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SYDNEY



# Growing up making decisions

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## Words used in this report

| Word                    | Meaning  |
|-------------------------|--|
| Autonomy                | Autonomy in decision-making means making decisions for yourself.   |
| Cognitive impairment    | <p>Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life and may require support to make decisions.</p> <p>People with cognitive impairment include people with intellectual disability or foetal alcohol spectrum disorder (FASD) they were born with; an acquired brain injury; autism; neurodiversity; or psychosocial disability where cognition can be impaired through episodes of mental distress or emotional trauma and medication.</p> <p>Cognitive impairment is not static, it can be episodic, improve or develop, and it can also degenerate. The ability to make decisions can exist along a spectrum, can be context sensitive, and can change. The ability to make a decision is always the starting assumption.</p> |
| Dignity of risk         | The freedom to make choices and take risks in order to learn, grow and have better quality of life, on an equal basis with others.   |
| Family                  | Family in this report is inclusive of any family-like care relationship.   |
| Out of home care (OOHC) | <p>Out of home care means where children and young people live (up to the age of 18) who are not able to live with their parents.</p> <p>There are different types of out of home care. This includes foster care, relative or kinship care, family group homes, residential care, and independent living.</p>   |
| Parents                 | Parents in this report is inclusive of <i>any</i> adults in a parental care role.  |
| Stakeholders            | In this report, stakeholders means a person or organisation who has a role in supported decision-making or increasing autonomy in decision-making.   |

| Word                      | Meaning  |
|---------------------------|--|
| Supported decision-making | <p>Supported decision-making can be better understood as the process of decision-making support by which a supporter acknowledges that a person with cognitive impairment at all times retains full legal personhood, and inalienable Human Rights, and seeks to identify the 'will and preferences' of a person requiring decision-making support and communicate those to others when required, so that the person requiring support is at all times empowered to exercise their legal capacity, and direct choice and control over their life goals.</p> <p>Supported decision-making is to be contrasted with substitute decision-making, where decisions are made for the person by a third-party. This includes schemes where a Court or Tribunal, if satisfied that a person is not able to make decisions that are in that person's best interests, will appoint a person to make decisions for the person with cognitive impairment after considering what their 'best interests' are, effectively denying the person with cognitive impairment their legal personhood, autonomy, and legal capacity. Substitute decision-making may be assumed by a family member, carer or service provider undermining the rights of the individual to make their own decision – supported or otherwise.</p> |
| Supporter                 | <p>A supporter is a person who:</p> <ul style="list-style-type: none"> <li>• assists a person with cognitive impairment to identify and express their will and preferences</li> <li>• upholds and gives effect to the persons rights</li> <li>• assists them to understand the process of decision-making; assists them in identifying choices, and</li> <li>• ensures that decisions subsequently made by the person requiring decision-making support are acknowledged as decisions of that person for all legal purposes.</li> </ul> <p>Supporters can be in 'informal' arrangements (such as a family member or trusted friend) or a more 'formal' arrangement where a supporter (including a family/trusted person) is appointed by an agency as a service, and there is a written agreement between the</p>  |

| Word                         | Meaning  |
|------------------------------|--|
|                              | parties as to scope and obligations; for example, in respect of decision-making support.   |
| Transition                   | Moving from childhood to adulthood – part of growing up.   |
| Will, preferences and rights | <p>‘Rights’ are all human rights and fundamental freedoms.</p> <p>‘Will’ means larger life goals, political perspectives, emotional and spiritual development and views, gender and sexuality identity for example.</p> <p>‘Preferences’ means choices regarding day-to-day- activities, aesthetic preferences, and similar.</p> <p>‘Will’ and ‘preferences’ is also regularly connected with ‘rights’ in the sense that supported decision-making is about giving effect to the will, preferences and <i>rights</i> of a person requiring decision-making support.</p> <p>‘In cases where it is not possible to determine the will and preferences of the person, the default position must be to consider the human rights relevant to the situation as the guide for the decision to be made’ (ALRC 2014, para 3.53).</p> |
| Young people                 | <p>In this report, young people are aged 15 to 30 years.</p> <p>In this report, when we say young people, we are talking about young people with cognitive impairment</p>  |

## Abbreviations used in this report

|           |   |
|-----------|---|
| ALRC      | Australian Law Reform Commission  |
| Committee | The United Nations Committee of the Rights of Persons with Disabilities       |
| CRC       | The United Nations Convention on the Rights of the Child                      |
| CRPD      | The United Nations <i>Convention on the Rights of Persons with Disability</i> |
| CYDA      | Children and Young People with Disability Australia                           |
| IA        | Inclusion Australia   |
| ITCSD     | Intensive therapeutic care for significant disability                         |
| NDIA      | National Disability Insurance Agency  |
| NDIS      | National Disability Insurance Scheme  |
| OOHC      | Out of home care  |
| SPRC      | Social Policy Research Centre, University of New South Wales                  |
| TSIL      | Therapeutic supportive independent living                                     |
| UDHR      | Universal Declaration of Human Rights   |
| UNSW      | University of New South Wales   |

# Summary

This research project, **Growing Up Making Decisions**, was funded by the National Disability Research Partnership. The research was led by the Social Policy Research Centre, with Children and Young People with Disability Australia, and Inclusion Australia. The research was conducted by and with people with disability.

Many young people with cognitive impairment grow up without the support and skills to express their will and preference to make decisions about their life. This is likely to result in other people making decisions on their behalf. Evidence given at the Disability Royal Commission shows this can result in abuse, neglect, harm or exploitation. **This research examined what supports young people with cognitive impairment need to develop skills to identify what they want and do not want, and make decisions for themselves.** The research also tried to understand if this was different for young people living with family and young people living in other settings.

**The research started by looking at what was already known.** Making decisions provides an opportunity to exercise rights. Making decisions helps build a person's identity, provides them with control, allows them to maximise life choices, and provides protection in vulnerable situations. There are different expectations of young people and adults (over 18 years old) when making decisions. Everyone, including people with cognitive impairment, have the right to make decisions and express their 'will and preference'. They also have the right to access support when making decisions. For people under 18 years old, other people or organisations may ensure that decisions are in their best interests or in some cases make decisions for them. Where this happens the young person's views should also be considered.

The research team **talked to three different groups of people:**

- young people (aged 15-30) with cognitive impairment
- families of young people with cognitive impairment
- other stakeholders working with young people with cognitive impairment.

The research first looked at **what young people needed.** We found:

- Young people want to make decisions across different aspects of their lives.
- Young people had to make some decisions based on age, including about leaving school, finding a job, or where to live.
- Young people in out of home care need to make a lot of decisions when getting ready to leave out of home care at the age of 18 – more than other young people.

- Young people and their families talked about different support needs depending on the type of decision, their age, and in different settings.

The research then looked at **what supported young people to develop skills**. We found:

- The process depended on the support needs, the type of decision, and the supports around the young person.
- Long-term, incremental learning was considered very important – starting as early as possible.
- Similar to supported decision making, the learning process was enabled by people who young people trusted or had good relationships with.

The research then looked at **what improvements could be made**. We found:

- Systems such as education, health, NDIS, and out of home care, could be improved so that young people have the opportunity and support to be part of the decision-making process.
- More information should be provided about rights – to young people with cognitive impairments and their families, and also society more broadly.
- More information and resources should be provided to young people, their families and services about supporting young people to build capacity in decision making.
- Programs are needed to support young people build capacity in decision making – including specific areas such as leaving out of home care, NDIS planning, moving to adult health care, leaving school, finding employment, moving out of home.

This research shows that learning to make decisions is a natural process for children and young people as they grow up. For young people with cognitive impairment, this is a more conscious, intentional and resource intensive. This process **needs support both at home and in other settings – including the education system**.

**More research is needed** to understand:

- what happens when young people are not supported to build their capacity in making decisions
- how to support young people with high support needs
- how to support young people living in institutional settings
- how to support young people in culturally responsive ways. This is important for First Nations young people and young people from multicultural backgrounds.

# 1 Introduction

This study seeks to build understanding about how young people with cognitive impairment can be supported to develop skills to express their will and preferences and make decisions. The project **identifies the policy, organisational arrangements and practices that respect and support the evolving capacity of young people with cognitive impairment to express their will and preferences and make decisions**. This study seeks to:

- Identify what supports young people need to develop capacity to identify will and preference and make decisions
- Understand if and how this varies for young people living with family, in out of home care, and in other settings.

The UN CRPD reaffirms that all people are equal before the law and that impairment should not be the basis for the denial or diminishment of legal capacity. People with disability have a right to supports to exercise their legal capacity on an equal basis with others – referred to as supported decision-making (Kayess & Sands, 2020). When growing up, some decisions may be made for young people by others in their ‘best interests’; however, children have the right to have their opinions taken into account (UN CRC). Children and young people develop skills as they mature to identify and express their will and preference to make decisions for themselves. For many children this is supported at home, and by access to education and peer and support networks. However, for children and young people with cognitive impairment, they may not have access to those opportunities. Providing limited opportunities for children to identify and express their will and preferences, or access to supported decision-making, leads to a reliance or an assumption by others to make decisions for them.

When young people are denied the opportunity to develop their capacity in decision-making, this may lead to the person being unable to make decisions and/or never being given the opportunity to exercise their will and preference. Young people with cognitive impairment are then at risk of becoming ‘eternal children’ – infantilised throughout adulthood. A denial of their personhood causes psychological harm and an increased risk of being subject to restrictive interventions such as guardianship orders which can further remove legal capacity from a person (United Nations, 2014, [27]). This results in the ongoing denial of an individual’s fundamental rights under article 12 of the *United Nations Conventions on the Rights of Persons with Disability* (CRPD). Identifying will and preference is not limited to making decisions but is also a protective factor in being able to identify where they are not comfortable or feeling vulnerable and the ability to identify and

articulate their concerns. Capacity to make decisions is also required to access and navigate services and systems; for example, disability services (NDIS) and transitioning from out of home care. If an agency considers a person not to be able to make such decisions, they may seek the appointment of a guardian.<sup>1</sup>

While supported decision-making for people with disability has received attention from policy makers, practitioners and academics, and resources exist or are being developed to support the process (Laurens & Kayess, 2021), little attention has been given to developing capacity for decision making.<sup>2</sup> Further, capacity and support for developing capacity may differ for young people with cognitive impairment living in different settings, including those living with family, in out of home care, and in other settings. This study seeks to understand the needs of young people with cognitive impairment living in different settings, the supports available to them, and any additional supports required to make this transition to exercise their fundamental rights.

The objectives of this study are therefore to:

- Identify the policy, systems and practices that respect and support the evolving capacity of young people with cognitive impairment as they grow up.
- Identify the needs of young people in developing autonomy, and explore how this differs for young people living in different settings – including living with family, living in out of home care, and living in other settings.
- Identify the existing resources and supports to develop autonomy
- Identify any additional supports required in different settings. Identify any changes required by policy makers, service providers, advocates, family members and people with disability to ensure that young people with cognitive impairment are respected and supported in transitioning to a rights and preferences framework.

Participants in this project included young people with cognitive impairment living with family, in out of home care, and living in other settings (including independently); parents

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<sup>1</sup> The Annual Reports of State/Territory Offices of the Public Advocates/Guardians highlight an increase in guardianship appointments for people with cognitive impairment and psychiatric disability associated with the roll out of the NDIS (to advocate for the person's preferences, identify and manage risks, make decisions about NDIS services) and increased awareness for consent to restrictive practices (ACT Public Trustee and Guardian, 2021; Department of Justice Western Australia, 2021; NSW Trustee and Guardian, 2021; Office of the Public Advocate (South Australia), 2021; Office of the Public Advocate (Victoria), 2020, 2021; Office of the Public Guardian (Northern Territory), 2021; Office of the Public Guardian (Queensland), 2021; Office of the Public Guardian (Tasmania), 2021).

<sup>2</sup> See for example a tool developed by La Trobe University to provide an evidence-based framework on the process of supporting people with cognitive disabilities to make decisions – available from <https://www.supportforddecisionmakingresource.com.au/> (accessed 25 May 2022).

and carers; and other stakeholders working and supporting families. This provided an opportunity to understand what policies and practices work and what changes are required in different settings.

This report:

- describes the approach and method (Section 2)
- presents the context of evolving capacity to express will and preference and make decisions (Section 3)
- describes the needs of young people and their families who participated in the study (Section 4)
- identifies the resources and supports families use (Section 5)
- identifies further supports required (Section 6).

Section 7 concludes the report and makes recommendations for further work.

## 2 Approach and method

The study uses an evidence review and interviews with young people, families/carers, and other stakeholders, to understand what supports young people with cognitive impairment need and receive to respect and support their evolving capacity to make decisions, and move towards exercising their will and preference. The study received ethics approval from UNSW HREC (H210677).

The method aligns with:

- the CRPD in that the research is by and with people with disability, and considers impairment being an equally valued aspect of human diversity and human dignity (General Comment 6).
- *Australia's Disability Strategy 2021-2031* (DSS, 2021) in that the study considers decisions made across each domain (employment and financial security; inclusive homes and communities; safety, rights and justice; personal and community support; education and learning; health and wellbeing; community attitudes). Examples of decisions are provided in Appendix B.

### 2.1 Evidence review

A **review of academic and grey literature** identifies prior research in supporting young people to transition from childhood into adulthood. This has been synthesised within the context of moving from a 'best interests' decision-making framework for children as outlined in the United Nations *Convention on the Rights of the Child* (CRC) to a 'rights, will and preferences' framework as articulated in article 12 of the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD). The CRPD also notes that 'best interests' applies to children with cognitive impairment under the age of 18. The 'rights, will and preferences' decision-making framework is commonly applied to those over the age of 18.

The review sought to identify challenges experienced by young people with cognitive impairment in this process, including how they may understand it. It also examined implications of this for stakeholders, including service providers and government institutions. The review, presented in Section 3, provides the conceptual foundation upon which this research was undertaken and informs the analysis.

## 2.2 Data collection (Interviews)

Interviews were conducted to gain insights from young people (n=17), parents (n=13), and other stakeholders supporting young people (n=22), about how they grow up making decisions and how evolving capacity is being supported.

### 2.2.1 Young people and their parents

Young people (aged 14-30) with cognitive impairment living in Australia were invited to participate in the study through their representative organisations (Inclusion Australia, CYDA, and their member organisations). This included young people who had lived or were living with family, out of home care, or other settings. Sampling was purposive which allowed Inclusion Australia and CYDA to reach different demographics. Potential participants were provided with clear, accessible information about how to take part and only interviewed with their informed consent. Interviews were led by a community researcher and were conducted face-to-face where COVID-19 public health orders allowed (for example, in Western Australia) or using Zoom. Community researchers included young people with disability so that participants could be interviewed by their peers. Interviews were recorded with permission of the participant and transcribed for analysis. All research materials were provided in Easy English (this included recruitment material, the information statement and consent form, the discussion guide, and the verbal consent process).

Parents of young people with cognitive impairment (aged 14–30) were also invited to participate in the study following the same recruitment method as the young person. ‘Parents’ in this report is inclusive of any adults in a parental care role. The term parent is used throughout to distinguish between the young person within the family and those adults with a parental care role. The discussion guides for both young people and parents are presented in Appendix A.

Community researchers from CYDA and Inclusion Australia interviewed 17 young people with cognitive impairment and 13 parents of young people with cognitive impairment. In addition, one young person provided a written response (young people n=18, parents n=13). Participants in the study came from five states and territories (ACT, NSW, SA, VIC and WA). Slightly more than half of young people interviewed used the pronouns he/him. All except for two parents identified as the mother of a young person with cognitive impairment.

There was some representation from First Nations and migrant communities, and the LGBTIQI+ community, as well as regional communities, but numbers are too small (<5) to be reported. Most young people were living at home with their family (most lived with mum,

dad and often with siblings). Some young people (<5) had experience of living in other settings, such as out of home care or living independently. More than half of the interviews are dyadic, meaning the young person's parent was also interviewed (separately) as part of this study.

Young people interviewed had a range of type and level of support needs and reasons to need support. Some young people chose to have a support person with them to participate in the research – for some this was a paid support worker, for others this was their mum (who was also interviewed separately).

Data from young people is presented in this report with the reference (#YP) followed by the number of the participant (1–18). Data from parents are presented in this report with the reference (#PC) followed by the number of the participant (1–13). No other personal identifiers are used.

## **2.2.2 Other stakeholders**

Interviews with stakeholders sought to identify how evolving capacity is being supported at an individual and a systems level. Stakeholders invited to participate in the study could participate in either an interview (alone or with others) or provide a written response.

The research team identified stakeholders who provide services and supports for young people and their supports (including disabled persons organisations and representative organisations, and other stakeholders working with young people with disability), and stakeholders involved in systems supporting young people across the domains of *Australia's Disability Strategy* (DSS, 2021). This identified several service areas where stakeholders may be involved in supporting or promoting the development of autonomy in supported decision-making, including different educational settings, disability support, disability advocacy, justice, and other services and systems supporting young people. Participants were purposely recruited to participate in the study and identified and recruited through existing networks.

A total of 22 stakeholders from 16 organisations participated in the study either in an individual interview or as part of a group interview. Stakeholders included foster carers, advocates for young people, advocates for families, disability support services, stakeholders working with services and young people in out of home care, and statutory bodies. Stakeholders included people with disability, people with cognitive impairment, or parents of young people with disability and provided multiple insights.

Data from stakeholders are presented in this study with the reference (#SH) followed by the number of the interview (1–12).

## 2.3 Data analysis

The interview data were analysed thematically to answer the research questions. Data was coded (using NVivo) to identify: the needs of young people (and their families); resources currently used to support young people as they grow up making decisions; and what additional supports were needed. Building on prior work on supported decision-making (Laurens et al., 2021), supports were considered in terms of systems; services; parents, carers and peers; and individuals themselves.

## 2.4 Limitations to the study

The study is subject to a number of limitations. The participants in this study are not representative of the populations of interest. For example, the recruitment process may have attracted families already engaged in building autonomy in decision-making. It is likely that the study did not include families *not* engaged in building autonomy in decision-making or include young people living in all forms of out of home care or institutional settings. While we asked participants to tell us their preferred pronouns, we did not ask their gender.

The level of support needed was not captured and we made a conscious decision not to label people in any way – other than identify participants as either a ‘young person’, a ‘parent’, or a ‘stakeholder’. While some young people found it harder to engage in interviews than others, all interviews were conducted verbally or supported by written responses, without communication tools such as talking mats. The results of this study may need further testing with a broader range of young people with cognitive impairment to ensure the findings are inclusive of people with different communication and support needs.

Due to time limitations, organisations with additional ethical requirements, such as Departments of Education and TAFE, were unable to participate in this study. Some stakeholders who were unable to participate referred us to information on their organisation’s website and suggested other stakeholders to invite to participate.

Finally, there are specific terms used in service sectors and systems relating to specific concepts that may not be described the same way in family settings. For example, the term ‘dignity of risk’ is an expression used in a service system context rather than family context. However, this is a normal part of growing up where parents give children more freedom to take risks and learn from any consequences. Similarly, evolving capacity in a systems context is equivalent to growing up making decisions in a family context. While

this report has made every effort to be as accessible as possible, specific terms are used in specific contexts.

## 2.5 Research outputs

This report is one of a series of outputs from the study. Other outputs include:

- Accessible Easy Read summary and short closed-captioned video (with Auslan) of findings
- Conference presentation by community researchers on the method and key findings
- Other outputs to support young people and their supporters growing up making decisions
- Academic paper to address the gaps identified in the literature and to contribute to international knowledge.

Considerations for improving research practice in this field, and how the research may be translated to have impact, are included in Appendix C.

## 3 The context

This section provides the human rights context for this study, specifically the international treaties forming the basis of rights for children and young people with disability (Sections 3.1 to 3.3). This section also presents a discussion of the literature, specifically, evidence of how legal personhood operates (Section 3.4), different conceptualisations of the transition to adulthood (Section 3.5), and challenges to the linear model of transition (Section 3.6). This section then summarises the motivations for, and focus of, this study (Section 3.7).

### 3.1 The CRPD and the development of identity

Article 12 of the United Nations *Convention on the Rights of Person with Disabilities* (CRPD) provides for the equal recognition of people with disability before the law. It is a key foundation upon which the rights of persons with disabilities are promoted and protected. Article 12 does not provide new rights. Article 6 of the 1948 *Universal Declaration of Human Rights* (UDHR) declares that '[e]veryone has the right to recognition everywhere as a person before the law'. Rather, article 12 (and the CRPD more broadly) identifies persons with disability as particular members of the community who are vulnerable to marginalisation, and who continue to experience denial of identity despite the UDHR (Kayess and Sands, 2020). Article 12 *reaffirms* those human rights declared in 1948. Article 12 – Equal recognition before the law, states:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

We argue that article 12 applies to all people with disability including those under the age of 18. All persons with disability have the right to develop their will and preferences and have their will and preferences respected. All people with disability have a right to access support to assist them in the process of making decisions. How will, preferences and rights (and hence agency) may be realised is different for children compared to adults. This is because social interactions are mediated through domestic legal systems which provide for an ancillary best interest framework for those under 18, and otherwise prescribes age limits for certain activities (entering into contracts, voting, marriage, etc.).

Article 12 plays a crucial role in affirming the importance of individual identity and autonomy and supporting its ongoing development. It does this by identifying the integral role that individual decision-making (and respect for those decisions) has in the development of a person's identity and sense of autonomy. Deci and Ryan (1985; 2000) and Ryan and Deci (2017) have identified that autonomy, along with competence and relatedness, is a basic psychological need. It is through the meeting of these psychological needs that we 'flourish' (Ryan, 1995).

A key method by which article 12 is operationalised is by advocating a 'mechanism' to assist persons with disability to make decisions that reflect their 'rights, will and preferences', support them in exercising their legal capacity, and to protect their personhood broadly (if they decide they require that assistance). This 'mechanism' has become known as supported decision-making and is in CRPD article 12(3) (*emphasis added*):

States Parties shall take appropriate measures to provide access by persons with disabilities to the support *they may require* in exercising their legal capacity.

Thus, while the CRPD is focused on a presumption that people with disability exercise legal capacity at all times, some persons may need some level of support in making some decisions (United Nations 2007, 88-90). Attention should be directed to identifying what supports an individual person may require to exercise their legal agency (ALRC, 2014, 47).

'Support' encompasses a broad range of activities that can be both formal and informal (United Nations, 2014). Support is not to be confused with substitute decision-making as found in many guardianship arrangements, where someone makes a decision based on what they think is in the others best interests – such an approach is not seen as being

consistent with respect for an individual's autonomy and identity and violates the principles of human rights law (United Nations, 2014).

The CRPD provides some safeguards to prevent the overriding of autonomy – key is that any supporter of a person requiring support for decision-making must do so with a full consideration of that persons 'rights, will and preferences' as stated in CRPD article 12(4). Failing to respect and understand a person's rights, will and preferences is a source of psychological distress and represents an assault on an individual's identity, personhood and right to self-determination (Wiesel et al., 2020). Decision-making support, therefore, is an active undertaking by a supporter who has a positive obligation to assist the person requiring support for decision-making to identify and express their 'will and preferences' *and* thereby giving effect to their autonomy and legal capacity (United Nations, 2007).

Relatedly, article 12(2) not only states that persons with disability enjoy legal capacity but that *States Parties* must actively support measures to ensure this occurs. Legal capacity in the context of the CRPD can be seen as both a right to make decisions as a person recognised before the law, and to have those decisions recognised as valid and enforceable at law (Callaghan, 2016). Legal personhood is not realised if choices and decisions made are not recognised (Glen, 2017). Gerard Quinn (2010) describes legal capacity as follows:

[L]egal capacity is the epiphenomenon. It provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe—a web of mutual rights and obligations voluntarily entered into with others. So it allows for an expression of the will and the lifeworld. That is the primary positive role of legal capacity. . . . Legal capacity opens up zones of personal freedom. It facilitates uncoerced interactions. It does so primarily through contract law. . . . [It] is entirely right to focus on issues like opening and maintaining a bank account, going to the doctor without hassle, buying and selling in the open market, renting accommodation, etc. This is how we positively express our freedom. This is how we can see legal capacity as a sword to forge our own way. . . . Viewed as a shield, [legal capacity] also helps persons fend off decisions made against them or otherwise 'for' them by third parties.<sup>[3]</sup>

## 3.2 Challenges to the development of identity

There are two related caveats to consider with article 12 of the CRPD that are relevant to how a young person with cognitive impairment 'grows up', develops identity, and exercises legal capacity. First, as noted, there is a significant obligation placed on States Parties (or governments) and hence policy makers to provide the structures and resources to enable the legal capacity of persons to be realised. This would include resourcing support for decision-making initiatives. Thus, people with cognitive impairment are reliant on policy makers 'getting it right.' This is not always the case.

Second, for a person over 18 years of age with cognitive impairment to realise their identity, legal capacity, and legal personhood (in the sense decisions they make reflect their 'will and preferences' and are legally or formally recognised as theirs), there is an *implication* they have some knowledge of their rights, will and preferences, and knowledge and experience of how to make decisions. If not, then they are at risk of being subject to variations of substitute decision-making and otherwise having their identity development suppressed or denied. Similarly, that person's family/carers/supporters may also lack knowledge of rights and process and inadvertently deny identity. Structural and other societal impediments to recognition also exist.

These 'caveats' provide insights into how to effectively support the development of identity and capability in children to express legal capacity as they transition into an *adult* decision-making framework and world space. Simply, children and young people need instruction, support, opportunity, and practice in making decisions (including risk taking) so that they develop a sense of responsibility and are equipped to make decisions in adult life and 'flourish'.

Werner (2012) identifies three broad challenges to identity development and recognition that broadly correlate to the discussion. The challenges identified provide a further conceptual framework to this report and its considerations.

- 1. Challenges that relate directly to the capability of the individual.** This can be seen in things such as having difficulty in following the general decision-making process of:
  - a. framing of the situation
  - b. generating possible alternatives
  - c. evaluating potential consequences associated with the alternatives
  - d. selecting a decision response.
  
- 2. Challenges related to a professional caregiver.** For example, lack of experience/knowledge in supporting someone to make a decision consistent with a rights-based framework. Families broadly should be included here as well.
  
- 3. Challenges within the system.** These can be institutional, and service related, involving a lack of awareness of supported decision-making, or failing to resource its availability or failing to recognise it as valid. It can also encompass things such as community attitudes and the material standard of living of the person with disability for example.

### 3.3 Moving from best interests to rights, will and preferences

The 'caveats' and 'challenges' to realising rights under the CRPD noted above can be further contextualised in the changes to legal status and decision-making recognition that a child experiences as they move into adulthood. This identifies similar implications for how support should be provided to young people with cognitive impairment. Until the age of 18, a child or young person (regardless of whether they have a cognitive impairment) exists in Human Rights and Australian law within a framework based on the 'fundamental principle' that any decisions made for them should be in their 'best interests' (ALRC 1997, [16.6]).

Article 3(1) of the United Nations *Convention on the Rights of the Child* (CRC), which also applies to children with disability, states:

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the **best interests** of the child shall be a primary consideration.

In Australian law, for example, the *Family Law Act 1975* (Cth) was amended in 1995 to specifically include a reference to 'best interests' and make the Act consistent with the CRC. Section 60CA of that *Act* states

#### **S 60CA – Child's best interests paramount consideration in making a parenting order**

In deciding whether to make a particular parenting order in relation to a child, a court must regard the best interests of the child as the paramount consideration.

Children come under the legal responsibility of their parents or carers or other guardian or recognised body. This is enshrined in article 5 of the CRC:

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the **evolving capacities** of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

The CRPD also applies to children with disability and similarly notes in article 7(1) and (2):

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the **best interests** of the child shall be a primary consideration.

It is also worth noting relevantly CRPD article 3(8) which states ‘the principles of the present Convention shall be’:

Respect for the **evolving capacities** of children with disabilities and respect for the right of children with disabilities to preserve their **identities**.

However, there are limitations with the ‘best interests’ and respect for ‘evolving capacity’ approach to developing a child's capacity to act with agency. First, ‘evolving capacity’ is a term that lacks precision. Capacity to make decisions does not take a step-by-step linear approach – decision-making capacity is dynamic and ‘evolves’. There is considerable variation in capacity amongst all children and young people as well as those with cognitive impairment. Assumptions as to capacity at a point in time, particularly if based on age, may be erroneous. A ‘one size fits all’ approach to policy development and service delivery for a person with cognitive impairment must be rejected in favour of approaches that respond to the needs of individuals and their capacity at any point in time.

Second, ‘best interests’ is not a term explicitly defined in CRC or the CRPD.<sup>3</sup> The ‘best interests’ principle as a basis for decision-making in legal and care and protection contexts has, while being seen by some as a good starting point, received criticism for lacking ‘certainty’ and ‘objectivity’ (for example, see ALRC 1997, para.16.9). In *Marion’s Case* (1992, p259)<sup>4</sup>, the High Court of Australia’s majority decision stated that ‘the phrase “best interests of the child” is imprecise’, though did note that there are many imprecise concepts the court must grapple with. Crowe and Toohey (2009) note that in Australia a distinction has been made between ‘narrow’ and ‘wide’ approaches to considering the interpretation of ‘best interests’. Narrow approaches look only at things that impact wellbeing directly. A wider view considers matters such as the wellbeing of the parents and the broader family environment to the extent they impact the welfare of the child. Different courts in Australia have adopted these different approaches (Crowe and Toohey, 2009). The related issue with best interests, at least in Australia, is the way it is often tied to ‘paramountcy’ as in *Family Law Act 1975 (Cth)* section 60CA noted above – best interests are the paramount consideration. This ‘paramountcy principle’, dependent largely on judicial discretion, has been described as an ‘inherently vague’ way to determine how much weight should in fact be given to the views of the child (Crowe and Toohey, 2009).

Third, how best interests and evolving capacity are understood and applied across *formal* contexts such as in the courts and legal system and by service providers compared to *informal* contexts primarily in the home is different.

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<sup>3</sup> While not binding, ‘best interests’ is explored further in General Comment No. 14 (2013) to the UN *Convention on the Rights of the Child* (CRC/C/GV/14).

<sup>4</sup> *Department of Health & Community Services v JWB & SMB* (“Marion’s Case”) (1992) 175 CLR 218.

Importantly, article 12 of the CRC (not to be confused with article 12 CRPD) does state that a child has a right to express views on matters that affect them. Article 12 CRC states:

1. States Parties shall assure to the child who is capable of forming his or her views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with age and maturity.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

This is also reflected in the CRPD at article 7(3) which states (*emphasis added*)

States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be *provided with disability and age-appropriate assistance to realize that right*.

In Australia this principle is incorporated widely into relevant child welfare legislation. In section 10 of the *Children and Young Persons (Care and Protection) Act 1998* (NSW) it is referred to as 'The principle of participation'. It includes rights to being provided with information and similar. Children can often have a specialist lawyer or child representative provided to assist them in legal matters. For example, section 68L of the *Family Law Act 1975* (Cth) allows the court to appoint an Independent Children's Lawyer to represent a child's 'best interests'. Child representatives are also widely available to be used across other institutional settings. For example, in the National Disability Insurance Scheme (NDIS) a person up to the age of 18 can have a child representative who has special duties to the child under section 76 of the *National Disability Insurance Scheme Act 2013* (Cth).

These *formal* arrangements for including the child's 'voice' are incredibly important, notwithstanding criticism of 'best interests'. They provide some structure and oversight so that (hopefully) the child can experience some opportunity to exercise agency in a manner that may be commensurate with their actual 'objectively' considered capacity. Importantly, while we often discuss article 12 CRPD in the context of *adults*, as noted in article 7(3) of the CRPD above, assistance and support should also be provided to a child to assist them in realising their right to express a view on a matter.

However, no such oversight exists, at least not to the same public degree, in *informal* domains. The informal domains are critical to a child's development – the most important of which would be the home or primary space of residence. Parents and carers are

expected to recognise and consider the ‘evolving capacities’ of the child when making decisions for them, in order to adjust the level of input the child can have in the final decision (United Nations, 2013). This assumes that parents and carers are aware of concepts such as ‘evolving capacity’ and what it means. It assumes that even when resources and support may be available, the parents and carers are engaging with them. Without any of the institutional supports available to a court to assist it to reach some modicum of objectivity in determining ‘best interests’ for example, how is the parent or carer of a child with disability to make a decision in the ‘best interests’ of their child that is, in fact, in their best interests? Of course, this a challenge for every parent regardless of whether their child has a disability or not, or whether there are additional siblings whose needs must also be met.

At age 18, a young person with cognitive impairment is legally considered an adult and according to the CRPD, ‘best interests’ no longer applies. The presumption is that the individual is now to exercise a higher degree of agency than prior. If the person does need assistance, then CRPD article 12 states the supporter must consider what your ‘rights, will and preferences’ are to support you in a manner consistent with recognition of legal capacity and personhood. This transition from a ‘best interests’ framework with decisions largely made for you (at least in *informal* contexts) – where it is *assumed* your ‘evolving capacity’ has been recognised with opportunities for decision-making and supports tailored to that as you ‘grow up’ – to a ‘rights, will and preference’ framework with associated ‘adult’ expectations and assumptions appears quite linear and abrupt. However, the transition to ‘adulthood’ for children with cognitive impairment is argued to be ‘characterised by wider scope, longer duration and attenuated experiences’ (Codd and Hewitt, 2020, p40). This is not a suggestion to extend ‘best interests’ into adulthood, rather, it reinforces that supports and resources to develop decision-making capacity should start earlier and be provided for longer.

It would be of value to see evolving capacity more explicitly linked in practice to recognition that the child should participate in broader risk-taking activities and progressively more complex decision-making. This develops the sense of personal responsibility and ‘capacity’ to navigate an adult world on their terms. This is particularly important for children and young people with cognitive impairment. A reliance on linear life stage markers associated with age to situate development and ‘capacity’, for example, is not appropriate for any children and young people to determine attainment of ‘adulthood’ and the capacity to make decisions – discussed further in Section 3.5 and 3.6.

### 3.4 How legal personhood operates in practice

Three key questions emerge from the identification of the ‘caveat’ above and the idea of identity development. They require continued examination to determine how legal personhood operates in practice.

The first question asks, **how prepared are young people with cognitive impairment to navigate the transition to adulthood, especially in relation to making decisions?**

Research consistently identifies that children and young people with cognitive impairment must be provided with targeted and specific training to encourage their decision-making skills so that their values may be ‘actualised’ (Werner, 2012). As Glen (2017) argues

[A]lthough decision-making may appear to evolve ‘naturally’ for neuro-typical children, it is a skill that must be explicitly and systematically taught to those with intellectual and developmental disabilities, beginning not at transition, but at the start of the educational journey, as early as pre-kindergarten. (p517)

It is a skill that must also be practiced and encompasses risk taking. However, research shows that many children and young people with cognitive impairment are not adequately involved in decision-making (Beresford, 2004). Leonard et al. (2016) found that less than two-thirds of young people transitioning to a post-school life were involved in the decision-making process about their futures. In a review of the literature on ‘dignity of risk’, Marsh and Kelley (2018) identified that while risk taking is widely recognised as a significant way to provide dignity, develop identity, and enhance quality of life, care and other service providers remain overwhelmingly ‘risk-adverse’. Salt and Jahoda (2020) argue that a paternalistic perception that children and young people lack the capacity or capability to make decisions and need to be protected remains pervasive amongst the broad community and results in their ongoing infantilisation.

The next two questions ask: **how is this transition from a ‘best interests’ to a ‘rights, will and preferences’ framework understood by a young person with cognitive impairment?** And relatedly: **how does a child or young person understand ‘adulthood’?**

These questions have not received significant attention in the literature (Midjo and Aune, 2018). Research suggests that little is known about how children and young people with cognitive impairment think and feel about their own transition processes broadly, what adulthood means, and what this means for the development of their adult identity (Salt and Jahoda, 2020; Salt et al., 2019; Midjo and Aune, 2018). When undertaking a study investigating how young people with and without mild intellectual disabilities experience and perceive their own behavioural autonomy, Salt and Jahoda (2020) were able to locate

only two studies which focused specifically on the perspectives of young people with cognitive impairment on their transition experiences.

The same questions can be adapted to inform studies involving parents/caregivers, professionals, institutions, and service providers. In contrast to the lack of research focusing specifically on the perspective of children and young people with cognitive impairment growing up and making decisions, there is a growing body of work that looks at the experience of families, particularly parents and caregivers, in the transition process, including the provision of supported decision-making.

### 3.5 Understanding transitioning to adulthood

At its simplest, transition to adulthood refers to the 'life stages' that a person goes through as they mature. It is considered a 'multi-faceted' event or process that can have an extended period (Pallisera et al., 2014; Foley et al., 2012). Beresford (2004) identifies two broad elements that assist in framing investigation of the transition process:

- transitioning between services (from child to adult), and
- transitioning between legal status (from child to adult).

Examples of the latter would include leaving school, entering the work force, and leaving home (Beresford, 2004; Salt et al., 2019). While the transition process is a time of challenge for all children and young people, in both transition elements identified above, it is recognised that children and young people with disability and their families face considerable additional difficulties (Pearson et al., 2021; Gauthier-Boudreault et al., 2018; Leonard et al., 2016; Stewart et al., 2014; Pallisera, 2014). Specific stressors for the family and care givers arise both in navigating systems to access appropriate support for their children and for themselves (Codd and Hewitt, 2020). These can be ongoing.

Beresford (2004) describes the process of transition for children and young people with cognitive impairment as 'complex, extremely problematic and, in many cases, highly unsatisfactory' (p582–83). Poor outcomes have been identified in several domains including social relationships, employment and independent living, and health and wellbeing (Young Southward et al., 2017). Pearson et al., (2021), argue that:

Youth transitions for young disabled people are complex and require a multifaceted response that can both promote individual agency whilst also tackling structural disadvantage and inequality. The latter is much harder, and arguably more expensive, but without it there is a danger that attempts to improve transition for young disabled people will fail. (p1304)

It has been increasingly acknowledged in the literature that policy responses to support the development of identity and recognition of personhood consistent with the CRPD must consider all three challenges identified by Werner (2012) in a holistic manner – otherwise they will fall short of achieving meaningful outcomes (Stewart et al., 2014). In this case, a meaningful outcome is one that supports a young person with cognitive impairment to engage in decision-making processes on matters important to the development of their identity – in other words, matters that develop an understanding of *their* will and preferences and encourage a feeling of autonomy. The disconnect in policy between intent and actual outcome can be magnified when policy interventions are structured within linear models of identity development and attempt to define what success in development or decision-making may look like.

### 3.6 Challenging a linear approach to transition

To better understand the complexities surrounding the development of identity to ensure rights under article 12 CRPD can be realised, we must reimagine the idea of ‘transition’ as it relates to the individual experiences and circumstances of people with cognitive impairment – particularly those who have complex support needs. Complex support needs:

[A]re created by the intersection between a person and a complex system of services including education, health, disability ... mental health, homelessness, youth justice and child protection. (Smith and Dowse 2019, p1327).

Indeed, misunderstanding transition by ignoring intersectionality for children and young people with cognitive impairment can be identified as the overarching theme that binds the three challenges noted above by Werner (2012). Smith and Dowse (2019) argue:

While there is a general acknowledgement that people with complex support needs require integrated and coordinated approaches to support, understanding transitions for young people with complex support needs remain singular and siloed. ... [T]here is a tendency to examine transitions in and out of specific service domains and/or sectors, rather than examining the overlaps and interconnections of transitions. (p1328)

Pearson et al. (2021) argue that this failure to recognise the individual needs of a young person within a larger life and structural context has meant that transition into adulthood remains a significant policy failure across OECD countries.

Research identifies that this misunderstanding of transition is seated in the ongoing conceptualisation of development being a step-by-step, linear, and singular process for all young people – one that has a predefined end stage (Pearson et al., 2021; Smith and Dowse, 2019; Beresford, 2004). This is particularly evident in institutional and service

provider settings where attainment of a certain age corresponds to a service 'cut off' or 'transition point' – such as out of home care, or the transition from paediatric to adult medical specialists – despite the person still requiring or benefiting from the supports provided from that service even though they have reached 18 (Beresford, 2004).

However, a growing body of research argues the transition to adulthood is 'non-linear, fragmented, multidimensional and extended, reflecting the complexity of young people's life experiences' (Pearson et al., 2021, p1294). Adherence to traditional predefined markers of attaining adulthood, such as securing employment and achieving some financial independence, are argued to be increasingly outdated, overly 'normative', and 'unhelpful' when considering the reality of contemporary experience (Pearson et al., 2021; Smith and Dowse, 2019). Pearson et al. (2021) argue that they are 'particularly harmful to young people with disability, many of whom face additional and significant barriers to achieving these markers' (p1294).

Quite simply, given that children with cognitive impairment do not progress along the standard development 'curve' (assuming it is valid at all) in the same manner as children without cognitive impairment (Beresford, 2004), traditional markers of development set up children and young people with cognitive impairment for failure. Thus, on many standard life stage tables, the young person is forever infantilised, always to be relegated to a childlike state of development, regardless of them attaining legal adulthood or otherwise feeling that they have achieved adulthood according to their conception of such. Despite criticism of the traditional linear model, Smith and Dowse (2019) note that a linear approach that approximates some idea of life 'stages' 'still dominates research, policy and practice around transitions for young people with complex support needs' (p1328). As discussed below, this is not necessarily a bad thing – if done with an awareness of the limitations. Interestingly, evidence suggests that the traditional social role transition markers of 'adulthood' identity such as ending formal education, marriage, parenthood, and so forth are under challenge by *all* young people in Western societies (Salt and Jahoda, 2020; Salt et al., 2019), with some traditional 'life-stage markers occurring later in life, if at all, and without following a prescribed order as they have in the past' (Salt and Jahoda, 2020, p1318). Salt et al. (2019, p902) identify research that suggests that rather than social role transitions being a significant indicator of 'adulthood', the emphasis has shifted to character qualities or psychosocial characteristics such as:

- "making independent decisions"
- "accepting responsibility for oneself", and
- "belief in one's own autonomy".

A key motivation for this project was to further explore these psychosocial characteristics and indicators of adulthood that Salt et al. (2019) identifies to expand understanding of the shifting emphasis around transition by young people with cognitive impairment. In our current study, we note that many of the young people expressed their understanding of transition and adulthood in similar ways to that identified by Salt et al. (2019).

Some researchers argue that all attempts to conceptualise transition should be abandoned in favour of developing a new theoretical approach that captures 'complexity' and shines a light on what happens 'between' transition events (Salt et al., 2019). However, Salt et al. (2019) argue that even post-structuralist approaches that recognise transition as dynamic, are still rooted at some level within a structure or 'phases'. The existence of 'stage' or 'phases' itself may not be the problem. Rather, it is the meaning that is ascribed to them. Do they support the development of a person's identity and autonomy? Do markers of success or attainment reflect what the *individual* sees as valuable?

Rather than completely abandon a linear approach, Smith and Dowse (2019) argue that the current preferred approach of critical researchers is to focus on critiquing the *deficiencies* in the traditional linear and age defined/social role transition model by emphasising that transition is 'interconnected, ongoing and independent' (p1328). It is an approach where supports are provided that are sensitive to the 'continuities' in a young person's life and reflect how the young person is experiencing transition (Smith and Dowse, 2019). Such an approach can provide a strong foundation for a person to exercise agency in the context of CRPD article 12.

The risk of adherence to a traditional linear approach to development is linked to a key theme of this report. Not appreciating the dynamic nature of identity development and personhood which is realised through expressing will and preferences in the decision-making process, and having that decision respected by others (Glen, 2017), results in persons with cognitive impairment being treated as 'eternal children' (Codd and Hewitt, 2020).

Despite an obligation on parents, care givers and decision makers to respect the evolving capacity of a child (United Nations, 2013), children and young people with cognitive impairment in Western societies continue to be provided far less opportunities growing up to practice independence, experience autonomy, explore notions of 'self', and engage in risk-taking behaviour when compared with children without a cognitive impairment (Salt and Jahoda, 2020; Flynn, 2020; Midjo and Aune, 2018). Without sustained exposure to decision-making opportunities growing up that explore and reflect the persons developing understanding of their 'rights, will and preferences', it is not clear how the *adult* person with cognitive impairment is able to exercise their fundamental rights or have these respected.

Children and young people remain locked in a 'best interests' framework into adulthood, associated with a life stage attainment of a child (Flynn, 2020).

Feeling that you have agency or autonomy in your life is regarded as a basic psychological need and is a key recognised developmental goal amongst Western societies (Salt and Jahoda, 2020). If acting in the 'best interests' of a child with cognitive impairment results in that child experiencing less autonomy as they transition into legal adulthood then the child's 'best interests' have *not* been considered. The 'best interests' for a child and young person must always include opportunities to understand and express their rights, will, and preferences in increasingly complex ways, including through taking risks. Considering 'best interests' demands a consideration of the future 'adult' individual. It is not about keeping someone locked in the present.

### 3.7 Motivation for this study

Importantly, young people with cognitive impairment today are more likely to be more aware of their rights, and to expect greater opportunities for inclusion and participation equally with others (Midjo and Aune, 2018). The extent to which this translates to a young person with cognitive impairment experiencing an 'adulthood' that reflects their will, preferences, rights and aspirations is not clear from the literature. Midjo and Aune (2018) argue that young people with cognitive impairment remain vulnerable to having a version of a 'pre-structured adult life' imposed upon them. Even in cases where the parents and young person with cognitive impairment are adopting a 'de-traditionalized and individualized path', the expectations surrounding this are not always matched by an institutional or service provider perspective on what identity, personhood or 'self-determination' means (Midjo and Aune, 2018). It can ignore that 'self-determination and autonomy can be expressed in a variety of ways' (Salt and Jahoda, 2020, p1326). Salt and Jahoda (2020) argue that infantilizing connotations towards persons with cognitive impairment – that they are vulnerable or incompetent for example – remain widespread despite efforts to promote rights and agency.

Article 12 of the CRPD affirms a presumption that a person with disability has full legal capacity. It also provides an obligation on States Parties to provide the resources to support persons with disability to make decisions that reflect their rights, will and preferences and enable the full expression of their individual identity. This does not create an assumption that all young people and adults with cognitive impairment require decision-making support. Nor should assumptions be made that all young people and adults with cognitive impairment require the *same kinds* of decision-making support for the *same kinds of decisions*, at the same time.

Finally, we cannot make assumptions about what ‘autonomy’ and ‘adulthood’ means for a young person with cognitive impairment. What is critical is that children and young people with cognitive impairment are provided decision-making space to explore a conception of identity, adulthood, and autonomy which *they* are comfortable with, and which does not have to conform to any external model. For example, in their 2020 study, Salt and Jahoda (2020, p1325) note:

The majority of our participants demonstrated a degree of reluctance to take full control over their own lives, opting to rely upon external support in domestic and financial ... decision-making domains. Consequently, it is possible that young people may not always be proactive in seeking additional opportunities for autonomy.

We need to guard against a ‘new paternalism’ which brings a preconceived notion of what autonomy means. There are no ‘degrees of autonomy’. *Choosing* support, or not, *is* acting with agency – it is an example of autonomy. Some people may require greater or lesser support. The point is that appropriate support needs to be available to assist a person to choose the direction of their lives. Children and young people with cognitive impairment need opportunity to explore goals, choices, appreciate consequences, and make decisions that matter to them to develop their identity and conception of adulthood. Identifying their ‘will and preferences’ allows the young person to act as ‘active agents’ in their life course development and exercise their rights (Notara, 2021; Barrat et al., 2020). Emphasising ‘will and preferences’ should not begin in legal adulthood. Conceptually, article 12 of the CRPD can or should apply to a person under the age of 18, despite references to ‘best-interests’ elsewhere. Young people need to know that support is available to them to assist with making decisions. This support must be responsive to and supportive of their individual identity constructs, goals, and aspirations.

To get this support right, it is crucial that institutions and service providers listen to the voice of young people about what autonomy means to them, what decisions matter to them, and their experiences of what does and does not work in decision-making and decision-making support as they transition into legal adulthood (Notara, 2021). Therefore, this study seeks to:

- Identify what supports young people need to develop capacity to identify will and preference and make decisions – identified by both young people and their families
- Understand if and how this varies for young people living with family, in out of home care, and in institutional settings.

The remainder of this report examines:

- The different needs of young people in developing autonomy (Section 4)
- The resources available to young people to develop their autonomy (Section 5)
- Further supports required for young people to develop their autonomy (Section 6).

We also consider, where possible, whether there any differences for young people in different living arrangements.

## 4 Needs of young people in developing autonomy

This section describes the needs of young people as they grow up making decisions. This is based on what interviewees told us. Where quotes are used, they are identified as 'young person' (#YP), 'parent/carer' (#PC) or 'stakeholder' (#SH), along with the participant number.

### 4.1 Types of decisions being made now

Young people talked about different types of decisions they were making now. Day-to-day decisions ranged from when to get up out of bed, to what activities to do or to try, what to wear, what to eat, and who to spend time with. Young people also talked about longer-term decisions or choices they made, including:

- Deciding which support worker they preferred and what they wanted support with
- Continuing at school, choosing different subjects, changing schools, or going to TAFE
- Deciding to look for work, getting a job
- Learning to drive
- Moving out of home
- Making decisions about health, such as diet and exercise
- Making decisions about their own identity.

Young people and their parents also talked about deciding not to do something – including flying, eating certain foods, or attending a school activity. One young person, in considering whether to learn to drive said:

I want to get a licence, but also I'm quite glad not having one and using public transport or even a scooter ... because I don't want to pay for bills and all that right now. ... I want it, but I also am just fine without it. Make sense? I decided to at least to wait at least until 21, 22 years of age. (#YP9)

### 4.2 Types of decisions young people want to make in the future

Young people were also asked about the decisions they wanted to make in the future. One young person answered 'good ones!' (#YP13). Young people identified a wide range of decisions they want to make in the future, including:

- Getting a job, changing jobs (#YP10), starting a business
- Saving up for something, such as a new computer
- Moving out of home (#YP10), buying a house and ‘having everything really properly set up’ (#YP8)
- Getting a driving licence ‘without my licence, I can’t get a job, without a job, I can’t get a house’ (#YP3)
- Travelling, ranging from finding a different way to get home from work and practising that new route (#YP10) to travelling overseas
- Transitioning (gender)
- Having a relationship and a family.

One young person, based on their experience, did not want to plan too far ahead, ‘because if you decide now, it may not happen’ (#YP11).

### 4.3 Different support needs for different decisions

Every young person who took part in this study had different support needs when making decisions – ranging from no support to significant support. The type of support provided also changed depending on the type or scale of the decision and the potential consequences of that decision.

The literature suggests types of decisions can be divided into big and small decisions, determined by scope, who might be involved, who might influence that decision, the timeframe, and the consequences of that decision (Douglas & Bigby, 2020). This approach was used to think about some potential examples of ‘big’ and ‘small’ decisions (Appendix B). However, in practice, big and small decisions are subject to perspective. A big decision for one person may be whether to move out of home, for another it may be whether to get out of bed or whether to look for work. Similarly, people have different perspectives of small decisions depending on the support system available. For example, what may appear to be a small decision may involve supports doing a lot of work for that decision to appear small. This section explains the different support needs young people identified for what they considered to be small and big decisions.

Many of the young people were comfortable making what they considered to be smaller decisions. That said, they did not always get to have their voice heard. For one young person, it depended on the support worker; with some ‘I decide’, and with others, ‘I think they already decide for me’ (#YP4).

For what young people perceived to be larger decisions, they needed more time, more information and support, and often talked to more than one person about the decision (mum, dad, friend, support worker). Some young people had support to identify and talk about different options, looking at the pros and cons, in order to make a decision. Young people asked other people they had good relationships with and trusted.

Parents told us they did different things to support young people making different types of decisions, giving the young person 'independence where you know it's safe to do so' and less independence or more guidance in other areas (#PC12). For example:

There's such a range of decisions. We could put decisions on a continuum, from little every-day decisions to big decisions about directions in life or health care things. And it depends. Some decisions, it's completely open, whatever she decides and any option she chooses seems completely fine. ... And then, if it's a decision that I have the idea that a certain direction or outcome is probably good, then I will give information relevant to that, like why I'm thinking that. I'll say to her, 'look, I'm really hoping you are blah, and these are the reasons I'm hoping that' and ... 'what are you thinking? Why?' If maybe she's not wanting to do that, 'what are your reasons for that?' (#PC1)

Some decisions are being guided by parents or made by parents.

He wants to have that freedom but with a lot of decision-making, he just gets so overwhelmed and confused with and everything else and then I'm having to break everything down going, "Okay. Well, you want to do this. This is going to be the outcome. But if you want to do that, this is going to be the outcome" and then most of the time he'll say to me, "What do you think I should do?" because it gets so confusing for him in the end trying to explain that, "I think you'd be better off doing this." Nine times out of 10, he'll agree with me. (#PC4)

One young person talked about the need for someone else to make decisions only in an emergency (#YP8 – in relation to diabetes). Another young person said:

My parents, they made decisions about medical and that sort of stuff, but everything else... they generally leave up to me... the usual 'parents' sort of stuff, they usually make those decisions for me, which I'm fine with. (#YP1)

While many of the young people we spoke to said they had autonomy, they also said they were either influenced or felt pressure from others when making decisions – particularly when they feared they were being judged (#YP16). This varied depending on their confidence generally and on the decision they were making (#YP16).

Stakeholders highlighted that what a young person wants and what their parents want are not necessarily the same. It was important to hear what the young person wants – 'often their interests are aligned, but sometimes they don't' (#SH1).

For young people with significant support needs, parents, and other stakeholders, sometimes made decisions based on the young person's 'best interests'. Further, there were also decisions parents were unsure whether the young person would ever be able to make safely themselves, such as 'financial decisions' or 'critical life decisions' (#PC12). They added:

I just remember how important independence was for me. It just meant everything to me to have it. So I want to be able to help him have that. Like when – yeah so it is – where are those points in time where he can feel like “Hey I did that,” and you know it feels good. So let him have it. You know wherever he's safe. (#PC12)

#### 4.4 Different support needs at different ages

Parents recognised that it is 'a natural process for young people to make more of their own decisions' as they got older, and their role was to provide information rather than make decisions for them (#PC1). This recognises the importance of the 'progression of choice' as the person gets older (#SH7), as well as making age-appropriate decisions. Another parent said, 'its just one of the joys of becoming an adult ... you start to take responsibility for your choices' (#PC9). However, as one parent said, this was also a scary time for young people as their 'pathway isn't the same as [their siblings]' (#PC3).

Some parents and young people commented on decision-making becoming easier as they got older for the small day-to-day decisions – such as what to eat, what to wear. But as the young person got older, some of the decisions became larger and the decision-making became harder.

While young people may vary in terms of their support needs, parents highlighted several factors that affect the support needed at different ages. This included:

- Communication skills
- Decision-making skills
- Decisions to be made
- Previous experience making decisions
- Age – teenagers ('when he was younger, it was a lot easier', #YP11) – in terms of supporting young people who sought more independence, as well as supporting young people who were going through significant physical changes
- What peers are doing
- Changes when moving to high school (parent involvement decreasing significantly at high school compared to primary school)

- Changes at the beginning of every school year – to both teachers and routine
- Changes in health care providers – for example, moving from paediatric care to adult care
- Availability of services and supports
- Level of independence sought.

Parents explained the intentional steps they took to provide children with skills to develop their autonomy as they grew up, especially given the significant changes going on in young people's lives from the high school years onwards. Parents started this process early.

I have always tried to communicate to [my son] that he does have choice. So I've always tried to give some sort of choice even if there wasn't much choice to make. So that he was growing up understanding he has choice, he has a right to a choice. (#PC2)

Parents also recognised that being a teenager is challenging and they also had to deal with this – talking about lethargy, boredom, having stronger opinions, and 'operating on a different time zone' ('their clocks change a bit and wanting to have those big discussions late at night and I'm just not ready', #PC5).

Some young people and parents said that as the young person got older, when they needed support, they might receive support from others – not just parents. This included peers, paid support workers, or other disability services. One young person said as they get older they would like people similar in age to help them make decisions (#YP6). Stakeholders also said that young people they worked with were mindful their parents wanted the best for them and loved them, but were sometimes 'overprotective' and 'still making decisions for [them]' rather than providing 'opportunity to try different things' (#SH6).

Support needs changed at different ages based on the types of decisions available (for example, what to study, learning to drive, and social activities), experience in making decisions, dignity of risk, and who young people sought support from.

## 4.5 Different support needs in different settings

Most young people who participated in this study were living at home with their parents. When asked who they went to for support, most said they would ask their mum/foster mum. A small number had moved out of home and were living independently, but would still ask their mum for support. Mum (rather than any other family member) was the default for young people we spoke to in this study. Some young people we spoke to had lived in

out of home care (OOHC) or with other carers and asked for support from a close trusted person – either a foster parent or support worker.

While many young people living in OOHC have the same support as if they were living with their family, some young people in OOHC may not experience the same stability. They may not have access to ongoing trusted relationships, and if they have experienced different OOHC placements, may be unsettled or leave school early. This may affect the support available to them to build their autonomy in decision-making, and whether they had long-term trusted relationships with others who could support their decision-making.

Supports and services provided in OOHC settings may have been established upon intake and not subsequently revised. For example, if a young person enters OOHC under very traumatic circumstances they may need high levels of support. One participant highlighted that this high level of support might continue, preventing opportunities to build independence or capacity in decision-making over time (#SH3).

While in OOHC, ‘the ultimate decision maker prior to 18 [years of age] would be their allocated case worker’ (#SH3). The focus of decisions was often on the ‘basics in life; a roof over their head, someone who cares for them, going to school, getting all their health things looked after’, rather than other social experiences their peers may be accessing (#SH3). Stakeholders identified that young people in OOHC were not necessarily afforded the dignity of risk, given the ‘care and protection’ culture of government agencies, particularly where there is a ‘history of complex trauma’. (#SH3).

Young people leave OOHC at the age of 18 (#SH3), with variations by state/territory in the type and duration of support provided after transition (Mendes, 2022).

That expectation that we have for kids in out-of-home care to be ready to be adults at 18. To me, it seems to be quite an unrealistic expectation that kids turn 18, they leave home and can be fully independent. ... So I think, what we are expecting of kids in the out-of-home care space is really not the social norm at this particular point. People don't turn 18 and leave home anymore. .... So, it is a bit of an unfair expectation that we have on these young people in out-of-home care. Throw in an intellectual disability on top of that, it's a tough gig. (#SH3)

One young person told us that living in OOHC had been too ‘controlling’; they could not make decisions for themselves and fought to have a guardianship order removed (#YP8). While they had decided what sort of housing support they wanted when leaving OOHC, there was nothing like it available (#YP8). Stakeholders recognised the limited options available in some areas (for example, education, accommodation) and that not being able to fulfil choices affected trust with young people (#SH3). However, they also added:

Outside of that family environment, some young people thrive because they're immediately given opportunities they didn't necessarily have in a home environment where it's done, as I said, with the best of intentions in their intent to nurture, but things have been done for them. And so, whilst it might not be immediately about decision-making, the fact is sometimes outside the family home, they are exposed to opportunities to be making some, at least, simple decisions for themselves and experiencing new things. And you can see quite quickly a level of functional capacity and greater independence develop. ... Understandably we want children at home, but in some ways, [OOHC] can provide those opportunities they weren't previously exposed to. (#SH3)

One stakeholder said a higher level of supports were available in OOHC through community services compared to supports provided by the NDIS, and therefore many young people experience a decline in services when they turn 18 (#SH3). They also highlighted the difference in evidence required to provide those supports, with evidence being much higher for the NDIS (#SH3).

## 4.6 Summary findings

Young people with cognitive impairment identified the types of decisions they were making now and decisions they wanted to make in the future. Young people and their families also identified their support needs depended on the type of decision, their age, and in different settings. Young people and other stakeholders also identified the types of decisions young people are required to make when leaving out of home care.

The next section identifies what helps young people make decisions and what helps develop their autonomy as they grow up.

## 5 Existing resources and supports to develop autonomy

Young people and their parents identified several different resources and supports that helped them make decisions. They also explained how this changed over time to help develop the young person's autonomy – to help them make more decisions and different decisions as they grow up. Stakeholders interviewed also identified opportunities and resources including supports available to young people in different settings.

Given only a small number of young people interviewed had lived in non-family settings, the resources and supports provided in other settings were mostly identified by stakeholders who participated in the study.

### 5.1 Systems that support young people

For many families that participated in this research, the NDIS gave young people access to support services that could help them build autonomy. Having access to a paid support worker, and someone the young person felt comfortable with, provided another trusted person who could provide information or advice, and help support both decision-making and increasing autonomy.

I think the financial support from the NDIS is absolutely essential to allow him to talk to other people about decision-making, about education, about potentially moving out of the house, about relationships, about consequences, about responsibilities and all of those sorts of things. So without that, he wouldn't be able to have those support networks to also help with those decisions. So I think that's absolutely essential. (#PC11)

Parents also commented on support workers being able to take the pressure off parents. For example:

If she's got her support worker there, taking that decision away from me or having someone else help her make that decision becomes easier. Because I'm not – like I'm the good guy and the bad guy for my kids. ... And to hear it from someone else's point of view, I think that's helped a lot having that support person there. (#PC7)

The support provided by different professionals varied.

Young people living in out of home care, either through foster care arrangements or other residential settings, had access to the same systems. One foster carer said however that 'working with the kids seems very very easy compared to the systems', which were very bureaucratic particularly 'with interfacing agencies like education and health' (#SH10).

Many young people and parents also talked about the support they received at school. While for many, school had been challenging due to the lack of supports and understanding, or because of bullying, there were some examples of support for developing autonomy at school.

This year, being in Year 11, they take on more things about learning how to pay bills and what you have to do. I think that's important for kids – more so kids with disabilities .... Having those everyday life skills, skills that they're going to need later on in life to help themselves and make those decisions. Everything from cooking and budgeting to paying bills and opening bank accounts and stuff. (#PC7)

Another parent talked about a short course their son did at TAFE, one day a week:

It was teaching them – they touched on a bit of financials, like learning how to do a budget. They showed them how to react in work environments and things like that. They took them out in the community and doing things like that. That was amazing. That's what we need more of. So he's learning out there. At school, they only do it a couple of times, whereas this was on a weekly basis. That's what I think he needs more of, is that these courses are solely to get these kids out and help them making decisions. So they are out in the community. (#PC4)

External supports to help grow autonomy and experience of decision-making is important – particularly when support from parents or ongoing support from trusted others is not available. School was considered to be a key part of increasing young people's understandings about their rights, the choices they may make, and how to make them. As noted by a report by the Association of Children's Welfare Agencies (ACWA):

The benefits of engagement with education are immediate and long-term – schools can provide an environment where a child or young person can experience some success, build self-esteem and social networks. Schools are often the “constant” in the fragmented life of a young person in OOH, and school staff can come to know the young person well. (ACWA 2021, p28)

Education settings have the potential to provide structured learning about different aspects of decision-making and teach many life skills through living skills subjects (such as living in the community) provided as an alternative to mainstream subjects (#SH4). One organisation provided community level education to teach self-advocacy to young people, targeting students in education (#SH1). The same organisation also provided legal support and advice and representation in discrimination to young people over 18, or to parents and guardians for young people under 18 years old (#SH1). It should be noted that legal representation and advice can be available for any competent minor who requests it.

## 5.2 Services that support young people

Some families told us of different strategies professionals had provided them with to help the young person make decisions and grow autonomy in decision-making. Professionals providing support included:

- Allied health services, including speech therapy and occupational therapy
- Health services, including psychiatrists and psychologists
- Disability services, including support workers and case managers/coordinators
- Educational staff, including teachers, other school staff and tutors
- Vocational workers, for example helping young people access tertiary study and employment.

A large number of different services were accessed by young people. Young people and parents talked about services and resources that supported them in a generic sense rather than focusing on one service. Examples included:

- **Having ongoing support from a trusted person.** As one young person said ‘I really like this support co-ordinator. She gets me’, adding ‘she made me confident and I could hear her more clearly, and she helped me understand things that I didn’t know’ (#YP14). Having continuity in support once trust had been established was important.
- **Being introduced to new strategies to support growing decision-making** and growing autonomy in decision-making at home
- **Providing information about what services are available**, including who parents and young people can talk to for more support, recognising services were continually evolving
- **Having external age-appropriate support through the teenage years.** One parent talked about the benefit of a sports program with young people the same age which also involved discussions about healthy living, reducing alcohol intake, avoiding drugs and vaping, healthy eating, exercising, and socialising, as well as providing opportunities to help out with the younger kids. The combination of exercise and socialising helped the young person feel good about themselves, calmer, and enabled them to make better decisions (#PC11).
- Service providers ‘**understanding and accommodating**’ the role of a family member, carer, friend or paid support workers in the context of the will and preference of the young person (#SH4).

- **Slowly transitioning young people towards making decisions for themselves.**

Stakeholders we spoke to also talked about general approaches and supports provided in specific settings. For example, stakeholders identified the importance of slowly transitioning young people to make decisions for themselves, letting young people know they have the power to make that decision 'regardless of family and everybody else', but that family and other people 'can be involved and can help [them] make those decisions' (#SH2). In another example, while working with young people to explore employment opportunities, one stakeholder was able to identify opportunities either unknown to or not considered possible by young people or their parents (#SH7).

Several stakeholders interviewed were involved directly (associated with provider organisations, and foster carers) or indirectly (in supporting services) in OOHC and identified resources and opportunities for young people to make decisions; however, it was unclear how young people were supported to build autonomy in OOHC. Placements in OOHC end when the young person turns 18 years old. From the age of 15-16 years old, a leaving care plan is developed, where the case worker 'consult[s] with the young person about what they want in the future' (#SH3) to help transition from care arrangements to independence. The process focuses on developing skills needed when leaving care (#SH8) rather than supporting young people to grow autonomy over time (#SH3). Therefore, the level of involvement the young person has in this process 'really depends on the level of disability', their experience of making choices (#SH3, #SH8), and whether they 'are able to verbally express what they want' – or whether case workers are able to 'augment or support' young people who are unable to express preference verbally, recognising that training and development in this area was sometimes lacking (#SH3). Decisions made at this time were likely to be complex, particularly when accessing the NDIS (#8). There may be further complexities if a care leaver turns 18 while in custody (#8). The process may have varying levels of input from a foster carer (in foster care settings) about what the young person wants. The case worker may also identify whether the young person needs 'a public guardian post-18 as well, to help with decision-making or financial management' (#SH3). One stakeholder identified the 'case worker [as] the ultimate decision maker ... so it really depends how well a case worker knows a child and how experienced they are at interacting with people with disability' (#SH3).

There are also specific programs to support young people develop NDIS plans before leaving OOHC to ensure capacity building and daily living skills are incorporated into their plans to support their leaving care plan goals (#SH3). For young people in OOHC who are NDIS participants, there is some capacity building prior to leaving care, from 12 onwards, although more from '16 onwards, when you are getting a lot more funding' (#SH3). There

are also other services available, including TSIL [therapeutic supportive independent living], about 'building independence' with a specific focus on living skills (#SH3).

As for any aspect of decision-making, case workers in OOHC settings could only enable decisions where options were available. For example, 'we might seek [the young person's] views on what placement they would like, but we can't always deliver' (#SH3).

When you look at someone who's in an ITCSD [intensive therapeutic care for significant disability] placement or something like that, when we've got three locations or something across the district, we've got people who come from Tumut and they're living in Dubbo. So they've got absolutely no say in the decision because of the level of support they're required, that's the only place they can go. (#SH3)

Failing to meet preferences often affected the trust between the young person and the case worker. Young people are often without trusted supports when they are in care far away from family and informal supports (#SH3).

Agencies are required to follow up with a care leaver after they leave care; however, this may be insufficient to provide ongoing or intensive support (#SH8) – such as reflecting on decisions made and where necessary making different choices.

### 5.3 Parent/carer/peers supporting young people

Young people in this study said they relied on their parents, particularly their mum, for support when making decisions. As they grew older, they also looked for support from other people (#YP9), including support workers (see Section 5.2 above) and their peers. Although not all young people were 'really into peers' (#SH4).

Parents in this study said they understand how their children learn, what their strengths are, and how to best support them (#PC8) – often learning through 'trial and error' (#PC7).

Society would so often make us look at their deficits rather than their strengths ... and I think for us to focus on their strengths to see how they can best learn, best cope, best thrive, build their self-esteem on that, instead of implying that, "Okay, you've got some struggles here with making decisions," but letting them know, "Hey, that's okay. Let's maximise the strengths we've got." So I do support them with, I guess you can say, a strength-based system for each of my two kids. (#PC8)

Each family is working out how to support the young person in their own way. Some parents referred to peers, either individuals they had met through school or through peer support groups, while others undertook training. Parents also explained how they had consciously and actively encouraged their child to make decisions from early on, and how they had helped developed these skills over time. One foster carer talked about providing

different experiences and opportunities of work 'just in preparation to start the conversation' about life after school (#SH10). Some organisations work with families, and specifically parents, to help build their capacity recognising they are able to provide ongoing support – rather than just at key transition points (#SH7). Such training helps parents recognise bias, understand how to support decision-making, and understand how to build the young person's capacity over time (#SH7).

The approach taken by parents was tailored to the young person's needs. However, there were a number of similarities in how parents provided support – factors raised by both parents and young people interviewed. In terms of overall approach, this involved:

- **Ensuring the young person starts as early as possible to make decisions** – starting with simple choices (A or B) and increasing the types of decisions made (either exploring ideas or considering more choices) to build autonomy
- **Parents providing encouragement, committing to the process of building autonomy (continuity, repetition), and then 'giving up control'** as experience and autonomy of the young person increased (#PC6)
- **Preparing young people to make decisions well in advance;** for example, considering different decisions in life that young people make about relationships, school, further education, looking for a job, independent living skills, and preparing young people ahead of time (#PC8)
- **Ensuring support is available from more than one person** (although often one main trusted person – mum) to avoid parental bias (#PC2)
- **Always being available to provide support.** Ensuring the door is always open ('keeping that open door of communication and relationship with her, ongoing for decision-making... letting her know I'm always available' (#PC8)) or talking at the right time ('choosing those moments like when he does start talking, I make myself available' (#PC5)).

Parents and young people also shared techniques they used to help support decision-making and build capacity over time. They include:

- **Finding information and breaking it down,** identifying long and short-term consequences of different choices, identifying alternatives, relating information to previous experience, and sharing more information. One example given was that staying at school for Year 13 'gives me an extra year to think things through and not feel rushed' (#YP9).

- **Providing time to make decisions and not rushing**, allowing time to think, talk and decide
- **Identifying possible barriers and finding ways to overcome them** (#PC12)
- **Listening and watching the young person**, recognising ‘what’s ultimately important is [their] happiness, not mine, [theirs]’ (#PC12)
- **Accepting a level of risk** for most decisions – letting a young person make mistakes (except where it is dangerous, or involves loss of a lot of money (#PC6))
- **Leading by example** (#PC10), modelling behaviour (#YP12), and talking through their own decisions (‘I’ll be honest and show them moments too when I’m struggling with decisions or if I’m getting overwhelmed’ (#PC8))
- **Reflecting on decisions made and learning from them**, even if it was not the outcome they wanted (#PC8), such as what they might do differently next time (#PC13).

Parents used different tools and techniques to support young people, including visual aids, story boards, charts, role playing, conversations, videos, and lists of pros and cons. Tools used changed over time, again with trial and error. As one parent said:

You just can’t pigeonhole people with intellectual disabilities into one pigeonhole, because it doesn’t work for everybody. Everybody is different. (#PC7)

One young person also said visual aids could be used both ways. Young people use pictures or photos to help explain to their parent what they mean:

There’s been times where I try to explain something to mum, but it either doesn’t come out right or yeah. If it doesn’t come out right or it does and mum just doesn’t understand it whatsoever, and I just try and look up a few pictures to try and show her. (#YP9)

Other parents said, like for any young person, there needed to be some level of encouragement to try new things. One parent said:

Sometimes it’s a delicate balance between pushing him when you need to but backing off when you need to as well, which is incredibly challenging for any young person, you know, that’s the dance of parenting teenagers, I think. ... So, helping him to see that he is more capable I think sometimes, trying to give him the confidence to make decisions and give him the confidence in the skills that he actually has and that he is employable. (#PC11)

Parents also recognised the need for young people to develop their capacity to make decisions without them. One parent said:

...because everything he does where he's not just with me he is having to make those decisions. So yeah, I guess that's probably the other way is just having him in things that are still safe but that doesn't have Mum or Dad there to be able to tell him what to do. Just expose him as much as we can to help him learn and grow as well. (#PC12)

Parents and young people both recognised that making mistakes was an important part of learning.

Some mistakes are enormous and will have massive consequences, you know, potentially like buying alcohol, etc. There are some mistakes – sometimes your best way to learn is by making mistakes, having that complete control of certain decisions and if it comes unstuck, you've just got to be there to help and support them, not to say, "I told you so" but just to be there and say, "Okay. Well, how did you come to make that decision and what do you think you could do better next time? Is there anything else that could help you to either not make that mistake again?" (#PC11)

Parents talked about ensuring young people had control, but also learned from decisions that did not have the desired outcome.

I won't tell them what to do different. I will put it back to them so that they've got that sense of control. Even with my youngest who's ten, I'm moving away from telling him what he should have done, just saying to him, "Well, what could you have done?" because I think when the young person feels that they've got that control and they do have that control, I think that really helps launching them into having their own independence with that, and learning, because they will make mistakes. (#PC8)

Parents also recognised their limitations. Often this was a limitation of time, around their own work, and around other children and caring responsibilities (#PC6). Limitations also related to the sorts of decisions being made. One parent shared an example of supporting another child:

My daughter has just bought a truck. ... She's like, "Oh, what do you think?" and I'm going, "It's big." I don't have any familiarity with four-wheel drives or trucks or any of that sort of stuff, so when she's asking my opinion, I can't help at all because that is way outside of anything I know. Our ability to assist with decision-making is really based on our own experiences and what we have familiarity with. If you don't, that's where, like you were saying, you need other people there to complement what you're doing that may have the knowledge around that side of things. (#PC4)

One parent referred to training at La Trobe University about support for decision-making – to help young people make quality decisions (#PC6). Young people also learned from experiences of others (#YP16).

Parents and young people were both clear on what not to do. One parent said:

I mean, the worst thing that we could probably do is tell him what it is he needs to do. He's a young person and he needs to make his own way in the world. (#PC11)

One young person said they did not like 'pressure to do something' they did not want to do (#YP6). Another young person said:

People I trust mainly are the ones I trust to make decisions for me. People I don't know – that don't really know me from a bar of soap, make a decision, they're trying to make out that I'm stupid in one way. That's what I don't like. (#YP8)

Parents also recognised that people change their mind – and that is ok too.

For young people living in different settings, such as in OOHC settings, how their capacity to make decisions is developed 'comes down to the focus of the mindfulness of the foster carers or the service involved' rather than the nature of the placement (#SH3).

Some foster carers, of course, are just across all of that, very focused on the individual and their development and wanting them to be as independent as possible, even if they're going to remain living in that environment with them. ... And some services do it better than others too. Some of the out of home care services are bigger providers, some of them have their own disability arms to them, or they have their own specialist services. So, they're probably getting more therapeutic clinical support, that help them to encourage them to think about some of that. But yeah, anecdotally, as I say, I don't think there's necessarily a difference simply because of the nature of the placement. (#SH3)

The same is likely to be true in any other living arrangement. One stakeholder indicated for young people with higher support needs in OOHC settings, 'there isn't a lot of focus on trying to encourage the young person to make more decisions for themselves or have that independence given their level of disability' (#SH3).

Support was also available from advocacy organisations, supporting families and young people by providing information, training, access to peer networks, as well as individual advocacy (#SH5). Advocates can help young people 'make good choices ... [by] laying out options' and are 'trained to work with people with various disabilities and have approached in different ways to be able to comprehend that consent process and comprehend what the participant needs' (#SH5). Providing support to the whole family helps prepare parents to step back and allow the young person to exercise their growing autonomy over time, with support as needed (#SH5).

Disability representative organisations (DROs) also provide training. This includes promoting person-centred decision-making and supported decision-making in group homes by providing training for people with disability, staff and family members (#SH6). DROs and advocacy organisations also provide information about supported decision-making, including resources for people with disability about 'what is supported decision-

making, rights, rights to support, who could support, etc.’ (#SH6). They also provide support for young people leaving school and identifying options for the future (#SH6), and provide supports for families in building capacity of people with disability and their families (#SH7). Effective supports (advocacy, information and training) were developed with people with disability and often delivered by people with disability (#SH5, #SH6).

While some DPOs, DROs and advocacy services target the person with disability, others focus on the family either as a unit, or focus on parents, and provide long-term support (#SH7). As one stakeholder said:

Some of our messaging will go directly to families, because we don't want to be naive about what that takes or simplistic about what that takes, we don't want to bring a group of people with significant needs into the room and leave their families outside and pretend that change will happen. So it's kind of like a both approach, I think. (#SH7)

Many advocacy organisations also work more broadly to build the capacity of people with disability and their families with a goal to help people with disability live good, purposeful, meaningful and inclusive lives’ (#SH7).

## 5.4 Individuals supporting themselves

Young people identified they had different support needs – reflecting the diversity of participants in the study. Young people ask others they trust in their support networks for help making decisions. One young person said:

If I can't think of anything good to convince myself, because there could be times where I do that and I'm like what the hell am I telling myself here, because I convinced myself it sometimes works, but I also just don't feel convinced. So I ask another person to see what they think and I think about it more. ... If I don't convince myself, I go to another person to see if they give me any other ideas. (#YP9)

Sometimes young people avoid making decisions, such as going to a party, in case their decision upsets other people (#YP9).

Young people told us that the people they relied on to support their decision making changed over time. While young people continued to be supported by their parents, as they get older they wanted support from other young people, and paid support workers or other services. Young people in this study wanted information about options and consequences, but most were clear about making decisions themselves.

Young people interviewed used different approaches to finding out information and deciding what they wanted to do. They include:

- Talking to other people – peers, support workers, teachers, their boss, family, friends
- Looking for information online
- Writing things down
- Talking to more than one person about a decision (#YP1) as they may ‘have a different view’ (#YP4).

Talking to peers was of particular importance as young people grew up – both for support and encouragement.

I think my peers encourage me a lot. ... I think with my friends there, I can tell them, not that they're wrong, but I can tell them that it's not right for me. Like we can share stuff and know that there's no judgement, there's no expectations. We're just like supporting each other. Whereas like family, parents, healthcare professionals, it's different because there's like a power imbalance there. And I don't feel like I can just assert myself the same way. (#YP16)

Formal peer support networks ‘support young people to see themselves and their peers as experts in their own lives’ and provide ‘opportunities for young people with disability to learn new skills and information that will support their decision-making in the future’ (#SH12). Talking to peers provides an opportunity to talk to people who have ‘been there and done that’, sharing and learning from each other’s experiences (#SH12). Some young people also said they supported others to build confidence in decision-making (#YP18). One young person said:

Having a disability gives you a lot of knowledge in some ways to help others and, like you said, creates that safe place. (#YP12)

However, peers were not always a good influence. One young person said.

Bad examples of people helping me make decisions are peers at school. They try and manipulate you to get what they want. ... If they are helping me make the decision, I'm the one that gets in trouble, not them. (#YP11)

One stakeholder said there needed to be ‘more opportunities for peer support, and to build a culture where peer support is an acceptable and available form of support for people with disability and their families, in addition to or instead of more formal traditional (paid) disability supports’ (#SH12).

Some young people talked about their right to make mistakes, and fighting for the right to make mistakes. One young person said:

I want to have the right to mistakes. Yeah I made a lot of mistakes and I still do now. But I still want to make them. (#YP8)

For many young people, their parents and support workers helped develop their skills. For some young people, they went to specific training or sought to learn specific life skills (#YP3). This included assertiveness training (#YP16) or programs at school or TAFE. Some young people also shared their experiences with others to help them learn. For example, one wrote a blog post about their experience at school which is on a disability organisation's website (#YP18). Another, when asked what would they say to other young people, said 'keep it at your own pace' (#YP9).

Young people also said what they did not like. This included:

- Surprises or being rushed
- People deciding for them in general
- People deciding for them for specific areas, such as 'what you're going to do for a living' (#YP9)
- Not being pushed to talk about something or make a decision (#YP17).

Young people said they trusted their parents. One young person said: 'She's really calm... And if she feels like I'm not making the right decision, she will pull me aside and give me the pros and cons' (#YP11). Stakeholders were concerned that not every young person had a strong and trusted relationship at home, whether they lived with their family or with others (#SH8).

## 5.5 Summary findings

Young people and their parents identified many ways young people received support in decision-making and building autonomy in decision-making as they grow up. As noted in Section 3 above, the process of building capacity for young people with cognitive impairment is a very natural process used for supporting any young person growing up. However, consistent with the literature (Glen, 2017), as parents with other children highlighted, the process for supporting young people with cognitive impairment is a much more conscious, intentional and resource intensive process. This is potentially as the external environment has little or no enablers to drive or support this process. Further, the process of building autonomy in decision-making is different for everyone, varying by support needs and the supports around the young person. This section identified common themes about how this is supported.

Similar to previous research, this study shows that young people were supported by people they trusted and had good relationships with – with family and peer relationships being key. Young people also wanted to and needed to be allowed to make some mistakes. In terms of building or enhancing capacity, study participants highlighted the importance of active and supported long-term incremental learning. Without this, there is a risk that young people are unable to express will and preference for significant decisions in their life – in particular, where to live, who to live with, relationships, finance, education or work. The next section talks about additional supports required.

## 6 Identifying ways to support young people exercise their autonomy

### 6.1 Improving systems to support young people

Participants identified the need to improve systems that support young people to develop skills to exercise their autonomy as they grow up, in expressing their ‘choice or making decisions, or resisting if necessary’ (#SH11). Increasing autonomy, developing skills and experience in decision-making, supported or otherwise, should reduce the need for guardianship arrangements to be put in place (#SH11).

If there was work done from an early point it would make a huge difference. Some relate[s] to communication. So many people with disability that we work with don't have the critical support they need to be able to adequately communicate their view – to adequately understand information they're being provided and to clearly communicate their views. ...That's a real concern for us ... that capacity building work with individuals to understand, to maximise, to have experience in making decisions, to have information about different options that are available in order to be able to make a choice, or to know the consequences of some of the decisions. (#SH11)

Rather than systems supporting young people to develop skills to exercise autonomy as they grow up, some current systems do the exact opposite, creating barriers to participation. For example, participants at a recent roundtable hosted by the Disability Royal Commission identified a link between the introduction of the NDIS and an increase in the number and length of guardianship orders in place:

We are actually seeing an increase in the number of people with intellectual disability under guardianship orders. It's rising dramatically as a consequence of the NDIS. In terms of data, we have 555 guardianship clients that were NDIS participants, so 74% of people under guardianship in Victoria as at May were NDIS participants. ... We are seeing guardianship orders for longer periods of time. (Disability Royal Commission, 2022c: p36).

NDIS participants were referred to guardianship processes where they were considered not to have capacity to make the decisions required for ‘sometimes quite unproblematic administrative NDIS-related decisions’ – possibly in an effort by agencies to mitigate their own risk (Disability Royal Commission, 2022c: p35).

Participants in this study also identified several areas that have the potential to help young people develop greater autonomy in decision-making. This includes education, health, law and administration, out of home care, and societal attitudes (discussed in turn below). Any changes to any system or service to help young people develop greater autonomy in decision-making should be made in consultation with young people with cognitive

impairment (#SH8), and particularly to identify priorities given the 'litany of things that are important' (#SH11).

### 6.1.1 Education

Research participants highlighted that education can provide opportunities for *all* young people to:

- Learn about rights, diversity and inclusion
- Learn about different decisions through the curriculum, including decisions about relationships, consent, diet and lifestyle, what to study, whether to go to TAFE or university, or whether to find a job, what sort of job to look for, as well as financial management
- Make decisions and gain independence outside of the home
- Make decisions about adjustments needed at school, and how to transfer adjustments needed to other settings (#SH1).
- Learn about 'how to complain and advocate for yourself effectively' (#SH1)
- Learn how to 'cope on their own without their parents' (#PC4).

**Education (going to school) 'plays a big role, not the only role, [but a] massive role in fostering autonomy in young people from an early age'** (#SH6). Education settings are even more important for young people living in OOHC:

If a child is engaged in school that can become their constant and that's where really strong relationships can be framed. I have observed specific examples where school almost becomes the hub for that young person and that school teachers, particularly if they're attending a special school, almost are the person who knows those young people best. So, they're in a unique position perhaps to provide some of that support. So, perhaps it goes to what does the education curriculum for those young people look like? What are the pedagogical methods that they might use that will encourage that level of decision-making and decision-making support around that? Can they to some extent, not necessarily substitute for family but compensate for the lack of family through both the content and the way that they go about their pedagogy. (#SH9)

While school is 'an important and potential constant for a young person' (#SH9), this was not always possible for young people who became dislocated from school (#SH9).

**The young people and parents in this study spoke about how their experiences at school varied.** One participant said from their family's experience, some schools were

more supportive forms of education than others, with variations in schools and class sizes, additional supports available (for example, one had playground supervision across the school day to allow young people to take a break outside), and different programs across the stages of learning to help them transition to adulthood (#SH4). They recognised they had been lucky in their experiences, but that it came down to finding the right fit for the young person (#SH4). Some young people, through school, were able to attend courses provided at TAFE, or Certificate II training by other providers, that covered a range of life skills, including taking public transport, making decisions out of home, and learning new skills – including work readiness (#PC4, #SH4).

One stakeholder highlighted good experiences were often due to individual staff members, and were not available to everyone:

What we hear is that if you've got a teacher who's keen and a principal who's keen, then you'll be fine. If you don't, then that's the end. And we see that a lot. And so sometimes something's working really well with a teacher in one year and then you go into a different year and a different teacher and they're just not interested or they're not capable or they don't have the resources and don't want to, or the principal changes and suddenly the funding goes or the supports go. And I think you're just so much at the mercy of an individual for what supports you get at the department level. Of course, we've got these wonderful inclusive policies. But, the actual day to day is very different from what we see. (#SH1)

This led to significant variations within and across schools.

I think practice is going to be more likely to occur in environments where there is culture and beliefs and positive attitudes, and opportunity and supporting school mission, vision, values, teacher training, all of that kind of stuff. The reality is you've got inclusive schools out there and you've got schools who just don't know what to do, or they're fearful, or they're gate-keeping or whatever they're doing. So they're I think calling out that there is a variability in practise across schools. (#SH6)

While Education Departments had policies in place, it was unclear what supported their implementation in terms of training, resources and accountability (#SH6, #SH7).

Innovation was considered by study participants to be lacking at a systemic level.

I haven't come across many really innovative pioneering stories about the schools. I think they're still a bit lagging in their attitudes to choices being made at any age by a young person growing up with an intellectual disability. So that's a bit systemic. (#PC2)

While some states have inclusive policies, it is unclear what is in place to consistently support their implementation – in terms of training, resources and accountability (#SH6, #SH7). There is also opportunity to build this into teacher training (#SH6).

**Many young people in this study had poor experiences at school.** Several had been subject to bullying and either moved to a different school if an alternative was available – or left school altogether. Young people said they were often singled out at school because of their disability and the supports they received. Further, not all schools were accessible in terms of infrastructure<sup>5</sup>, reasonable adjustments in the classroom, or in terms of the curriculum.<sup>6</sup> While stakeholders recognised ‘education is significantly better for people with disability than it was two decades ago’ (#SH11) it was still far from ideal; many families still sought advocacy services to help young people access or stay in education (#SH1, #SH7).

**Some stakeholders were concerned that school was reinforcing dependence,** and perceived ‘the goal is to get them through school, not to survive beyond school’ (#SH2). For example, one stakeholder observed discussions and decisions about adjustments at school were often between teachers and parents – regardless of the students capacity – rather than encouraging self-advocacy by the student (#SH2). Another said there needed to be ‘the philosophy and the belief that children with disability do have a voice and the right to learn and be included’ and to ‘support teachers and schools and educational leaders to create autonomy, supportive environments, and ... support schools to foster self-determination in kids with disability’ (#SH6). They added, ‘it’s a bit unfair to ask them to make decisions [about what they want to do when they leave school] when they haven’t been given decision-making opportunities through school’ (#SH6).

Stakeholders were concerned that young people with higher support needs were overlooked in decision-making processes while at school due to lack of understanding and lack of will. Further, they missed out on opportunities to learn about rights and structures through subjects such as Personal Development, Health and Physical Education (PDHPE), life skills and options that help identify preference and make decisions. One said:

The education system for mainstream kids is very much set up to help them on their way. But that seems to wane [become less] the greater the level of disability and I think some of it stems from a perception that people with a disability may not ever be able to make decisions. But I think we now know that, with the right sort of supports, people can contribute significantly to all kinds of purposeful things in their life. Some of it’s about communication, what efforts do we make to really understand how a person can communicate if they’re not using verbal communication. Even developing relatively simple systems so that they can say yes, I want to do that, or no, I don’t want to do that. Or that they might take a longer

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<sup>5</sup> One stakeholder said, in relation to the lack of accessible bathrooms at a school, ‘we are in 2022 and we still can’t get some of this integration and disability stuff right’ (#SH10).

<sup>6</sup> See The ATEND submission to the 2020 review of the Disability Standards for Education. Available at <https://www.atend.com.au/download/attachment/72-2/> accessed 11 May 2022.

period to get engaged in something than a person who doesn't have the same level of cognitive impairment. So, I think it's just recognising that people with a disability have different abilities and they may need more help. (#SH9)

**This lack of understanding or will to make education inclusive** was potentially higher for students with 'invisible disabilities' such as psychosocial or learning disabilities; it took time to 'work out what adjustments are appropriate ... and what can actually be done, and what a teacher should be required to do, and what a school should fund and not fund' (#SH1). Without appropriate adjustments, there is an increased risk of students being suspended or expelled for what is perceived to be poor behaviour rather than behaviour people had no control over (#SH1, #SH4). For one family, 'home-schooling [during COVID lock downs] actually meant that [the young person] was more engaged with school at home than [they] were ever at school' due to the amount of time they had spent on suspension before and after lockdowns (#SH4). Being excluded from school also meant being excluded from opportunities for social development – both formally (through the curriculum) and informally in social interactions and relationships with peers and teachers.

Participants identified opportunities for teachers and principals to be trained in more inclusive education, and for the broader school community to have a better understanding of disability and inclusive education.

You're constantly having to educate others as a parent. And because every new space you go in to, they just don't have the awareness or the knowledge of how to work with a child with a disability. My son goes to a State school. He has a fulltime aide but each year with the new aide is learning [how to support] him. Each year with the school it's educating the new teachers. It kind of all feels like it's on you as the parent to have to do all that work. Like the school aren't very proactive in understanding children with disabilities. (#PC12)

There was also opportunity for one person within the school to support young people with cognitive impairment as they went through school. As one parent said:

We didn't really have anyone in the State system who understood the sort of connection between his cognitive ability and his behavioural difficulties and fitting into that school system because he was mainstream schooled. There wasn't really someone independent that would support us going through the school. (#PC3)

There were also ways to improve transition out of school. One stakeholder talked about a pilot project where their staff go into a school to work with young people over time to identify interests and skills, often facilitated by discussion with their peers, and identify pathways for when they leave school (#SH7). Other stakeholders were trying to overcome something referred to as the 'polished pathway', where young people with cognitive impairment were in segregated schools and then in segregated employment (through for example Australian Disability Enterprises), leading to a lifetime of exclusion from the

community and facing greater risk of violence, abuse, neglect and exploitation due to isolation (#SH8). This polished pathway comes about due to the low expectations of young people with disability and lack of opportunities offered to them. This polished pathway could be overcome by encouraging young people into open employment (#SH8), by going through the same pathway as all children to help them explore what they would like to do and seek opportunities to enact their preference.

Disability standards for education 'seek to ensure that students with disability can access and participate in education on the same basis as students without disability'.<sup>7</sup> The standards have enabled some progress to be made, giving 'young people the knowledge that they have the right to be included in education', with 'more young people with disability going on to further education' (#SH2). However, their implementation has still been lacking and access to inclusive education is still an issue fought by legal advocates (#SH1, #SH10). Some stakeholders commented that schools were not adequately preparing young people for leaving school – either going to work or participating in further study. For example, students with cognitive impairment transitioning to further education often needed support in communicating support needs, and building autonomy and confidence in different settings (#SH2).

Further education has a different philosophy [to schools] and a greater reliance on self-advocacy to prepare students for employment, including supporting them use tools while studying that can be transferred to a workplace. (#SH2).

### **6.1.2 Health**

Contact with the health system can be quite complex. Some health and allied health providers were able to ensure the decision of the young person was taken into account, and also went to the extent of helping young people develop their capacity and confidence in decision-making. However, this was not experienced everywhere. Some young people often felt decisions were made for them or forced on them (#YP16).

I'll nod my head and listen to all of the thoughts and eventually, like you, I've definitely felt like they've put so much time and effort of telling me this sort of stuff. Like it's the only option and I have to go through with it. That took away a lot of autonomy and agency. At this point I still struggle with some of those things, but it feels really nice to be able to say no. .... So people that have taken that really holistic view of what health is, are the ones that I like and trust a lot, opposed to people who have a very medical view. So there's people I've seen who I would not see again, and not trust them to make any decision about me. (#YP16)

They added:

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<sup>7</sup> See <https://www.dese.gov.au/disability-standards-education-2005> (accessed 16 June 2022).

I don't mind some of my medical practitioners to help me make decisions, particularly if they help me to understand, keep me informed about what it is that I'm choosing between. But a lot of them, I don't feel like they're helping me based on my best interests, it feels like they're helping me because it's their job, and they have certain things that they're supposed to do. (#YP16)

This experience picked up the culture held of some practitioners in health about their duty of care about consent to health care (Australian Law Reform Commission, 2014, p282). One parent talked about the lack of understanding of cognitive impairment by many health care providers – speaking about the young person and not to them (#PC7).

A particular challenge experienced by young people and their families/carers was the transition from paediatric care to adult care and the impact this break in continuity of care had on decision-making. The trust and understanding of communication needs between specialists and the young person and their family/carer had to be rebuilt with a new practitioner – this was made more difficult with the lack of face-to-face services during the COVID pandemic (#PC11). This shift to adult care also occurred during a transitional time in the lives of young people – when the young person is pushing for independence, when it may also be difficult to distinguish between transitional factors, cognitive disability and mental health (#SH4).

### **6.1.3 Law and administration**

As discussed in Section 3 above, the 18th birthday triggers several automatic changes to conditions for making decisions under both law and policy. This includes:

- Transitioning out of out of home care
- Transitioning from paediatric care to adult care
- Having greater control over finances
- Requiring a young person who turns 18 while living with younger siblings in foster care to hold a working with children check (#SH4)
- Being able to enter into a contract
- Being legally allowed to drink and gamble.

Further, when you turn 18, the implications of making a decision can be much greater – by the types of decisions that can be made (loans and contracts, irreversible medical interventions) as well as the implications of those decisions (such as financial liability and criminal responsibility). So, the trust in the decision a young person makes is subject to

greater safeguards, and the safeguards need to be proportionate. As stated in article 12(d) of the UNCRPD:

Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

For many administrative issues, there was no or little adjustment for cognitive impairment, even for accessing the NDIS. One young person said:

Sometimes with NDIS stuff, they're like, 'here's a massive thing that you have to fill out' and you have no idea what it means. ... So I usually get help from my parents or my support co-ordinator or whatever, and especially stuff that's like...it should be for everyone because, like you don't know who might need help with stuff. But especially for stuff that's like, for people with disabilities. There should be stuff that's accessible. (#YP17)

As society was 'calling for representative decisions' (Disability Royal Commission, 2022b: p22), this resulted in systems and services defaulting to substitute decision makers when administrative processes were inaccessible.

As one stakeholder said, 'its not just that you turn 18' and make all decisions independently (#SH1). One parent suggested there should be a transition period:

In an ideal world, it would be nice to have a different status other than guardian or parent where you have a voice but it's not an overruling legal voice. So at the moment, do we change our status from parent? Do we become a legal guardian? We don't know. We don't know what to do where he can make his own decisions and we can help him. So, in an ideal world, there would be kind of a mid-legal status where we don't have to go through a whole process but we still have a voice in his choices. (#PC3)

While some organisations may have appropriate processes in place to get instructions from the young person and their family if needed (#SH1), others may not. Examples were given of young people suddenly having full control of their finances at 18 with no oversight offered to parents (#SH4). While a young person's financial autonomy is important, it was also considered important to support this transition process and involve family where appropriate. A recent roundtable participant highlighted the need to build 'quite specific capability around managing money' (Disability Royal Commission, 2022b: p33).

One parent suggested making videos available to services that could explain things to people with disability, such as consent or agreement to something, so that it would not fall to parents to continually have to explain things for the service (#PC2). Another area

identified for improvement was making proof of age or identify cards from Service NSW a valid form of identification for online ID (#SH4) – equivalent to a driving licence.

One stakeholder highlighted some legislated systems still considered people in a binary way:

At the moment we're living in this binary world, you either have capacity, you either can make the decisions or you have to have a guardian. Now the world both of ... people with disability is not that binary. There are all shades of grey between those two positions. (#SH11)

They added, people need to be supported in making decisions without 'undue pressure by another party or undue influence' (#SH11). Some young people, for example those living in out of home care settings, may not know their rights or who to report a complaint or harm to, or if they do know about them may find them difficult to access such as telephone services (#SH1).

#### **6.1.4 Out of home care**

Organisations responsible for providing OOHC perceive the young people in OOHC to be vulnerable and at risk, and consequently may not be giving the young people their right to learn and grow, building experience and autonomy in decision-making, and taking risks along the way. Family courts or agencies 'may make decisions that are in the best interest of the child' when they are young and enter OOHC, but the ruling or decision remains in place which 'doesn't necessarily align with the rights of the child as they age' (#SH8).

Young people in OOHC are the responsibility of the Minister, and as one stakeholder said:

...there needs to be a bit of a wake-up call about what that really means in practical terms. Whether it's about the way that they structure the system, the way that they fund the system, the way that the staff are trained, I mean all of those sorts of things really fall out of that rights-based approach. (#SH9)

Service providers contracted to provide OOHC follow the requirements of their funding contracts, as well as the policy and direction of the funding agencies, which may be translated locally into policies, procedures and practice manuals (#SH9). The OOHC system may also place constraints on young people exercising their will and preference due to administrative controls; for example, being able to be On Country if the distance travelled exceeds that permitted by the care arrangement (#SH10).

In terms of building autonomy in decision-making, 'there is a policy and expectation' for young people in OOHC to transition to independence. Planning is expected to start around the age of 15 and continues until they leave OOHC at 18. One stakeholder reported it was difficult to see 'where the young person's views and wishes [are] within that', and it was

difficult to see any resources that had been made available to young people to support them in the transition planning (#SH11). They therefore believed ‘a lot of decisions are still happening without [the young person’s] involvement or an attempt to get their involvement’ (#SH11).

[Young people in OOHC who] may have had multiple [placement] breakdowns, they may have come into care late and foster care didn’t seem to be an option for them. Many have experienced significant trauma ... they’re potentially disengaged from education ... to get those young people engaged in opportunities around self-determination and autonomy and independence ... can be very challenging. ... We [need to] start much earlier in the sort of systems process to be thinking about giving children and young people opportunities for decision-making and independence. To suddenly overlay it when they’re mid-teens is potentially not actually going to be that effective. (#SH9)

Young people in OOHC ‘need the capacity to have as much say in what their future looks like as possible’ and therefore need to build autonomy and skills in decision-making to identify and make their choices (#SH9).

One of the things that they’re going to have to be responsible for or have support around is about how to engage around specialist services for their disability once they’ve turned 18. Again, whether that’s NDIS, whether it’s mental health or other kinds of community-based support. This arbitrariness of turning off the tap at 18 can be really quite tricky. (#SH9)

As this study shows, developing autonomy in decision-making needs to start as early as possible (#SH11); yet stakeholders recognised there were often other priorities for services supporting young people in OOHC (#SH11), particularly for young people with significant support needs and complex medical needs (#SH9). There is however the potential to make this a requirement of OOHC settings through contracts and policy change.

The support available to young people in long-standing foster care arrangements and residential care may be different.

There maybe be a group of those who are in long-standing foster care arrangements and are reasonably well supported. But do the foster carers and or the case managers recognise the importance of this particular element of that young person’s development at that stage in their life? Even if they recognise the importance of it, do they know where to find the support they need in order to be able to meet that need? (#SH9)

Young people did not always have somebody to ‘travel with them in their life ... that constant significant relationship ... or series of significant relationships ... that helps most of us through life, particularly when things are difficult’ (#SH11). They perhaps needed ‘a relationship-based model of support that travels with the child ... but I don’t think the

system has found a way to deal with that' (#SH11). Other stakeholders also recognised some OOHC settings are very different to family environments, 'where families are strong advocates'; they added, 'let's recognise that difference and let's make sure we fill those gaps' (#SH9).

Where young people have access to the NDIS, they may be able to access services to support the development of decision-making skills and capacity. However, for young people with low to moderate support needs, capacity development needs to be provided from elsewhere (#SH8, #SH9).

As noted in Section 6.1.1 above, for some young people in OOHC, the school environment was particularly important in providing continuity and forming trusted relationships. However, as one stakeholder noted:

There's a lack of real connection between say service providers in the out of home care space and those education environments. Even though the policies and the therapeutic framework would say that there should be a closer relationship, in practice I don't see that as much. (#SH9)

A report by ACWA, '*Falling through the gaps? Delivering the best possible outcomes for vulnerable children and young people with disability*' (2021), identified opportunities for greater engagement, collaboration and cooperation between key stakeholders and across state and federal governments at the intersection between systems such as disability, child protection, and other systems (including justice). These intersections often created additional problems where some decisions were made before the age of 18 (such as planning to leave care), others after (such as funding for housing), despite the decisions affecting each other (ACWA, 2021: p22).

This was a particular issue when there were 'behavioural challenges through mental health, through disability, through trauma', such that the young person's experience of school 'ends up being a whole series of expulsions and suspensions because educators really don't understand where those kids are coming from' (#SH9). Schools had a role in terms of providing 'welfare, psychological support, and behaviour support embedded within their system, so [the young person] can cope better on a day-to-day basis' (#SH9).

But bearing in mind that we also have to respect the rights of other young people at school to learn and teachers to get on with the teaching. But I think that process of okay we're going to suspend you because you've done the wrong thing, it alienates kids and over a period of time, their attendance at school becomes less and less. They become targets for their peers as opposed to being embraced by their peers in an inclusive way. (#SH9)

The findings of this study are not new. After many reviews, the OOHC system understands what the issues are and what needs to change; however, it needed to overcome the

barriers to making the changes required (#SH11). The relational component of OOHC, and other social supports, was often missing.

It is a great tragedy that we failed to understand how important relationships were in our social support models and they've become increasingly transactional as you know in nature and character. But even if you believe the power of transactions is giving agency to people which it does, there is this absolutely overriding need to have some sort of relational element in all of those service system models. (#SH11)

Without support and education, young people with cognitive impairment leaving OOHC may be more likely to transition to Guardianship orders. As one participant at a recent roundtable on supported decision making said:

**Most of those children [leaving OOHC], if they're linked to the NDIS, their first avenue, once they turn 18, is the Guardianship Board.** So we've got the highest number currently in Australia in children in OOHC that shouldn't be moving into guardianship because **there haven't been the appropriate education avenues.** So if we get this right now, we can change systems and save money, and make it right for everyone. (Disability Royal Commission, 2022a: p42)

Another said:

There's very little education about parents' rights and the young people's rights if they are living in out-of-home care. And in terms of fluctuating capacity, we are talking about young people with a disability. So because of their age, they often have a fluctuating capacity. And **they might not have had the training and education yet to be able to learn about their rights, and it might take more time then to scaffold that learning to help them understand how to make a decision.** And this then obviously is a life course journey and has great impacts down their path once they have been in that system for a long time. (Disability Royal Commission, 2022b: p63)

### 6.1.5 Reducing stigma

Many young people and parents identified ongoing stigma for young people with cognitive impairment in different settings; as a result, young people were not given the opportunity to make decisions themselves. Participants identified the need to educate the broader community about supporting young people to grow up making decisions, supporting young people to develop confidence and autonomy in decision-making through experience. One parent said:

A lot of people assume that kids with an intellectual disability are stupid. So they talk about them and I don't think people give kids with an intellectual disability enough credit. (#PC7)

Most young people who participated in the study said they wanted to make their own decisions. Sometimes they were unable to as decisions were made for them by others.

Sometimes they felt other people judged them for making decisions themselves. Parents also felt judged. One parent said:

You are also afraid of the judgement of others as well in the decisions that you're making because you almost feel like people are watching you that little bit more because you have a child with a disability as though "I wouldn't let my child do that." You know and it's like well you'd let your child do that wouldn't you? Like why can't I?"

One parent suggested the need to provide information to the broader community, and in particular to services and systems, to ensure the needs of young people with cognitive impairment were understood and met (#PC7). This extended to increasing other people's expectations of the rights of young people with cognitive impairment to make decisions.

In most settings, young people had to share information about their disability for adjustments to be made. If disability had been a source of bullying at school, young people may be unwilling to share this information with others outside of school. One stakeholder said, 'if you don't identify strongly or positively' as a person with disability (including for cultural reasons), you may choose not to share that information.

You don't have to disclose, but the issue, I suppose, we see from a discrimination perspective is, if you then find that you're not getting supports you need or you're finding that things aren't working out and you want to then say, look, you haven't made adjustments for my disability. If you haven't disclosed or you haven't asked for those adjustments, you're in that catch 22 ... There is a lot of concern about disclosing ... and having that label (#SH1)

What stakeholders said was needed was 'a stronger emphasis on people's abilities and seeing supports as something that enables them to maybe use their abilities' (#SH6).

In parallel to reducing stigma, there were opportunities to increase understanding of different communication and support needs more broadly, recognising that everyone has different access requirements (#PC12, #SH10). This was particularly important for professionals dealing one-to-one with the young person. As one parent said:

... be understanding that when they say, "Do you understand what I've told you?", if he says "yes", that doesn't necessarily mean that he does understand the big picture of everything. ... I think when you have people in an official capacity like Centrelink workers and all those kind of people, they don't necessarily have that level of understanding. (#PC3)

Research for the Disability Royal Commission about changing attitudes to address stigma found that simultaneous, long-term strategies that include contact, information and presence of people with disability are most effective (Idle et al., 2022).

## 6.2 Improving services to support young people

Young people and their parents identified several ways services could be improved to support the development of autonomy in decision-making, to include young people in conversations and ensure choices are directed to young people, and to support young people where necessary in making decisions. Parents highlighted the importance of everyone involved with the young person (family and services) supporting this process.

- **Providing generic information resources** (not targeted at a particular diagnostic group; #PC7) in different formats **to support developing autonomy in decision-making**, and about preparing for decisions in key areas of life ('social decision-making, relationships, community, education, job opportunities' (#PC8)). Resources should be targeted at young people, families/carers and service providers.
- Recognising the importance of trusted relationships, **encouraging services and systems to provide greater continuity of support** as young people grew up; in particular, through school and health services. This was particularly important as people transitioned systems (for example, paediatric to adult care), but also over time within systems (for example, across school years).
- **Providing and identifying services that focus on supporting young people and services that can help support increasing autonomy**, such as through mentoring, to help them 'prepare for young adult life' (#PC8). Participants highlighted that while there were specific services that supported younger children and adults, there were not as many services designed to support young people transitioning to adulthood. This may include services being provided by young people to young people, recognising the balance between the benefit of having young people as supports but also the experience that comes with age (#PC2).
- **Providing adequate stable funding for services**, and reducing wait times, so that decisions can be implemented before they become redundant (#YP8, #PC8)
- **Increasing access to advocates** (additional funding of advocates) to resolve barriers to access and discrimination (#PC10).

Stakeholders also identified ways to improve services to support young people develop and exercise their autonomy in decision-making. This included:

- **Improving the awareness and understanding of cognitive impairment** in different systems and services – in particular, distinguishing between 'young people pushing their independence, what might be a mental illness, and what might be a

cognitive disability' (#SH4). Then 'being able to respond to and support' the person and be 'conscious of how you support individuals with specific skills like decision-making' in terms of person-centred practice (#SH3). For staff in non-specialist services, they may not have regular contact with young people with cognitive impairment and therefore may be unfamiliar with the supports required (#SH3).

- Organisations and professionals **taking a human rights approach**; 'if you're thinking about rights first, you're more likely to do the right thing' (#SH9). This includes: asking the young person 'what might you need support with to help you participate' (#SH8); providing examples as young people may not know what to ask for (#SH8); and involving the young person in meetings 'at an age appropriate time' when the meeting is about them. If something is not working, ask the young person to explain why it is not working (#SH1). This sometimes requires professionals to 'overcome their own professional identity', where 'caring is a dangerous and suffocating thing', in order to 'help the person become more independent' (#SH4).
- **Working with young people to build their experience, capacity and autonomy in decision-making** in order to 'think about their goals and their future' (#SH3), recognising the 'dignity of risk' and 'supporting and facilitating people to advocate for themselves as far as possible' (#SH4). Schools and support services have a critical role in this process. As one stakeholder noted, 'sometimes [young] people make a decision that's different to what you would make, but it doesn't mean that's wrong or that they don't have the right to make that decision. Sometimes the duty of care comes in too fast, or too strong' (#SH4).
- **Resourcing community level capacity building programs** and services where people can learn about supported decision-making.
- **Building self-advocacy skills of young people and their families/carers** to help them communicate their needs with services.
- **Automatically providing support for decision-making in specific areas**, such as planning meetings for the NDIS; this provides independence from the service provider who has a vested interest in the plan, and helps avoid being locked into services where the person may be subject to violence, abuse, neglect, or exploitation (#SH8).
- **Providing culturally appropriate support in decision-making**. It is important to understand 'there are some cultural obligations' in decision-making (#SH8) and, in OOHHC settings for example, carers should consult family members and others to

ensure those obligations are met – especially for bigger decisions that take time to make (#SH9).

- **Improving interagency collaboration** and reducing segmentation between service types caused by funding models. Specifically, improving collaboration between NDIS, Education, Community Services, and any other service providers, ensuring leadership and accountability for collaboration, and ‘leveraging capabilities across each’ (#SH9). Improvements in collaboration can range from service planning down to individual case work. Collaboration in service delivery is critical across the life span and at key transition points; for example, when completing school or when leaving out of home care (#SH6).
- **Sharing resources and expertise** in growing autonomy and supporting decision-making, both by centralising resources (allowing agencies to avoid duplication and address gaps, #SH7) and sharing good practice through a community of practice to build on what is working well (#SH6).
- **Resourcing advocacy organisations** to provide community-wide training to help develop autonomy and support decision-making for young people and for parents to support young people. This should include resourcing advocacy organisations to provide young people with individual advocacy services – particularly where young people do not have access to trusted supports or where there are barriers to exercising their will, preference and rights (#SH5).

In OOHC specifically, suggested improvements include:

- **Ensuring young people have the opportunity to make decisions** and informed choices from an early age to be able to make more complex decisions when they transition out of care (#SH3).
- **Providing training and support for case workers** working with young people with different support needs, to support decision-making in a way that meets the young person’s communication needs (#SH3). Then **supporting young people to make decisions** when transitioning to other services and supports when leaving OOHC, rather than making decisions on their behalf.

Stakeholders recognised that good practice is often known; however, several barriers needed to be overcome to implement good practice. As one stakeholder said, ‘if we can’t actually fund it, then we can’t do it’ (#SH8).

## 6.3 Improving supports for other people supporting young people

People supporting young people, including their families, peers and others, needed support to assist young people to develop autonomy. Families needed assistance to be able to support the developing autonomy of their children. Many parents felt isolated (#PC7), and others identified other specific resources, including care and financial resources, to provide young people the level of support required (#PC1). Parents also recognised that being a parent was hard – with or without a child having complex needs. Parents recognised children need challenges and they also need ways to protect them from influences of others who may be giving them unsound advice and getting them in trouble (#PC11). Parenting was also complicated by other responsibilities, including work, caring for other children, and other caring responsibilities such as ageing parents. Parents we spoke to had limited time to research how to support a young person with cognitive impairment, new service offerings, or other tools and resources they could share with the young person, or talk to anyone inside normal office hours.

To help prepare young people with cognitive impairment for future decisions, parents identified the need for easy to find information, resources and supports. Examples provided include:

- **Understanding the principles and benefits of supporting and growing decision-making capacity (#PC1)** ('I think having that perspective, that understanding that, not only is it respectful and right for everybody to have that chance, but that the work of that support, is in everybody's interest' (#PC1)).
- **Providing information for parents and young people (#YP15, #PC11)**. This includes:
  - General information about building autonomy and supported decision-making
  - Information and examples about key significant decisions (see Appendix B for examples)
  - Visual aids or videos to help support a young person (#PC7)
  - Information to give other professionals involved with the young person, such as medical specialists
  - Information specific to foster carers and other OOHC providers, along with any specific jurisdictional considerations (#SH10).

- **Hearing the experiences of other young people and their families** about significant decisions and how they were made (#PC12)
- **Having access to peer support networks** for parents and for young people, and support for parents to take a step back (#SH12)
- **Having access to advocacy services**, training and support in multiple formats (including one-to-one consultations) to understand rights and grow autonomy (#SH5, #SH7)
- **Accessing supports as early as possible** (#PC12).

Several parents highlighted the time required to support and grow autonomy in decision-making. One parent also highlighted: '[parents] need to know that it will cost them some dollars and time, and they must be able and willing to sacrifice that. It's not going to come at no cost, never at no cost' (#PC6). Given the number of services and professionals young people with cognitive impairment may have contact with as they grow up, parents recognised the importance of having a shared understanding to support the young person to develop their autonomy in decision-making.

Parents also recognised the need to find others (both peers and professionals) that had a similar mindset. One parent said:

It can become difficult and sometimes even a bit shaming to be the parent amongst very conservative parents that lets their child consider getting a tattoo or drinks at a party or something. I need like-minded parents. I need organisations that are inspiring me and teaching me how to support [my son] around more and more independence. (#PC2)

Stakeholder also suggested ways to improve support for parents in supporting young people to develop their autonomy. This included:

- Including parents in decision-making processes, not as substitute decision-makers, but to help support the young person grow autonomy in decision-making (#SH7)
- Helping parents understand that autonomy is not achieved by offering choice alone, but by experiencing decision-making and understanding the consequences of decisions (#SH7)
- Providing a central hub of resources for people with disability, their families/carers, and professionals to access (#SH6)
- Encouraging peer (parent-to-parent) support (#SH7)

- Considering succession planning and considering ‘who is going to be there to actively and intentionally build people who will help the young person make decisions into the future’ (#SH7).

Peer support may be informal (from friendship circles, school and sporting peers) or formal – accessed through peer support or advocacy organisations. Peer support organisations rely on project grant funding to deliver services; short-term funding can affect staff retention and program delivery (#SH5). To improve peer support, resources need to be available to both informal and formal peers.

## 6.4 Improving supports for young people themselves

Young people also identified several ways they could build autonomy in decision-making for themselves. Examples include:

- Being allowed to slow things down and take time in making decisions (#YP1, #YP2)
- Being able to access easy read information everywhere – in all services, not just disability (#YP15)
- Having information about local accessible services
- Being allowed to make mistakes, and not be judged about decisions made. One young person said ‘I haven’t made enough bad decisions’ (#YP13)
- Providing different types of easy to find, accessible information about different types of decisions young people make as they grow up (#YP17)
- Providing information about decisions other young people with different support needs have made and how they made them (#YP11), including examples from different areas such as school, where to live, and finding a job
- Providing links to other young people making decisions through peer groups
- Training others to not make assumptions, and to not judge young people for decisions. (#YP16)

Young people were also very clear not to assume ‘that one way is going to be good for everyone’ and the importance of others ‘getting to know [them], what works for them, and what doesn’t work’ (#YP17).

Stakeholders also added that it was critical for young people to ensure their views are heard and understood, by others understanding their communication needs (#SH11).

Stakeholders added it was important for young people to have a clear understanding of rights and how to access those rights (#SH5) and build confidence and self-advocacy from an early age (#SH5, #SH8), with access to individual advocacy when needed (#SH8).

## 6.5 Summary findings

Young people, their families, and other stakeholders identified different ways to improve support for decision-making and build autonomy in decision-making as young people grow up. At a systems level, opportunities were identified to make significant improvements in education, health and out of home care, as well as broader areas such as law and administration and public understanding. At a service level, in addition to greater resourcing and information, greater effort should be made to ensure the young person is included in decision-making processes and supported in the process of learning to express their will and preference. For informal supports and the self-advocacy by the young person, participants identified the need for resources to support this learning process, including more accessible information and examples of young people with different support needs making decisions in different domains of their lives.

## 7 Conclusions

This study sought to identify what supports young people need to make decisions and develop capacity to identify rights, will and preferences as they transition into 'adulthood', and how this may vary for young people living with family, in OOHC, and in other settings. This report identifies the needs of young people (Section 4), the supports young people and their families use (Section 5), and other supports required (Section 6).

Building autonomy in decision-making over time is a typical experience for children and young people growing up through the adolescent and young adult years. The process starts from early childhood and continues through adulthood. These experiences include engaging in behaviour that may be risky and learning from mistakes. This process is supported by parents, peers, and systems. Schools have a role in providing critical life skills, such as day-to-day living, managing finances and healthy living; life choices in terms of what to study, and making decisions about what to do after leaving school; as well as specific obligations around civics and justice, including voting, consent, contracts and compliance with the law which are often triggered by age.

Young people with cognitive impairment may require additional support to develop their autonomy in decision-making – from family, carers and peers, paid support workers, and through school. In the absence of building autonomy in decision-making, there is a risk young people with cognitive impairment will not be able to have their will and preference heard, understood, and supported. As a result, young people progress into a version of adulthood that *they* have not chosen. In addition, young people are at greater risk of substitute decision-making interventions, including through formal guardianship orders, that will further deny them choice and control in core domains of their life. This has been demonstrated by young people being placed in segregated living and segregated employment arrangements where they have experienced violence, abuse, neglect and exploitation.

The young people and parents who participated in this study were engaged and committed to building autonomy in decision-making. They also demonstrated the types of decisions young people made are subject to individual context. What may appear to be a small decision may involve supports doing a lot of work for that decision to appear small. Additional insights were also provided by stakeholders involved with young people in other settings, such as out of home care. Stakeholders highlighted that young people leaving out of home care were required to make significant decisions about their future; however, some young people in out of home care may not have the skills and experience, or trust in the support of others, to make those decisions. This put young people at risk of others making decisions for them, including placement under guardianship orders. Further

research is required to understand the number of young people with cognitive impairment being placed on guardianship orders in response to the lack of opportunities to develop autonomy in decision-making, although data would only capture formal arrangements and will not identify informal substitute decision-making.

Parents who participated in this study went through an intentional process to support young people with cognitive impairment to build autonomy from an early age. However, many families needed more support to make this happen. Forms of support they wanted for themselves, and the young person, included time, information, financial support, practical examples, and tools to build autonomy. Like any aspect of parenting, families struggle when not everyone agrees on the best way to support the development of autonomy and what the goals are. The process was easier for families when all supporters (parents, other members of the family, peers, and professionals) agreed on the process and outcomes.

In addition to the detailed findings presented in Sections 4 to 6, this study highlights the importance of:

- **supportive and trusted relationships** (from parents and other family members, with peers, and professionals) and the need to work together to actively support and build autonomy in decision-making in children and young people with cognitive impairment as they grow up – incorporating the dignity of risk. While this is well known in terms of supported decision-making practices, this study identifies strategies and measures needed to support young people who may not have access to supportive and trusted relationships.
- **an inclusive education system** that provides all students with structured learning about the aspects of decision-making and life skills, helping young people understand rights, justice, and consent, and building decision-making skills in life domains, including relationships, education, healthy living, health, finance, and careers. Attending school is compulsory, provides continuity, and is independent of the support young people may or may not receive at home or in their community. Again, while disability advocacy in Australia highlights the need for more inclusive education, this study also highlights education's role in supporting the learning process to identify and express will, preferences, and rights.

The question remains, what happens when these supportive and trusting relationships are difficult or absent, school systems are not supportive of the young person's needs, or young people leave school early due to bullying or lack of support. Increasing supports through trusted relationships and improving the approach of schools is essential – but may not meet everyone's needs. For some young people, formalised support from early

childhood onwards through the NDIS and other health and social services is essential. Resources with a greater emphasis on peer learning may be useful for each of these groups to build from trusted relationships and informal education (Notara et al., 2017).

This study identifies the need for practices and resources to support young people with cognitive impairment, their trusted others, and the education system to build capacity of that young person in decision-making grounded in the young person's awareness of their rights, will and preferences (see Section 6). While this process of building capacity could be interpreted as a very natural process used for supporting any young person growing up, parents highlighted the process for supporting young people with cognitive impairment is a much more conscious, intentional and resource intensive process. This is potentially as the external environment has little or no enablers to drive or support this process.

Practices and resources focused on the young person are likely to have the greatest impact, particularly for young people who do not currently have access to trusted relationships, a supportive and inclusive school environment, or attend school. They may also be used by trusted others and educators to support young people.

While this study focuses on building autonomy for young people with cognitive impairment, the findings are equally relevant to people from other cohorts who did not have these opportunities when growing up. Further consideration needs to be given to understand building autonomy in culturally responsive ways with First Nations young people, and with young people from Culturally and Linguistically Diverse backgrounds. Further consideration may also be needed for young people in OOHC or who have left OOHC who have not had opportunities when growing up – particularly for young people accustomed to having decisions made for them.

This study highlights the support required throughout the adolescent and young adult years to provide experiences and opportunities to identify will and preference – not just at key transition points mirroring typical adolescent pathways. This provides young people with cognitive impairment equal opportunities to exercise their rights, including their dignity of risk on an equal basis with others. Expressing will and preference forms identity, provides control, maximises life choices, and critically, provides protective factors in terms of identifying and responding to risks and vulnerable situations on an equal basis with others.

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# Appendix A Discussion guides

## Discussion guide – Young people

### About you

- What is your name?
- How old are you?
- Where do you live? for example, state/territory or region.
- Do you live with someone? – for example, with family, with friends, in a group home, or someone else?
- What is your favourite thing to do? [can use as an example to refer back to]

### Making decisions now

- Can you talk about a recent decision/choice that you have made?  
*For example, what to wear, what to eat, what activities to do?*
- Who else makes decisions about you?  
*For example, this can be anyone such as a family member, other relative, support worker, house supervisor.*

### Making decisions growing up

We want to talk about making big decisions.

Big decisions are things like getting a job, moving out of your family home, having a boyfriend or girlfriend.

- Can you tell us about some big decisions you have made or are making as you grow up?
- What has helped you make decisions?  
*For example. What has helped you to start making a decision, make a decision, act on the decision, change the decision*
- What has helped you tell other people about the decision?

Thinking about when someone helped you make a decision.

- What was good about the way they helped you?
- What was bad about the way they helped you?

- What do you wish they did differently?
- Would you want that person helping you again? Or someone different?
- Who do you like helping you make decisions?

### **Thinking about the future**

- What decisions do you want to make in the future?  
*For example, getting a job, where you live.*
- What would you like to do differently when you make decisions?
- What else would help you make decisions?
- What would help other young people make decisions?  
*For example, thinking about a close friend or housemate with intellectual disability.  
What would help them make decisions?*

## **Discussion guide – Parents**

- Do you support a young person to make decisions?
- How do you support your child making decisions now?
  - How do you provide support?
  - What techniques work for you?
  - What challenges do you have supporting them make decisions?
  - What would make it easier for you to provide support?
- How do you support and encourage your child making decisions as they grow up?
- How do you support your child to develop their capacity to make decisions?
- How do you want to support and encourage your child to make decisions at specific life stages? For example, education, where they live, relationships, social activities, work.
- What do you need to support that?
- What would help other families support young people make decisions?

## Discussion guide – Stakeholders

- What are **current policies and practices in your agency/organisation to support evolving capacity of children with cognitive impairment, and in particular in making decisions?**
- What are current policies and practices to support and encourage children with cognitive impairment across different life stages? For example, at the end of school, where they live, with whom they live, starting work, building relationships, having families.
  - **How are these are adjusted for families, out of home care, and institutions?**
  - How are they adjusted for a young person, family and community's particular needs (e.g. Aboriginality, cultural background, gender, level of impairment).
  - In your view how successful is your agency at supporting this transition and ensuring that young adults are able to exercise their rights to make major decisions about their lives?
- What are the policy, resource and organisational facilitators and barriers in the three settings to improving practice?
- How could current practice in this area be improved?
- What resources would be required to support optimal practice?

## Appendix B Examples of decisions young people may make

The following table presents the different domains of Australia’s Disability Strategy and their scope, its relationship to the CRPD, and examples of large and small decisions across each domain based on Douglas and Bigby (2020). Large and small decisions were identified in terms of the scope of the decision, who is involved in making that decision, any other influences, the timeframe, and the consequences. This helped to identify potential stakeholders who may be involved in supporting young people to build autonomy in decision-making and provide examples as prompts during interviews. However, this treatment of decisions was also identified as problematic – discussed in Section 4.3.

| <b>Australian Disability Strategy</b><br>Domain (bold) and scope  | <b>Link to the CRPD</b><br>Full enjoyment of all human rights and fundamental freedoms on an equal basis with other children   | <b>Examples of large decisions</b>  | <b>Examples of small decisions</b>   |
|---|--|---|--|
| <b>Employment and financial security</b><br><br>Having a job and enough money to live well, plan for future, and have choice and control. | Employment: Right to work and the enjoyment of just and favourable conditions of work, and equal pay for work of equal value, that is freely chosen.<br><br>Financial security: Right to control their own financial affairs and have equal access to bank loans, mortgages and other forms of finance credit. | Employment <ul style="list-style-type: none"> <li>• Deciding to leave school – to either look for work or further training/apprenticeship</li> <li>• Deciding to look for work</li> <li>• Deciding what kind of job/work</li> </ul> Finances <ul style="list-style-type: none"> <li>• Opening a bank account and controlling account (increases with age as banking rules allow greater control)</li> <li>• Saving up for something / making a decision about larger expenditure (new online game, car, other)</li> <li>• 18+ entering in a contract and managing repayments – phone, gym, credit card</li> <li>• Accessing financial supports</li> </ul> | Employment <ul style="list-style-type: none"> <li>• Doing chores</li> </ul> Finances <ul style="list-style-type: none"> <li>• What to do with pocket money</li> <li>• Day to day expenses, buying gift for friend</li> <li>• Mobile phone usage</li> </ul> |

| <b>Australian Disability Strategy</b><br>Domain (bold) and scope   | <b>Link to the CRPD</b><br>Full enjoyment of all human rights and fundamental freedoms on an equal basis with other children   | <b>Examples of large decisions</b>  | <b>Examples of small decisions</b>  |
|--|--|---|---|
| <b>Inclusive homes and communities</b><br><br>Homes: meet needs; are accessible (to get in and around) and inclusive; affordable; preferred location; living with who you want to live with.<br>Communities: participating; time with family and friends; having fun; sport; religion; culture.<br>Accessible places, transport, communication, information. | The right to live independently and be included in the community and the opportunity to choose where and with whom they live. This includes access to cultural life, sport, recreation and leisure.  | Where to live <ul style="list-style-type: none"> <li>• When living at home (OOHC)</li> <li>• Moving out of home</li> <li>• Living with who you want to live with (family, partner, friends)</li> <li>• Choosing a culturally safe environment</li> </ul> Living independently <ul style="list-style-type: none"> <li>• Joining a sports club</li> <li>• Joining another group</li> <li>• Learning to drive</li> </ul> | Where to live <ul style="list-style-type: none"> <li>• Decisions about personal space – what is in it, what is not in it, decoration etc.</li> </ul> Living independently <ul style="list-style-type: none"> <li>• Travelling independently</li> <li>• Socialising</li> <li>• Sport and rec</li> <li>• Going out during COVID</li> <li>• Screen time</li> </ul> |
| <b>Safety, rights and justice</b><br><br>Rights: equal, fair, protected<br>Safety: be safe, feel safe, safe from violence, abuse, neglect, exploitation<br>Justice: police, courts, law and prisons meet needs of people with disability   | The right to protection both within and outside of the home, to all forms of exploitation violence and abuse, including gender-based aspects.<br><br>Right to legal capacity on an equal basis with others, and access to justice through procedural and age-appropriate accommodations. | Rights and safety <ul style="list-style-type: none"> <li>• Understanding rights – When to ask for help, Who to ask for help</li> <li>• Having an intimate relationship</li> <li>• Sexual identity</li> </ul> Justice <ul style="list-style-type: none"> <li>• Disclose harm (including online harm)</li> <li>• Making a complaint</li> <li>• Access a lawyer/advocate</li> </ul>                                      | <ul style="list-style-type: none"> <li>• Tattoos and piercings</li> <li>• Consuming alcohol, cigarettes, drugs</li> <li>• Having sex (and consent)</li> </ul>   |
| <b>Personal and community support</b><br><br>Supports and services: disability services, other services  | Access to residential and community support services to support living and inclusion in the community. Including   | Formal supports and services <ul style="list-style-type: none"> <li>• Deciding what is needed (financial/day-to-day)</li> <li>• Deciding who to provide it (age, culture, gender)</li> <li>• NDIS (applying, reviewing, managing)</li> </ul>  | <ul style="list-style-type: none"> <li>• Preference for carers</li> <li>• What to wear</li> <li>• Personal hygiene</li> <li>• What to eat</li> <li>• Who to ask for help or information</li> </ul>  |

| <b>Australian Disability Strategy</b><br>Domain (bold) and scope  | <b>Link to the CRPD</b><br>Full enjoyment of all human rights and fundamental freedoms on an equal basis with other children  | <b>Examples of large decisions</b>  | <b>Examples of small decisions</b>   |
|---|---|---|--|
| Formal supports and informal supports<br>Assistive technologies   |   | Informal supports <ul style="list-style-type: none"> <li>• Family and friends – who to ask for help</li> </ul> Technology – big investments <ul style="list-style-type: none"> <li>• Deciding what is needed and how to get it</li> </ul>                                     |  |
| <b>Education and learning</b><br><br>Learning: get what you want from school, learning and training; accessible and inclusive. Move from school to other education, work experience, job. | The right to inclusive education and are supported within the general education system to facilitate their effective education through individualised support measures to maximise academic and social development. | <ul style="list-style-type: none"> <li>• Where to go to school</li> <li>• When to change schools</li> <li>• What subjects to study</li> <li>• When you can leave school</li> <li>• Going to Uni/TAFE/Private College</li> <li>• What courses to choose post School</li> </ul> | <ul style="list-style-type: none"> <li>• Who to sit with (or not)</li> <li>• Who to have lunch with</li> <li>• What to have for lunch</li> <li>• What sport/activities to do</li> <li>• What to read</li> </ul>                          |
| <b>Health and wellbeing</b><br><br>Access to healthcare as soon as needed – both physical and mental health   | Enjoyment of the same range, quality and standard of free and affordable healthcare and programs.   | <ul style="list-style-type: none"> <li>• Choosing own doctor</li> <li>• Choosing treatment</li> <li>• Sexual health, contraception, pregnancy</li> <li>• Privacy around health – own Medicare card</li> <li>• Accessing mental health/counselling services</li> </ul>         | <ul style="list-style-type: none"> <li>• Deciding need to see doctor</li> <li>• Making a Doctors appointment</li> <li>• Whether and who to take for support to an appointment</li> <li>• Taking medication (e.g. pain relief)</li> </ul> |
| <b>Community attitudes</b><br><br>Positive attitudes; treat people as equals; be inclusive; respect   | Respect for the rights and dignity of persons with disabilities.  | <ul style="list-style-type: none"> <li>• Respect for race, language culture, identity</li> <li>• Treated in age-appropriate ways</li> </ul>   |  |

## Appendix C Improving the way we do research

As part of the project, the research team reflected on what could be improved about the way research with people with cognitive impairment, and their families and other stakeholders, could be improved. This information has been provided back to the National Disability Research Partnership Community of Practice, and shared with other researchers in the organisations involved.

### **Recruitment of research participants**

- The team found it easier to recruit parents than young people.
- To recruit young people and their families, both CYDA and Inclusion Australia drew upon their membership and connections to other organisations. This was likely to result in selection bias.
- Recruitment materials were tailored by both CYDA and Inclusion Australia to make them consistent with previous recruitment activities.
- Given recruitment was successful through family units, the number of people living in OOHC or other settings who participated in the study was minimal.
- Due to additional organisational requirements, government Departments of Education and TAFE were not able to participate in this study due to time and resource constraints.

### **Consent process**

- The consent process was complicated for people with cognitive impairment, and with additional practices used by interviewers (providing an agenda, explaining who to go to for help if needed), took up to 15 minutes. This was a lot of information to listen to and digest before the interview started. As interviews were conducted remotely, and young people tend to prefer to turn their camera off, it was hard to gauge at the point of consent whether the person was comfortable – this was easier face-to-face. However, it was clear during the interviews that the young person consented to participate and were willing participants.
- Few participants from the young person and family cohorts provided written consent. People did not have access to printers or were unable to complete the forms electronically – this included parents. The verbal consent process is long and dry, and

became a tick box exercise. One expression used by the research team was 'TLDR' – too long, didn't read.

- The research team is keen to understand better ways of gaining comprehensive consent without placing burden on research participants.

### **Interview process**

- One technique used by one of the research team was to introduce themselves comprehensively – answering the demographic questions themselves before asking them of the young person. This created a level playing field and created an immediate rapport between the interviewer and the research participant.
- Despite extended development and consultation within the research team, the interview questions did not work very well in practice. Researchers need to develop more authentic questions and trial them and revise them as needed.
- Some participants declined the voucher (n=2). Reasons given included vouchers being sometimes 'more hassle than they were worth' and happy that the money go back into the project.

### **Analysis**

- Analysing data as a large team is sometimes challenging. Where people have time, it is good practice to have different people looking at the data to ensure that interpretation is not affected by a person's perspective. Given the amount of data for this project, interviewers provided high level summaries of the interviews they were involved in. All data was coded by one researcher and the findings discussed with the broader team through a workshop process.
- Like any large team, it was not always easy to get together and talk as a group – particularly remotely.

### **Reporting**

The research team is committed to translating the findings from this study into outputs that have an impact.

- This report is available in multiple formats. This full report. A plain English summary. An Easy Read version. And a short video explaining our key findings, captioned with AusLan.

- Sharing the research findings at relevant conferences such as the Virtual Disability Conference 2022, as well as to other research teams that participated in this first round of funding from the NDRP.
- Providing outputs that can inform systemic advocacy – particularly around education, such as the review of disability standards of education under the *Disability Discrimination Act*.
- Informing organisations of opportunities to meet the support needs of young people and their families/carers. For example, by providing mechanisms to share examples of decisions and choices young people have made, including how they were made. [See for example, speak my language as a way to share stories <https://speakmylanguage.com.au/> ].

## Appendix D Resources identified during fieldwork

Research participants identified several resources they found to be useful. The list is not conclusive but provides an example of some of the tools available.

### **Learning Together (Australian Centre for Disability Law)**

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This is a toolkit designed to be used for students to access support at school. The online toolkit includes advocacy tips and information about how to think about what you want from your education, what your rights are, how to communicate with the school, how to build that relationship effectively, how to ask for adjustments, what adjustments might look like, and how to complain if you need to. The tool is also available in Easy Read and is supported by training.

More information is available from this link: <https://disabilitylaw.org.au/projects/education/>.

A supplement is also being developed for students in further education to help students understand what information to share and with who, how to ask for adjustments, how to decide what to study, among other things. Notably, in further education young people need to advocate for themselves and you may need permission to bring someone else to meetings.

### **Your Service, Your Rights (Inclusion Australia)**

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This is a project that will build the capacity of people with intellectual disability and NDIS service providers to understand people's rights when receiving services.

More information is available from this link:

<https://www.inclusionaustralia.org.au/project/your-service-your-rights/>

### **Make Decisions Real (Inclusion Australia)**

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Make Decisions Real is co-designed and led by people with an intellectual disability. It will help people with an intellectual disability and their supporters learn about supported decision-making.

Make Decisions Real involves:

- Mapping and evaluating existing supported decision-making resources in Australia.

- Co-designing supported decision-making workshops, videos and training resources for adults with cognitive impairment and their decision supporters.
- Running co-facilitated workshops about supported decision-making for decision makers and their supporters.

More information is available at this link:

<https://www.inclusionaustralia.org.au/project/make-decisions-real/>

## **My Rights Matter (NSW CID)**

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The NSW Council for Intellectual Disability is delivering a new project.

The My Rights Matter project delivers a program of activities that aims to promote and embed the right to decision-making and support for decision-making, for people with disability.

The program of activities includes:

- An online ‘Supported Decision-Making Hub’ with accessible resources – see [www.cid.org.au/myrightsmatter](http://www.cid.org.au/myrightsmatter)
- Engagement activities, including information access and support service
- A series of training and coaching workshops for a variety of audiences
- A ‘Supported Decision-Making Champion Leaders’ leadership program
- A Micro-Grants program centred around delivering community-led projects
- A clear systemic advocacy strategy and sequence of activities.

## **Peer Connect – A clearing house for resources**

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<https://www.peerconnect.org.au/stuff-peer-networks-talk-about/having-voice/supported-decision-making/>

## **Other supported decision-making resources**

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Inclusion Australia has also compiled a list of accessible resources available here:

<https://www.inclusionaustralia.org.au/resource/supported-decision-making-resource-directory/>