able to contribute in ways that align with their strengths and values.

This means fostering trust over time, building supportive networks, and valuing community knowledge. Genuine collaboration requires conditions that enable creative, respectful participation, including space for emotion, vulnerability, and hope. Engagement should enhance both individual and collective capacity to participate meaningfully.

In practice, collective action, relationships and wellbeing mean:

- Prioritising relationships built on mutual trust and shared purpose
- Designing inclusive, welcoming environments
- Encouraging creative input and shared leadership
- Using community and peer networks to strengthen involvement
- Supporting resilience, self-expression, and emotional safety
- Promoting personal and collective wellbeing throughout

Rights, Ethics, and Reflexivity

Co-production should be guided by a rights-based, ethical approach that prioritises participant safety, informed consent, and meaningful choice. Autistic people with high and complex support needs, and their families or supporters where relevant, should be respected as contributors and decision-makers throughout the process.

Ethical reflexivity is essential. This includes anticipating potential risks, protecting people from harm and tokenism, and adapting processes to support informed participation. Confidentiality should be upheld at all times, and contributions must be handled with care and integrity.

In practice, rights, ethics, and reflexivity mean:

- Embedding a human rights approach into all co-production activities
- Prioritising informed, voluntary, and ongoing consent
- Actively identifying and addressing tokenism
- Exploring issues that matter most to autistic people and families
- Supporting decision-making through reflective, inclusive processes
- Respecting confidentiality and privacy across all stages

Appendix 3: Quick guide to stages of engagement with autistic people with high and complex support needs

This quick guide summarises the six Recommendations for engagement sections. It highlights:

- **Essential practices:** minimum requirements for safe, ethical, and credible engagement with autistic people requiring high and complex supports and their families.
- **Enhanced practices:** actions to aim for when resources allow, which are strongly recommended but may be implemented progressively.

The full guidance document provides detailed explanations, rationales, and implementation options.

Stage 1. Facilitation skills

Purpose: Ensure that conveners and co-facilitators can safely hold space, share power, and include diverse communication styles.

Essential practices:

- Clarify roles at the beginning of each session to ensure it's clear who is a facilitator, researcher, participant, family member, or organisational representative.
- Practise active listening and assume competence in autistic people and in the families and supporters who know them best, even when communication is limited, supported, or non-speaking.
- Organise and actively facilitate turn taking to ensure no individual or group dominates, with particular attention to preventing more resourced or confident allies from overshadowing autistic people who require high and complex supports and their families, while gently encouraging quieter voices to participate.
- Watch for signs of distress or overload in individuals and utilise pre-agreed exit options and breaks without drawing attention to anyone.

Enhanced practices:

- Ensure facilitators are trained in autism-informed, trauma-aware, and power-conscious practices.
- Provide various ways for contributions during each session (spoken, chat, visual, written, or one-to-one follow-up).
- Follow up after sessions with participants who seemed distressed or unheard to check their wellbeing and adjust future engagement plans.

Stage 2. Define the purpose and plan

Purpose: Clarify why you are engaging, who needs to be involved, and what level of involvement (i.e., participation) and influence (i.e., power) autistic people requiring high and complex supports and their family/supporters will have on decisions, as the central voices in the process.

Essential practices:

- Make explicit from the outset that autistic people who require high and complex supports, together with their families and supporters, are the core voices for this work, and that other autistic people or allies are there to speak in support of them, not instead of them.
- Plan engagement based on the belief that autistic people requiring high and complex supports can and should be included when engagement is accessible, rather than seeing them as 'too hard' to involve.
- Plan for the additional time, budget, and support needs involved in engaging autistic people requiring high and complex supports, along with their families and supporters. Treat these as fundamental requirements for ethical practice, not as reasons to exclude them.
- Design initial governance and role frameworks that can genuinely support power sharing with autistic people who require high and complex supports, as well as their families and supporters, rather than merely symbolic involvement.
- Define the specific decisions that are genuinely open to influence and clearly explain this to autistic people requiring high and complex supports, along with their families or supporters.
- Determine the appropriate level of participation for autistic people who require high and complex supports, along with their families or supporters, for each activity (such as informing, consulting, involving, collaborating, empowering, or co-leading), record this in the project plan, and ensure it is feasible within the available project resources.
- Select a participatory approach that aligns with your goals, budget, and desired level of involvement and influence (for example, community-based participatory research, stakeholder engagement), and note why this approach is suitable for autistic individuals needing high and complex supports.

Enhanced practices:

- Identify the types of lived experience crucial for the project, such as communication profiles, support needs, regional or remote living, cultural background, and care roles, then plan to include perspectives from these groups.

Stage 3. Preparation

Purpose: Establish the supports, materials, and structures necessary for safe and meaningful engagement. This includes internal preparations by the project team and initial, low-demand contact with autistic individuals who require substantial and complex supports, as well as their families and supporters, so that formal activities are organised around their preferences.

Essential practices:

- Designate a convener as the fixed point of contact and, where feasible, as the main facilitator, ensuring they understand their duties regarding communication, accessibility, and follow-up.
- Prepare information in at least two accessible formats and at multiple levels of complexity, so that both supporters and autistic people needing high and complex supports can understand and take part in decisions. For example:
  - Autistic people requiring high and complex supports might need very simple visual stories, picture sequences, objects, or other creative, non-text-based explanations tailored to their communication strengths and sensory preferences.
  - Some parents and supporters might favour full plain language documents, while others might prefer Easy Read or short audio or video overviews.
  - Consult autistic individuals and their families to find the most workable combination for them.
- Offer multiple ways to participate and prioritise options that suit autistic people needing high and complex supports, such as home visits, familiar local community settings, and, where appropriate, online, phone-based, or other asynchronous methods. Enable people to switch modes as necessary.
- Plan and clearly communicate exit options, standard breaks, and wellbeing contacts so that people can discreetly step away or pause without feeling pressured, and know who to contact if they need support during or after the session.
- Allocate more time and budget for practical supports, including transport, support persons, and reimbursement of reasonable expenses for autistic individuals who need high and complex supports, along with their families or supporters.
- Establish shared communication and decision-making processes that include autistic people requiring high and complex supports and their families, with agreed response times, meeting formats, and clear decision rules aligned with their level of participation and influence.
- Design recruitment to ensure participation is distributed among a wider pool of autistic people requiring high and complex supports and their families, rather than relying on the same individuals repeatedly. When possible, plan for rotation or rest periods so that heavily involved families are not burdened with a continuous load.
- Plan tailored supports for autistic co-researchers and family advisers, recognising the emotional labour involved, and guarantee access to regular debriefing, supportive supervision check-ins, manageable workload limits, and participation adjustments that respect autistic communication, sensory, and regulation needs.
- Prepare internal project documents that are directly relevant to autistic co-researchers, autistic co-facilitators, and family advisors (for example, role descriptions, ethics summaries,

and payment information) in accessible formats, so that team processes as well as participant materials are understandable and usable.

Enhanced practices:

These practices are strongly recommended where resources permit, and may be vital for some autistic people who require high and complex supports to participate meaningfully.

- Where resources allow, expand on these formats by offering more creative and story-focused ways to participate, such as drawing, comics, simple play scenarios, or co-created narratives centred around the person's deep interests.
- Co-design engagement activities with autistic people who require high and complex supports, along with their families and supporters, ensuring each activity is tailored to their individual interests, communication styles, and sensory preferences, rather than applying a one-size-fits-all approach.
- At an organisational level, plan for long-term infrastructure such as a dedicated advisory network for autistic people requiring high and complex supports and their families. This ensures recruitment does not depend on the same small group of people for each project.

Stage 4. Initiation and early engagement

Purpose: Initiate contact in ways that foster trust, clarify expectations, and enable autistic individuals needing high and complex supports, along with their families and supporters, to feel safe, recognised, and heard.

Essential practices:

- Make sure to offer at least one initial contact before any group or formal session, with the convener as the main point of contact if possible.
- Adjust the length, mode, and sensory setup of the introductory meeting for autistic people requiring high and complex supports, as well as their families and supporters' cognitive and communication needs, and ensure sufficient lead time before the first formal session.
- Treat feeling safe and respected as a non-negotiable requirement for involvement, and support autistic people who require high and complex supports and their families to decide how much they want to be known personally and what they prefer to keep private.

Enhanced practices:

- Where project resources permit, utilise familiar settings chosen with the family, such as home, school, local community spaces, or low-pressure online environments, instead of only formal clinics or university settings.
- For ongoing work, spend time understanding the person’s communication style, sensory needs, and early signs of overload (e.g., cognitive, sensory, emotional), and use this knowledge to personalise future sessions and improve earlier plans.
- Include brief, consent-based social time and two-way conversation so that autistic people requiring high and complex supports, along with their families and supporters, see you as both a person and a professional, not just as someone asking questions.

Stage 5. Ongoing and across-stage approach

Purpose: Maintain participation, relationships, accessibility, and fairness throughout the project's duration, and adjust arrangements as needs and circumstances evolve.

Essential practices:

- Regularly review whose voices are influencing decisions, which perspectives are absent, and how power dynamics function, and check that autistic people who require high and complex supports and their families remain central rather than being overshadowed by more vocal or resourced allies. Adjust facilitation, roles, or processes to rebalance influence where necessary
- Provide regular, accessible updates on how feedback is being considered and used, and verify with autistic individuals and families that your interpretations and summaries are accurate.
- Use the agreed accessible formats and supports consistently at every stage, not just during recruitment or early contact.
- Incorporate planned breaks, movement options, and low-demand ways to pause into all sessions, making it simple for people to step away, adjust their position, or turn cameras off without attracting attention or needing to explain.
- Monitor psychological safety and signs of overload over time, then adjust methods, timing, demands, or environments when distress, overload, or shutdown occurs.
- Periodically review earlier participation arrangements, including timing, format, and mode of contact, to ensure they still suit people's energy levels, routines, and support needs.
- Structure sessions in shorter bursts or offer flexible pacing options instead of relying on lengthy, intensive meetings. Be adaptable with rescheduling or missed sessions to ensure participation isn't lost due to illness, fatigue, or caring commitments.
- Record key contributions and decisions in clear, accessible ways so that transparent feedback and corrections are possible.
- Be clear that not every autistic person or family needs to be involved at every stage for their contribution or the project to be valid. Different roles can have varying levels of decision making influence by agreement, with autistic people who require high and complex supports and their families at the centre, and this distribution of influence should be transparent.
- Establish a clear process for situations where autistic advisers strongly disagree with the project team. For example, identify the disagreement, review the reasons from all perspectives, and if differences persist, record them clearly and include a brief minority statement or note of dissent in project records or outputs.
- Aim to prevent over-reliance on the same autistic people and families across multiple projects. Implement rotation or "rest periods" for heavily involved participants, even if they are very engaged, and regularly check that cumulative workload and emotional demands stay manageable.
- Co-design terminology and language with autistic people and families, document individual preferences, and use communication that is precise, respectful, and recognises both strengths and support needs.
- When participation decreases or pauses due to health, fatigue, or crises, consider this normal and provide options to scale back or rejoin later, rather than viewing it as disinterest.

Enhanced practices:

- Where possible, replace long, intensive meetings with several shorter sessions, flexible pacing, or smaller topic-focused segments that allow for rest and reflection.
- Offer follow-up opportunities after each point of contact, such as additional comments by email, text, phone, voice messages, or brief one-to-one sessions, to ensure later-emerging views can still be included.
- In longer projects, schedule occasional sessions that specifically focus on how the engagement process is progressing, not just on the project topic, and use this feedback to revise methods, roles, and expectations.

Involve autistic people who require high and complex supports, along with their families or supporters, in checking interpretations and, where possible, co-analysing feedback so that summaries accurately reflect what they intended to communicate.

Stage 6. Completion and follow-through

Purpose: Respectfully close the engagement, honour commitments, and ensure contributions are recognised, visible, and linked to meaningful influence, while supporting the wellbeing of autistic people, families, and co-researchers.

Essential practices:

- Present clearly in simple language and accessible formats how participants' contributions influenced decisions, documents, or actions, and explain respectfully when ideas could not be implemented and why.
- Provide concise, accessible summaries of findings or outcomes to autistic individuals and families, emphasising where their input has made an impact.
- Thank autistic people who require high and complex supports, along with their families and supporters, explicitly for their time, expertise, and emotional labour, using language that acknowledges them as partners rather than just case examples.
- Ensure dissemination reflects participants' voices by providing accessible versions of key community-facing outputs for review (for example, Easy Read summaries, web pages, short videos), inviting autistic people and families to check how they are represented and to advise on preferred formats, audiences, and channels for sharing.
- Offer structured closure and emotional support for autistic co-researchers and family advisers, in line with the safety and wellbeing planning outlined in Section 1.3. This may involve planned debriefing, supervision, or peer support opportunities, as well as established limits on exposure to highly distressing material at the conclusion of a project.
- Provide forms of recognition that are meaningful, age-appropriate, and have consent, such as certificates, letters of appreciation, named roles, or co-authorship where suitable.

Enhanced practices:

- Where appropriate for the project, propose optional, low-effort opportunities for ongoing connection or benefit, such as introductions to peer networks, informal online gatherings, or access to relevant resources.
- In longer projects, recognise contributions at agreed milestones and at final completion so that appreciation and feedback continue throughout, rather than being limited to the end.
- Plan for timely, predictable payments by taking into account institutional HR and contracting delays, setting realistic timeframes in project planning, and communicating clearly with autistic co-researchers and family advisors about payment processes. Where policies allow, implement interim measures like staged payments or vouchers so participants are not left waiting long after their work is complete