

# Strengthening Participation of Children and Young People with Disability in Advocacy



**Children**  
with **Disability**  
**AUSTRALIA**

*A bigger voice for kids*

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# Strengthening Participation of Children and Young People with Disability in Advocacy

## Issues Paper

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# Summary

Participation by children and young people in advocacy and change-making can not only improve and foster positive change in their own lives, but also influence the lives of others. When young people's participation is supported, meaningful and engaged, multiple benefits accrue. Their perspectives and experiences bring a unique contribution and can result in rights-based empowerment, enacted citizenship and improved relationships. This has the potential to shape policy, to increase the relevance and responsiveness of organisations they use, and to influence change in their communities in positive ways.

However, there are significant issues and a range of barriers that discourage, prevent or actively exclude children and young people with disability from participating. A culture of low expectations, social and cultural barriers, relationship and identity difficulties and practical hurdles exist for many young people. As a result, many are precluded from participation, particularly around change-making activities.

With this paper we explore ways in which participation by children and young people with disability could be deepened and strengthened to support their involvement in advocacy and change-making at a range of levels. The paper provides a framework for understanding participation for young people with disability. It identifies current barriers to creating opportunities for young people from different perspectives — young people themselves, family, community, and service contexts. We showcase exemplars and outline strategies about how to plan, implement and evaluate meaningful participation which can also work as a practical resource for those working with young people in a range of domains. These 'how to' strategies take into account the broad scope needed to accommodate the diverse range of capabilities and preferences of children and young people.

The paper generates research evidence about what change can support more authentic representation of and by children and young people with disability, looking through four lenses at ways to promote participation — space, voice, audience and influence (Lundy, 2007). Creating spaces and opportunities for participation; promoting and facilitating participation with and for children and young people; ensuring participation outcomes are heard; and increasing the influence of young people's participation are all ways to embed and build on the pockets of existing innovative and inclusive practice we found in writing the paper and through CDA's experience.

Participation remains far from straightforward for many children and young people with disability. For some this is due to the nature of their support needs, but more commonly it is lack of opportunity, low expectations, inaccessible processes and structural barriers which discourages or prevents them from contributing.

The paper closes with CDA's call to action for promoting children and young people's participation in a range of ways, both directly through their work and in influencing the practice of others who work with and support children and young people to take their place as active and valued community members.





# Definitions

## Children

0 – 15 years of age

## Young people

16 – 24 years of age.

## People with disability

We use the definition of disability used in the United Nations Convention on the Rights of Persons with Disabilities, which defines disability as:

*...an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (UNCRPD 2006).*

Australian terminology generally adopts 'person first' language, but the term 'disability' rather than 'disabilities' is used to acknowledge the disabling impact of social and cultural forces on people with impairments. It is a hybrid approach from the UK terminology of 'disabled people'.

## Participation

Participation is a term used for different purposes to describe action taken in everyday life, such as simply attending school, social engagement, or participating in formal decision-making (Thomson & Holdsworth, 2003). For this paper, we are particularly interested in participation as decision making in the context of advocacy and change-making. This means children and young people being actively involved in decision making and having 'reason to believe that their involvement will make a difference' (Sinclair, 2004, p. 111).

## Student voice

Student voice is often the term used for having a say in the school context. 'Voice' in this setting is 'not simply about the opportunity to communicate ideas and opinions; it is about having the power to influence change' (West, 2004 cited in Office of Learning and Teaching, 2007, p. 5).

## Advocacy

Advocacy is taking action to create change and stand up for one's own rights or the rights of another person (Julia Farr Association, 2012). Parsons (1994, p. 11) states that advocacy is an 'unordinary word, use to describe a very ordinary thing. Most people know what it's like to need advocacy...but most people don't call it advocacy'. In this paper, advocacy means standing up for yourself or someone else when they have been treated unfairly. Lord, Guernsey, Balfe, Karr, and deFranco (2012, p. 3) state that 'advocacy can be used for many purposes: for personal needs, for the needs of others with disabilities, or for the needs of the disability community as a whole. Advocacy can also take place at many levels: locally, nationally, regionally, and internationally.'







# Introduction

Participation by children and young people in advocacy and change-making can not only improve and foster positive change in their own lives, but also influence the lives of others. There are demonstrated benefits in participation for children and young people with disability, for organisations they use, and for the wider community. When young people's participation is supported, meaningful and engaged their perspectives and experiences bring a unique contribution and can result in rights-based empowerment, enacted citizenship and improved relationships. This has the potential to shape policy, to increase the relevance and responsiveness of organisations they use, and to influence change in their communities in positive ways.

However, there are significant issues and a range of barriers that discourage, prevent or actively exclude children and young people with disability from participating. Some of these are social and cultural barriers, such as attitudes and low expectations. As a result, many are precluded from participation, particularly around change-making activities. Approaches which meet the needs of organisations and adults rather than children and young people are common, and limit and constrain participation. These barriers are magnified for children and young people with disability due to a plethora of cultural and practical issues, such as stereotypes, assumptions about capability, and inaccessible processes.

With this paper we explore ways in which participation by children and young people with disability could be deepened and strengthened to support their involvement in advocacy and change-making at a range of levels. The first section explains participation and the formal framework used to promote it through rights, legislation and policy. It considers the benefits for individuals, organisations and policy provided through participation, and asks critical questions about the degree to which these are met. These include individual wellbeing, community cohesion and policy shaping that is inclusive to children and young people's needs.

The second section sets out a way of measuring the effectiveness of participation. Influential models of participation explain participation in terms of empowerment, child-led approaches, and the varying roles or motives of organisations. Some current participation initiatives are provided here as examples of the ways that different types of participation might be most appropriate for different circumstances. The third section explores the issues and barriers for children and young people with disability in participating in advocacy. This includes an exploration of culture and attitudes, age and cohort, and practical barriers that prevent or discourage children and young people's participation.

Deepening and strengthening current participation practices is addressed in the fourth section. Strategies and suggestions for change are offered in order to promote and sustain participation practices in Australia. Core areas addressed include knowledge sharing, communication, meaningful relationships, resources and culture.

The final section is a consideration of the next steps which will be initiated by CDA to prompt change in response to the core issues raised in the paper. CDA aims to host sector specific workshops to promote, discuss and progress opportunities for participation of children and young people with disability in advocacy and policy development. In addition, CDA will develop

an online resource which outlines critical components of meaningful participation. An appendix lists a wide range of strategies as well as international and local initiatives which may provide ideas for promoting and improving formal participation practices.

The paper is based on evidence gathered through reviewing existing research on participation of children and young people in advocacy, research and service contexts. Wherever possible, we have prioritised research on the participation of children and young people with disability. Where the research does not appear to have been done, or is thin, we have drawn from research with children and young people more broadly, and have made it clear throughout the paper when we are writing more generally. To increase the practical value and interest of the paper, we have included a wide range of examples of current practice which demonstrate the points made in research. Finally, the perspectives of young people shared through CDA's public forums and publications are used to enliven the paper and to bring children and young people's voices into the discussion. We recognise the limitations of this inclusion of young people, and hope this paper acts as a springboard to future, more inclusive work.

In summary, the paper brings together research evidence about what change is needed to support more meaningful representation of and by children and young people with disability in advocacy and change-making. It will assist with further research, planning and practice at CDA, while also informing wider understanding and practice in spaces important to young people, such as school, youth and disability support, and community relations more broadly.









# Section 1

## Understanding participation for advocacy

In this opening section of the paper, we explore how participation is understood in the context of advocacy and change-making. The ways in which the participation rights of children and young people are articulated in legal and policy frameworks are briefly framed before we turn to a discussion of the role of family and who benefits from children and young people's participation.

### What is participation?

Participation is an ambiguous term. The difficulty in defining participation is that it is a term widely used for different purposes to describe action taken in everyday life, different kinds of social engagement — such as attending school or cultural activities — through to involvement in social change-making such as advocacy (Lansdown, 2010; Percy-Smith & Thomas, 2010; Rosenbaum et al., 2005). For the purposes of this paper, we consider participation as:

*children and young people participating in decision-making, defined as 'the process of sharing in decisions which affect one's life and the life of the community in which one lives' (Lansdown, 1995, p. 17).*

We use participation in this rights and advocacy context, which is about children and young people with disability being empowered to make choices, have a say and to influence decision making to bring about change in their lives.

As we are thinking about how children and young people may influence change through their participation, it may be helpful here to note that our definition of advocacy is broad. In order to capture the widest range of participation experiences possible, we understand advocacy as *taking action to create change and stand up for one's own rights or the rights of another person* (Parsons, 1994, p. 11 see also Lord et al., p.3 ).

Participation can occur at different levels, including at a:

- Local/individual level: such as decision making and influencing change for daily living.
- Structural level: influencing change in systems, such as within education and community.
- Systemic level: influencing change at a society/policy level (Lord et al., 2012, p. 3)

The concepts of contribution, capability and culture have also been identified as integral components to participation. For instance, in research with teenagers, these three elements were identified: 1. Young people have an important **contribution** to make in decisions that impact on their lives, organisations and communities; 2. Young people have the skills, knowledge and confidence [**capability**] to get involved with decision making; and 3. That a **culture** exists within which young people's opinions and contributions are recognised, valued and acted upon by wider society (McCready, 2011, p. 22).

Participation is also defined as being dependent upon varying factors of 'enlightenment', this meaning that children and young people have something important to tell us, which can lead to improved outcomes for them (Mannion, 2007). These factors are:

- The promise of *empowerment* (a rights-based approach acknowledging children's competence/capacity);
- Its potential for *citizenship* (children and young people's participation is about their 'place' in society, located somewhere between their current and future status as citizens); and,
- *Relationships/Relational* possibilities (participation is inherently social) (Mannion, 2007)

Young people who worked on a major youth advisory project in Ireland developed a set of core principles for participation which demonstrate how these concepts can be brought to life:

#### Core principles of participation — 'Participation and the Big Deal', UK, (McCready, 2011, p.25)

- Integrity — when young people are consulted and it is carried out honestly and not just because it has to be done;
- Voluntary involvement — core of what youth work is all about;
- User-led — a process that enables young people to take action themselves with their own agenda and addressing issues which they think themselves to be of value;
- Flexibility and quality of programmes — these should provide a variety of opportunities for children and young people's involvement and have built-in quality assurances to ensure that they best meet their needs;
- Partnership — the reciprocal nature of learning is important and that working together is crucial, central and important in any process;
- Removing block and barriers — these are identified and overcome. This is a reference to structures and approaches which may block progress;
- Accessibility — to and for all;
- Diversity — means aspirations, needs and circumstances are recognised and valued. This takes on board gender, race, faith, ethnicity, sexuality, age, disability. It is about a commitment to work to eliminate discrimination and challenge discriminatory behaviour in all its forms.



These definitions and understandings provide a base for us to explore the multiple purposes of participation — especially in considering how the different levels of participation can influence meaningful change at individual, structural and systemic levels. These benefits of participation are explored further below.

### What does participation in advocacy mean?

Participation is grounded in rights, and is about children and young people with disability engaging in meaningful decision-making to influence change. This can be done on three levels:

- Individual
- Community
- Systemic

What are the core elements of participation?

- Young people have a contribution to make
- Young people's capability to contribute is built — in skills, knowledge and confidence
- A culture for valued participation exists to receive young people's contributions

What happens when these elements are in place?

- Empowerment
- Citizenship
- Relationships



## Setting the stage — participation in rights and legislative frameworks

The right of all children and young people to participate in advocating change and have opportunities to influence decision-making is laid out at international, national, state and local levels. A number of developments have shaped the participation opportunities of children and young people with disability.

The rights of all children and young people with disability to the conditions needed to support their participation are mandated in both the United Nations Convention on the Rights of the Child (UNCRC) and the Convention on the Rights of Persons with Disabilities (UNCRPD) (see Lansdown, 2012). Among other rights, children and young people have the right to freedom of expression, non-discrimination, care and support, protection from violence, full and effective participation and inclusion, accessibility, and supported decision-making (Wapling, 2011, pp. 10–11).

The participation rights of children and young people with disability are spelt out in a wide range of legislation and policy in Australia at federal and state levels, including the Disability Discrimination Act (1992), Commonwealth and State Disability Services Acts, and the Disability Standards for Education (2005). The National Disability Strategy (NDS) 2010–2020 sets a reform plan for all Australian governments to address the barriers faced by Australians with disability and ensures that mainstream services and programs including healthcare, housing, transport and education address the needs of people with disability. Key to this ten year Strategy is the ‘engagement of people with disability in the further development, implementation and monitoring of progress’ (Commonwealth of Australia, 2011, p. 10).

The National Disability Advocacy Program provides people with disability access to advocacy, and operates with the aim of promoting ‘the rights of Australians living with disability by providing an advocacy service that ensures full and equal enjoyment of all human rights’ (National Disability Advocacy Program, 2013 para.1). This includes promoting and supporting the participation of children and young people in advocacy at individual and systemic levels.

These laws, policy agendas and practice frameworks contain aspirational goals about providing participation and advocacy opportunities to children and young people with disability to contribute and impact change at an individual, community and systemic level. However, critical questions arise around how effectively large scale rights and legislative frameworks are translated into meaningful participation opportunities. What role do families/ care givers have in enabling children and young people’s right to participate? What are the benefits, limitations and opportunities to translate these aspirational principles into practical action? When young people are involved in change-making, how influential is their participation? In the growing number and range of participation initiatives, how can we measure quality, depth and impact? The rest of this paper addresses these questions.



## What role do family, care givers and guardians have in enacting participation rights?

Both the children's and disability rights conventions require adults to listen to children and young people's voices and to take their views seriously. There is no age boundary for children and young people's right to participate; it 'extends to any child who has a view on a matter of concern to them' (Lansdown, 2001, p. 2). While all children have the right to participate, this occurs to varying degrees 'depending upon our orientation to their development' and the 'creation of settings that maximise children's opportunities to explore and initiate activities themselves' (Lansdown, 2001, p. 8).

At the same time children and young people need care and support from adults to enact these rights. As aptly stated by Lansdown (2001, p. 7), children and young people 'cannot and should not be left alone to fight the battles necessary to achieve respect for their rights'. All children and young people have a right to protection, support, love and care, which is dependent upon supportive relationships between family members (see article 19 UNCRC 'protection from violence', UNICEF [http://www.unicef.org/crc/files/Rights\\_overview.pdf](http://www.unicef.org/crc/files/Rights_overview.pdf)).

Key to family and parents' caring roles is making decisions on behalf of children and young people and being legally responsible for them. Furthermore, parents/carers are often key advocates for children and young people with disability. As such, it is a fine balance between providing care and strategies for empowerment when promoting participation opportunities. As the Convention on the Rights of the Child suggests, it is adults who 'need to learn to work more closely in collaboration with children [and young people] to help them articulate their lives, to develop strategies for change and exercise their rights' (Lansdown, 2001, p. 7). The role of family relationships in advocating participation opportunities needs to be acknowledged as a necessary support, as well as having the potential to be a significant barrier (considered further in Section 3).



## Who benefits from participation?

When children and young people with disability are engaged and active participants in change-making, multiple benefits accrue. There are many documented benefits arising from children and young people's participation — individual benefits for young people themselves, benefits for the organisations they are involved with, for informing policy, and systemic benefits for wider communities. However, there is limited evidence that these benefits are able to be realised to their full extent. The following section discusses the evidence on benefits of participation at each of these levels.



## Individual benefits for children and young people – wellbeing, citizenship and rights

The benefits of participation to children and young people at an individual level are well evidenced, where a significant body of research shows that meaningful participation improves children and young people's:

- social and emotional wellbeing
- social experiences
- sense of belonging
- social connectedness and inclusion
- citizenship and rights

(de Róiste, Kelly, Molcho, Gavin, & Saoirse, 2012; Graham & Fitzgerald, 2010b; Mannion, 2007; Notara & Robinson, 2013)

Through participation, children and young people with disability acquire new skills, enjoyment, emotional and social wellbeing, and a sense of belonging, social connectedness and inclusion (Foley et al., 2012; Hoogsteen & Woodgate, 2010; Notara & Robinson, 2013). In addition, positive participatory experiences can aid young people with disability as they move into adulthood, as they promote confidence in capabilities and self-efficacy (Dovey-Pearce et al., 2012). Other benefits include enjoyment and social experiences for children and young people. For example, the Voice, Inclusion, Participation, Empowerment Research (VIPER) conducted by and with young people with disability in the UK found that teenagers enjoyed being involved in participation experiences for improving student voice (such as engaging in young people's parliaments), and that participation in a group was 'a good way to socialise' (VIPER, 2012, p. 43).

Recent research demonstrates that children and young people's participation in schools can have substantial benefits for student wellbeing and the community by supporting them to feel positive about school, relationships with others in and out of school, and about their own health and wellbeing (de Róiste et al., 2012; Graham & Fitzgerald, 2010b; Mitra & Serriere, 2012).

A broader outcome from children and young people's participation is a sense of active citizenship. Citizenship for young people may be less about political participation, and more about 'enjoying rights and exercising responsibilities in the various types of community to which people belong' (Mannion, 2003, p. 180). The experience of participating can promote a sense of value in young people as contributing citizens with valid experiences and perspectives which are worth sharing (Department for Education and Child Development (DECD), 2012, p. 57).

Being involved in participation in advocacy and change-making also promotes and confirms the rights of children and young people. This happens at two levels — children and young people are able to see the impact of their own actions from having their rights activated and at the same time, they are enacting their participation rights (Lansdown, 2001, 2012).

There are clear and considerable benefits to participation for children and young people. However, even though children and young people with disability have participation rights, a number of researchers emphasise that participation needs further development and there is little evidence of good practice (Franklin & Sloper, 2006, 2009; Martin & Franklin, 2010).

## Benefits for organisations and communities

Organisations and communities can benefit from the participation of children and young people with disability in a number of important ways. Meaningful and positive participation of both children and young people with disability can enable the organisations they use, such as schools, sporting clubs, and after school activity venues, to be more responsive toward their preferences, concerns and issues. Organisations can consequently benefit from having their services used more regularly. At an organisational level, listening to and responding to children and young people has been found to:

- Enhance relationships
- Increase organisational relevance to children and young people
- Improve organisational ability to achieve outcomes
- Assist organisations to effectively target funds
- Enhance organisational credibility and reputation
- Offer organisations a wider variety of perspectives
- Improve organisational systems
- Help build capacity and sustainability within an organisation

(Kirby, Lanyon, Cronon, & Sinclair, 2003; Participation Workers' Network for Wales, 2010–2014 para.3)







Participation can also result in benefits to the wider community through improvements in community infrastructure (for example, when children and young people speak out about inaccessible or unsuitable playgrounds — see Brotherhood of St Laurence, 2014; Touched by Olivia, 2014), and in enhanced community relationships and greater community coherence that come with increased understanding and communication between younger and older people (DECD 2012, Davies, Williams, & Yamashita, 2004; 2012; Participation Workers' Network for Wales, 2010–2014). However, the bulk of this research concerns children and young people without disability, for whom participation is considerably less problematic and conflicted. For children and young people with disability, we know that the role of institutional structures, discrimination and deeply ambivalent social attitudes towards people with disability are frequently overlooked, and responsibility for inclusion is often set at the feet of people with disability and their families (Hill, 2006; Tisdall & Davis, 2004).

Although the benefits for communities of participation for children and young people with disability can be clearly demonstrated, there are significant barriers which impede participation in the first place. These barriers are discussed in detail in Section 3.



### Benefits for policy

As detailed above, policy at several levels stipulates the involvement of children and young people in decision making about their own lives and issues that are of importance to them. Meaningful participation has the potential to shape policy through listening and acting upon the views of young people with disability — and this process can increase policy relevance, improve services, and impact change that in turn can create specific benefits at individual, community and systemic levels.

However, while there may be political and legislative frameworks in place, in reality participation can be limited and tokenistic because adults determine the ways in which young people are heard or not heard, and because of the social and cultural positioning of children and young people, particularly those with disability (Kellett, 2011; Thomas, 2007). Thomas (2007) identifies a great deal of participatory activity occurring in the lives of young people, but finds that little of this activity connects in a genuine way with ‘real’ politics, despite the fact that many big issues in public policy concern children and young people — education, health, safety and so on.

Australian research with policy makers and young people (including young people with disability) about youth participation mechanisms and their effectiveness found a clear divide between the views of both groups about what works well for young people and the current structures dominating participation in policy initiatives. Both policy makers and young people saw value in youth-led, informal, creative processes which provided feedback with a purpose and which were part of an ongoing relationship with policy bodies. Despite this shared view, most current opportunities for young people to participate were formal, adult-led initiatives which were unresponsive to this knowledge (Vromen & Collin, 2010).

Realising more fully the policy benefits of participation by children and young people with disability requires implicit changes to the usual formal, one-off consultation meeting processes which currently feature particularly strongly in government policy development. While they benefit policy makers in terms of manageability and timeliness, they do not yield maximum opportunities for gathering young people’s contributions. Section 4 details suggestions for effective participation practice which could better support policy and practice.







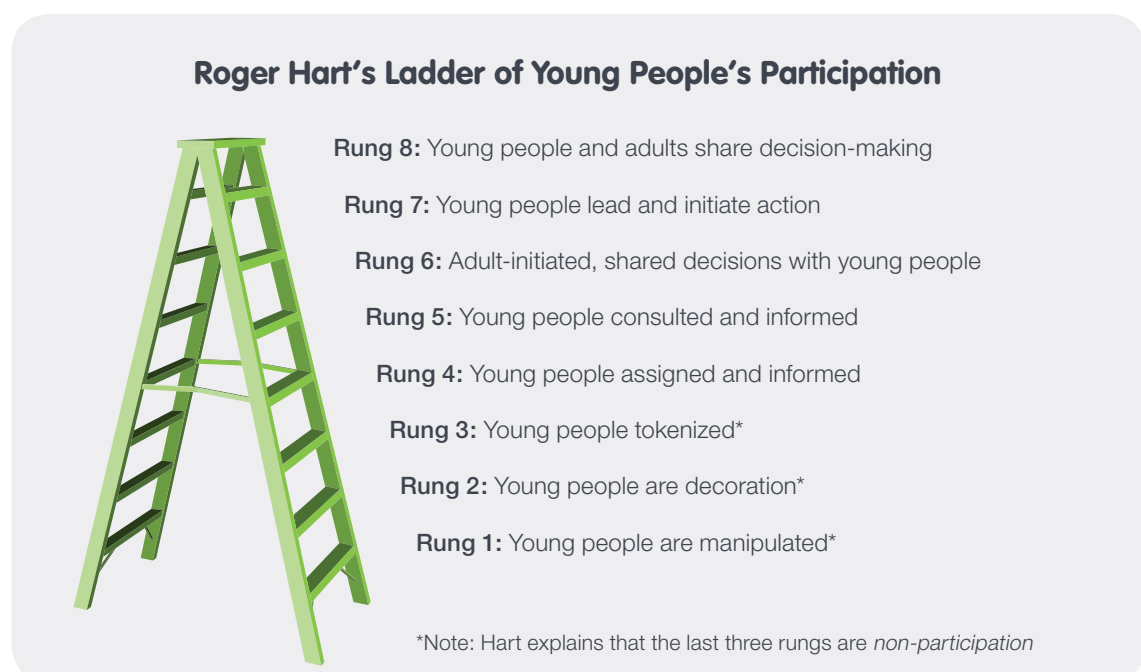


## Section 2

# Models for measuring depth and quality in participation

Measuring depth, meaning and quality in participation is difficult. In order to emphasise active participation and better understand whether it is meaningful for children and young people, several typologies or models of participation have been developed. These help to distinguish between different levels of empowerment offered to children and young people and to understand what types of participation might be most appropriate for specific circumstances. Some of these are explored below.

**Ladder of participation.** Hart's ladder of young people's participation is a well-known approach to all types of participation, based on Arnstein's famous ladder of citizen participation (Hart, 1992). Hart's ladder has eight rungs which reflect the different levels of power shared or used within participation activities. The first three rungs are defined as 'degrees of non-participation', representing processes which are adult-led, tokenistic or implemented to consult or involve children and young people for adult purposes. Moving up the ladder, the next five rungs represent increasing 'degrees of participation' where children and young people are empowered in the participation process and these experiences are increasingly child-led rather than adult-led. It is not until rungs four to eight of the ladder that children and young people have a voice in the decision making process, with rung eight being the highest level of participation, defined as 'child-initiated, shared decisions with adults' (Hart, 1992, p. 8) . Here, children and young people are fully immersed and empowered in the decision making process, collaborating equally with adults (see figure 1).



**Figure 1:** Ladder of Participation (Hart, 1994)

Adapted from Hart, R. (1992). *Children's Participation from Tokenism to citizenship*. Florence: UNICEF Innocenti Research Centre. Created by The Freechild Project — <http://freechild.org>

**Pathways to participation.** Shier reworks and condenses Hart's ladder to a five staged process, which moves from (level 1) 'children being listened to', to 'children sharing power and responsibility in the decision making process' (level 5). A key difference between the models is the emphasis on the responsibilities of the organisation to progress participation (McCready, 2011). The willingness of children and young people to participate at each level needs to be matched by the commitment of organisations involved, defined as 'openings, opportunities and obligations' (Shier, 2001) in order to improve levels of engagement and meaningful participation. Hierarchical approaches to participation need to be read with a degree of caution for children and young people with significant support needs or complexity in their lives, as implications can be drawn that the 'best' participation is on the highest, most autonomous, rung. A number of researchers have questioned this assumption, both for children with disability and for children more broadly. For children with disability, researchers argue that informed and supported choice may be a more effective measure for meaningful participation for young people than levels of control or responsibility, and that having a range of participation approaches available is key (Brady, Davey, Shaw, & Blades, 2012; Franklin & Sloper, 2006; Kellett, 2011; Tisdall & Davis, 2004). It is acknowledged by each of these researchers that the participation of children and young people will vary depending on the nature of the decisions to be made, and the ability, choice, age and preference of the child.

**Non-hierarchical approaches.** In response to concerns about ladders of participation, both Treseder (1997) and Kirby et al. (2003) developed non-hierarchical models of participation, in which no one level of participation is assumed to be superior to another. The context, tasks, decisions and participants determine the appropriate level of participation. These models recognise that individual children and young people may participate in different ways depending on their abilities, interest and availability. It is further argued that the first stage in any participation activity should be ensuring access to communication for those young people with communication needs (Franklin & Sloper, 2009).







**Figure 2:** From Treseder, P. *Empowering Children and Young People*. London: Save the Children (Treseder, 1997).

The following examples show how the model can be used to understand and measure diverse kinds of participation. The first two examples are one-off projects developed with the community and the third is an ongoing process of organisational development which engages young people. It is important that children and young people have opportunities to participate in enduring activities as well as time limited activities with a specific purpose and goal. This might be participation in school or policy development, input into the choice of activities in the classroom, or the use of reflection strategies to understand the full participation story over time.

### Participation in research: Assigned but informed

The Belonging Project found out what helps young people with cognitive disability who live in country areas feel like they belong and they are connected (Robinson, 2014). Thirty young people in three regional areas researched belonging and connection using a range of accessible research methods including photographic projects, pictorial mapping and interviews. All thirty co-researchers contributed substantially to the project, through interviews, workshops, analysing their photographic data, and in public exhibitions of their work. An easy English online survey was also completed by an additional twenty six young people with cognitive disability.

As the project developed, young people suggested a website to show their work more widely. At the end of the project, the photos that they chose to show more widely were included in a website for permanent display at [www.belonging.net.au](http://www.belonging.net.au).

*Young people did not choose the topic of the research, but once they had volunteered to be involved, they understood all steps and processes, how and why they were involved, and were able to influence the process and results.*



### Participation through demonstration: Consulted and informed

An inclusive sensory playground has recently been built at Auburn Primary School, NSW. The sensory playground has elements that are 'specifically designed to stimulate ... autistic and special needs students, but will also be available for use by the whole school community' (Auburn Public School proposal, 2013). The project went through a detailed consultation process with students, parents and teachers from Auburn Primary School. The consultation process included three stages. First the landscape architect for the project observed how all the students in the school play on the existing playground. Second the architect consulted with the Student Representative Council students, exploring what the students would like for the playground. From this process, the architect then designed the playground. Third, the architect consulted again with the same students, parents and teachers to provide feedback on the design. Some of the questions asked at this stage were 'what do you like about the design?', 'what does your child currently like to do at play time?' 'Can you offer suggestions to improve the playground plan?' Once the playground was built, all students were consulted within the school domain; teachers took their class of students to the playground to devise the rules — which allowed the students to have input over what behaviour was allowed on the playground.

*Children's views were incorporated in a number of ways into the design process, and their views were taken seriously. The project was designed and run by adults.*

### Participation in advocacy: Young person initiated and directed

Julia Farr Youth (JFY):

JFY is the youth arm of the Julia Farr Association, an advocacy organisation whose members 'believe in young people having the same opportunities as their non-disabled peers, and are passionate about bringing about change' (Julia Farr Association, 2012 para.3). The JFY members meet every month and are 'united by their focus on empowerment and their desire to raise awareness and amplify issues of concern' (Julia Farr Association, 2012 para.3).

JFY supports several initiatives to promote change at a policy, community and individual level that prioritise and privilege all voices, not the select few. The mentoring program provides mentors who are young people with disability 'who are passionate about people living inclusive lives, exercising control over their lives, and having the opportunity to develop to their full potential' (Julia Farr Association, 2012). The activities include: mentors sharing preferred leisure activities with mentees on a regular basis, and eMentoring which is an opportunity for young people aged 11–18 years to connect with mentors in an online chat forum. In 2014, JFY organised their first national conference for young people with disability.

*Adult initiated with shared decisions with young people. Adults had the idea but young people are involved in planning, implementation and making the decisions. Supporters are available, but not in charge.*





## Section 3

# What makes it difficult for children and young people with disability to participate?

There are a range of barriers that discourage, prevent or actively exclude children and young people from participating. Some of these are social and cultural barriers, such as attitudes and low expectations. Others are practical — participation processes which limit the depth and involvement of children and young people's influence, such as one-off, adult-led consultations. These barriers to participation are magnified for children and young people with disability, particularly younger children and those with higher or more complex support needs.

As we have discussed, despite the initiatives, policies and guidelines that promote and encourage full participation of children and young people with disability, the benefits from their participation are yet to be fully realised by organisations, communities and policy makers. Both specialist and mainstream structures and cultures continue to exclude and deny children and young people with disability participation opportunities that impact change.

When barriers to participation are not addressed, children and young people's participation could be either non-existent or ad-hoc and tokenistic, needs are not met or misinterpreted, and consultation could be conducted for adult purposes. As a result, participants are disempowered and gain little benefit from being involved. Their contributions are inadequately heard, leaving policy and practice consequently uninformed by the perspectives of children and young people with disability. These complexities, issues and barriers to participation are explored in this section.

### A culture of low expectations

Social and systemic practices and attitudes which set low expectations can leave children and young people with disability on the margins in both practice and policy. This makes it extremely difficult for them to influence change through their participation, as it is less likely children and young people will have the opportunity to be in positions where their voices can be heard (spoken and otherwise) and will be acted upon.

**In school.** Low expectations of young people as students held by teachers and support staff, primarily as a result of lack of training and expertise, feature in a number of research studies. This results in students moving through school with less knowledge than they might otherwise achieve, poorer social outcomes when their interpersonal relationships and conflicts are not well facilitated, and loneliness when lack of friends is not taken seriously (de Vet, Waitt, & Gorman-Murray, 2012; Emerson, 2012; MacArthur, Sharp, Kelly, & Gaffney, 2007). These matters clearly affect young people's capacity to participate, both as students and as young adults. At a broader level, students with disability continue to face significant barriers to being fully included and participating in their schools, due to 'negative attitudes and stigma, lack of understanding of inclusive education, and systemic barriers including limited funding and support' (Cologon, 2013b para.10).



**In services.** These assumptions can also be reflected in the disability support services used by children and young people. The pervasiveness of deficit models of disability mean that service providers may make assumptions based on diagnoses or other ableist assumptions about the limited current and future capabilities of children and young people, and on this basis, apply adult perceptions of what is ‘needed’ rather than developing creative strategies to find out children’s priorities more directly (Laghi, 2011; Martin & Franklin, 2010). Young people with disability in the VIPER study talked about how these assumptions affected the services they used, stating that ‘it is important that they are involved in decision-making, however they could not always see what difference being involved has made to decisions or services’ (VIPER, 2012, p. 43). In management and policy, the views and perspectives of children and young people are rarely prioritised when assessing the effectiveness of services or in developing new approaches to support (Vromen & Collin, 2010). Policy development which takes account of the perspectives of children and young people with disability can be influential on both the ways in which services are structured and the issues they prioritise.

**In communities.** People in the broader community often look to families, schools, and specialist services for their cues about how to respond and engage with children and young people with disability. When low expectations in these other domains are in view, they influence the ways in which community members intersect with young people with disability. The effects on children and young people who live with low expectations are feelings of being inadequately respected, unheard, and unrecognised for their potential and actual contributions (McCready, 2011; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012; Sonali, 2008).

*‘At the special school I attend, I’m treated like an idiot, like I can’t do what other kids can do. Their expectations of me are very low. They don’t treat me like an individual’*

**Sebastian, 15 years old (Listen Up! CDA National Publication, March 2014)**

## Social and cultural barriers

**Rights inequalities.** Children and young people with disability are faced with many social and cultural barriers to participation. First, there is a lack of priority placed on the human rights of young people with disability which impacts on participation opportunities. For example, children and young people with disability continue to face rights inequalities in education, access to goods and services, discrimination and safety from violence and abuse (Gerber & Castan, 2014, p. 1). Urgent change is needed at this systemic level to improve participation rights and opportunities to ensure all children and young people’s voices are heard and acted upon.

**Adult perceptions of children.** The way in which children and young people with disability are perceived by adults can also form a significant barrier to participation. Competency based understandings of childhood view young people with disability as ‘ineffective informants’, lacking capability. This positions children and young people with disability unequally, preventing their access to the same opportunities as their peers to express their perspectives on issues of importance to them and to influence change (Byrnes & Rickards, 2011). Researchers in childhood studies have challenged the marginalisation of children’s





participation, and argued for the acknowledgement of children as persons in their own right, worthy of recognition, respect and meaningful opportunities to contribute to change. Despite this shift in how childhood is viewed and further ratified by UNCRC and UNCRPD, it is often not reflected in reality. Adults often continue to view all children and young people as passive and incapable, and childhood continues to be viewed as a phase of ‘becoming’ a competent adult in the future instead of ‘being’ in the present, which means children and young people’s contribution in the present risks being devalued (Graham & Fitzgerald, 2010a; Martin & Franklin, 2010; Tisdall & Davis, 2004).

**Perceptions of disability.** Children and young people with disability are often further labelled with another layer on top of these adult perceptions of childhood, this being the ‘medical model’ of disability. The medical model socially constructs children and young people with disability as vulnerable, passive, and not being ‘able’ to make decisions for themselves (Knight & Oliver, 2007; Martin & Franklin, 2010). This positions people with disabilities in opposition to mainstream culture, and as a ‘problem that needs to be fixed’ (VIPER, 2012, p. 9). Underlying this mindset is the entrenched ableism that continues to exist. This can often result in ‘discriminatory attitudes and practices arising from the perception that a person who experiences disability is in some sense inferior to a person who does not experience disability’ (Cologon, 2013a, p. 6).

As a consequence of these mindsets and attitudes, adults may not listen, recognise or respect the preferences and needs of children and young people with disability and further, speak on their behalf. These negative constructs create significant barriers for children and young people in expressing their perspectives about issues of importance to them and in making decisions (Leeson, 2007).

*‘In my mind disability is defined by attitudes. A change in attitudes will lead to the acknowledgement and recognition of people with disability as individuals with some differences, but also gifts we can share...I would like to help change people’s mindset towards those with a disability, to include us as members of the human race with feelings, goals and aspirations.*

**Tim, 22 years old (Listen Up! CDA National Publication, March 2014)**



## Relationship and identity barriers

**Relationships and confidence.** While families are crucially important for most children and young people with disability (Notara & Robinson, 2013; van Hooren, Widdershoven, van der Bruggen, van den Borne, & Curfs, 2005), these social and cultural factors are pervasive and sometimes affect families as well. Some families and caregivers may have low expectations of their children's capabilities, which can impact on children and young people's personal identity and confidence in decision making and whether they feel deserving of 'having a say'. Overprotection can result in children and young people feeling uncertain about abilities and feeling reliant on others, limiting their willingness to 'have a go'. This can negatively impact children's social development, undermining their sense of self-belief, capability and feeling valued (Sonali, 2008). Children in this position might need extra support to feel confident to participate.

This is not to diminish the important and trusted support role of families in facilitating participation, particularly for younger children and children and young people with higher support needs. The role of families was found to be pivotal for communication in recent research about decision-making and life choices with young people aged 13 – 21 years old who communicate non-verbally (Mitchell & Sloper, 2011). Key components of families' roles in facilitating young people's communication and participation were being a trusted person, informing, acting as an intermediary, facilitating decision making and helping young people feel 'grown up' in their role as decision maker (Mitchell & Sloper, 2011). This confirms earlier research which emphasises the importance of drawing on familiar support but at the same time ensuring the views and perspectives of young people are prioritised (Knight & Oliver, 2007).

**Personal identity and labelling.** Another barrier that can significantly influence how children and young people with disability participate is the impact of the 'disability' label. Being portrayed as vulnerable, fragile, passive or challenging is challenging for young people. Young people with disability have reported frustration about being invited to participate on topics only to do with their disability, and about being viewed primarily as people with disability rather than in light of the many other family, friendship and community roles they hold (Robinson, 2014; Tisdall, 2013). Children and young people with disability may not be used to being asked for their views, and may not think their ideas are important (Lewis & Porter, 2004). In addition, some children and young people may go along with what others say for them, as this is what they are used to (Knight & Oliver, 2007). As discussed above, when children and young people are not offered adequate opportunities to develop a full and positive sense of personal identity through their relationships with others, low self-esteem, negative feelings from not being listened to, or alternatively feeling anger from feeling unable to 'fit in' can result (Boylan & Ing, 2005). Their opportunities for participation can be impacted by children and young people with disability not feeling allowed to 'have a say', not wanting to, or feeling unable to engage in decision-making.

*'What is the one thing you think everyone in Australia should know about disability?'*

*"You should NOT let disability define a person"*

**Melissa, 19 years old (Listen Up! CDA National Publication, March 2014)**





**Age.** The capacity and opportunities for participation that children and young people have at different ages and stages of their childhood differ considerably. This is not a barrier, but a reality for all children. However, the influences of labelling and adults viewing children and young people as incapable may mean that these differences are not as clearly recognised for children and young people with disability. Franklin (2013) reviews the limited evidence on children's participation, and suggests that certain groups are less likely to be involved. Younger children (under eight years), children and young people with communication needs and those who do not receive disability support services are identified in several studies as less likely to participate across a range of contexts (Franklin, 2013).

Opportunities for participation for young children are most often mediated by their families, and this is no different for children with disability. Young children most often participate at a more local level, and have perspectives on activities of their daily life — family, pre-school and school life, friendships, and their social or sporting activities — which are expressed in informal ways (Nind, Flewitt, & Payler, 2010; Notara & Robinson, 2013; Stalker, 2005).

As all young people go through adolescence they try out identities, and interpret and negotiate their place in the world with their peers. This can be a very challenging time. Often, emotions are exaggerated, young people can feel extra shy or angry; have general teenage angst against adults or other behaviours, such as egotism, risk taking, and feelings of omnipotence (Dovey-Pearce et al., 2012; Sonali, 2008). All the challenges of puberty and adolescence impact no less on teenagers with disability. Given the identity issues detailed above, some teenagers with disability may find adolescence particularly challenging and this needs to be firmly held in mind. For most teenagers, adolescence is a time of gradually increasing separation from family, but for many young people with disability, this transition can be much slower and more contested, both practically and emotionally (Dovey-Pearce et al., 2012; Singha & Ghai, 2009). The amount of additional decision-making that some young people have to make around health care and support for their complex needs can put extra pressure on them, compared to their peers without disability, and this impacts on their willingness to make decisions — they tend to go along with recommendations in the face of feeling they have too many decisions to make, which has implications for their inclination to become involved in other participation initiatives (Dovey-Pearce et al., 2012, p. 86).

## Practical barriers to participation

**Lack of opportunity.** Young people with disability in a number of studies expressed the view that those who most often have the opportunities to participate are people more able to articulate their views, and who are able to work within formal, adult-oriented approaches and contribute to mainstream agendas (Franklin & Sloper, 2009; Tisdall, 2013; Vromen & Collin, 2010).

Consultation processes commonly in use (such as Student Representative Councils or adult led focus groups) do not recognise alternative methods of participation that are more accessible to children and young people, particularly with cognitive disability (Martin & Franklin, 2010). The VIPER research, conducted in the UK, found a small number of standard methods were most used in organisations and government-run consultation to facilitate young people's involvement in decision-making. These were formal meetings or one-off consultations, surveys, or small groups which met regularly to research other people's views, sometimes using a survey or talking to groups in schools (Franklin, 2013; VIPER, 2012, p. 43).

Children and young people with higher support needs, those who are unwilling or unable to participate in sit-down meetings, those who need or want more relational support to boost their confidence, and those who need support to communicate are all discouraged from sharing their perspectives by this narrow approach to children's participation.

*'Communication involves not just indicating my basic needs, but more importantly, letting people know my thoughts and feelings. Yet at this crucial time, [in high school] I was denied the opportunity to use augmentative and alternative communication. This meant that my communication was restricted to people talking to me, without giving me a chance to respond. The clear message was that what I had to say was not worth listening to'*

**Tim, 18 years old (Listen Up! CDA National Publication, March 2014)**

**Structures.** Adult-dominated processes, one-off consultations and the lack of opportunity to influence the ways in which they were asked were all raised by children and young people as factors which made it difficult for them to participate in change making activities, and to feel like their participation mattered (Franklin, 2013; Hill, 2006). In addition the role of adults in aiding some young people's communication and decision-making is often unstated, yet influential and important to both acknowledge and consider, as for some children with disability 'decision-making is often not a solitary activity or process' (Mitchell & Sloper, 2011, p. 524). In addition to its undoubted benefits, the potential for power imbalances between adults and children needs to be acknowledged and addressed, particularly for those who need to rely on adults to facilitate their participation (Franklin & Sloper, 2009).

**Accessibility.** The level of accessibility of venues, processes and materials associated with consultation and reports were all raised by young people as barriers to their participation. The practices within meetings and consultation forums also sometimes detract from the experience for children and young people. The WeCan2 researchers, a group of teenagers with learning disability (aged 14–21 years old), conducted their own research project on youth advocacy in the UK (Kellett, 2011). They reviewed varied youth decision making groups over

a year (youth councils, anti-bullying meetings), finding a range of poor meeting practices that discouraged young people's participation. Often people 'speak too fast', people conducting the meetings 'use too many big words', 'have agendas with small writing and no pictures', 'some meetings are too long', some are at bad times of day, there is no financial support, and in some places, there is no disability access (Aoslin et al., 2008, pp. 7–10). A number of young people talked about how they valued a sense of fun and enjoyment in working with researchers and on participation projects, and how they did not like it when this was missing (Hill, 2006).

**Information.** Having access to accessible and translatable information is critical for young people to make an informed decision about participation. In several studies, young people discuss not being given adequate or accessible information on the purpose of the meeting or participation opportunity, understanding about decision making, nor explanation of the process (Franklin, 2013; Hill, 2006; Kellett, 2011; VIPER, 2012). When children and young people are not fully informed about the options available to them in deciding whether or not to participate, how they can be involved, and the implications of their contribution, their participation is not only significantly curtailed, but their capacity for meaningful consent is also impacted (Franklin & Sloper, 2009).

Lack of feedback about the outcomes of participation is a barrier to young people's participation at two levels. It is personally disconcerting to have participation go into a void, and not to know what happened as a result of your contribution. On a systemic level, Franklin and Sloper (2009, p. 26) note, there is little evidence about whether participation activities actually lead to changes in services, but '[t]he few reports available present a mixed picture and suggest that there may be some way to go before these become empowering forums for disabled children and young people' (2009, p26).

**Resources and skill development.** Making decisions and having a say does not come easily to many young people with disability, and takes practice. One-off consultation and poorly resourced participation do not provide the opportunity to support children and young people to develop skills over time in making choices and decisions, facilitating participation for those who need support, and training practitioners to assist children and young people to make decisions (Franklin, 2013).

The next section of the paper offers solutions and creative ideas to overcome some of the issues and barriers identified in this section and further reviews what might help in philosophy and practice to support young people's participation to impact change.





## **Barriers to participation for children and young people with disability**

### **A culture of low expectations:**

- In school
- In services
- In communities

### **Social and cultural barriers:**

- Rights inequalities
- Adult perceptions of children
- Perceptions of disability

### **Relationship and identity barriers:**

- Relationships and confidence
- Personal identity and labelling
- Age

### **Practical barriers:**

- Lack of opportunity
- Structures
- Accessibility
- Information
- Resources and skill development



## Section 4

# Making participation meaningful

It is clear that participation is multi-dimensional, and that varied intersecting features need to be considered in order for it to be meaningful and to influence change. However, as we have just seen, a wide range of barriers discourage and prevent children and young people from participating. In this section of the paper, we highlight some effective ways to implement, evaluate, and build capacity for sustainable participation practices which support children and young people's involvement in change-making — considering both formal and informal practices.

A number of factors influence how meaningful and effective children and young people's participation is, both for them and the systems and structures potentially affected by their advocacy. This section discusses strategies to promote meaningful participation through four different lenses:

- **Space** — ensuring opportunities are provided for children and young people to express a view
- **Voice** — facilitating children and young people's participation
- **Audience** — ensuring children and young people's participation is heard
- **Influence** — acting on children and young people's participation

(Lundy, 2007)

### Space — ensuring opportunities in organisations for children and young people to participate

**Creating opportunities for formal participation in organisations.** Listening to children's perspectives can be a formal exercise, predominantly initiated through community organisations, as shown through some of the case studies in this paper and the main focus of the participation literature. In this paper, we have identified a distinct gap between statements in policy and law about the rights of children and young people to participation and how this is translated to practice. Without the active development of opportunities for participation on a range of levels, children and young people with disability will remain unable to exercise their rights to participate and to influence change on levels wider than their daily life (and sometimes not even at that level). This is an important role for the advocacy community, but also for families, the school, social, and sporting communities which are part of every child and young person's life. Opportunities for participation need to be embedded into activities, designed at the development stage — too often it is an afterthought, and children and young people with support needs are those who most often miss out as a result.



**Financial and non-financial resources in organisations.** Young people themselves have pointed out that ‘disabled young people’s participation works best when... there is enough funding and time to do it properly’ (VIPER, 2012, p. 43). Other studies have found a similar need, and also identify skills and training, staffing, appropriate meeting spaces, and resources for facilitating meetings as necessary to ensure that children and young people are fully informed and can participate in advocacy and decision-making (Knight & Oliver, 2007; Mitchell & Sloper, 2011). We acknowledge that improving funding and materials to support ongoing, sustainable formal participation practices in organisations is an ideal scenario and does not represent the reality for most organisations.

**Equalising power structures in group dynamics.** Creating and maintaining an atmosphere which equalises power between children and young people and facilitators as much as possible will support unconstrained participation. Children with disability may be particularly sensitive to dynamics in which their voice is suppressed, and be unused to being asked for their opinions and views (Brady et al., 2012; Martin & Franklin, 2010; Mitchell & Sloper, 2011). This happens between peers, and also from adults to children in formal participation scenarios. Being sensitive to the dynamics of groups and having practical strategies in place to ensure that everyone has the opportunity and the resources to be involved (see following sections for details), lays the groundwork for positive participation experiences

**Helping children and young people feel welcome and comfortable.** The Youth Affairs Council of Australia resource, the “YERP” website, offers youth engagement materials which, while addressed to young people generally, give clear information about ways to create inviting and comfortable spaces when conducting formal participation opportunities — such as projects and programs within organisations:

### What works when involving young people

The best projects and programs that involve young people are ones that:

- young people see as relevant to their lives, backgrounds and experiences
- enable them to address issues in ways that respond to their own priorities, interests, and needs
- allow them to take part in a safe environment, particularly where the issues are personally confronting or challenging.

Opportunities should:

- provide chances for young people’s self-expression and creativity
- be flexible
- include activities that have a purpose — where young people will personally get something out of it
- provide chances to socialise and have fun.

Other things to consider will be:

- whether you need support from skilled youth workers (particularly important if you’re involving young people who don’t normally feel supported or included by the community)

(Youth Affairs Council of Victoria, 2013 <http://yerp.yacvic.org.au/>)

## Informal participation

**Creating opportunities for ‘informal’ participation.** Listening to children’s perspectives can also be informal, such as taking opportunities for conversation, listening to public presentations by young people or watching the way children use spaces. Examples and strategies for informal participation are not readily discussed in the literature. Some examples of informal participation could include: a casual conversation between a child and an adult about organisational practices, students deciding to form their own music group, a group of children and young people deciding to protest about an issue, a young person voicing their concern about a family issue. Families, parents, carers, advocates and significant adults in children and young people’s lives have an important role in creating opportunities for informal participation, and enabling and providing avenues for this type of informal communication, due to their close proximity in children and young people’s lives. As such, these significant adults have a vital part to play in advocating for spaces for young people’s ‘informal’ voices to be heard. It is important to note however, that these informal practices require the same skills in adults and ethical consideration as formal participation strategies.

**Ethics.** In any participation activity, formal or informal, children and young people (and their guardians) not only need to understand that their participation is completely voluntary and agree to their participation, but also feel enabled to leave at any point should they feel uncomfortable or simply change their mind. Taking an ethical approach to participation also involves thinking through all the aspects of the proposed involvement of children and young people, with a view to maintaining the dignity, respect and privacy of children and young people. In formal participation activities, this means ensuring things have been thought through before young people are approached to ensure their privacy will be maintained, that activities are age appropriate and geared to young people’s interests, that strategies are in place to minimise any distress to children or young people through the process, and that a back-up plan is in place if a participant discloses harm or abuse (Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013; Lansdown, 2001).

Information and participation practices also need to consider the above ethical approaches, in addition to a thorough strategy to ensure that participants are aware of how the information and or experiences that have been shared with adults, (such as during a casual conversation), might be used for other purposes. Ongoing awareness and informal strategies need to be in place for when these moments arise — such as asking the participants’ permission to use this information and informing them where and in what format the information will be used (i.e. next week, during a speech, at a meeting, in a report), and how privacy will be maintained.

## Voice — facilitating children and young people’s participation

As well as establishing a receptive and welcoming environment, practical strategies are needed to support participation for some children and young people with disability and to make it enjoyable. This section discusses two formal strategies to promote and facilitate voice — skills and training. A more detailed explanation of both formal and informal communication methods are explored in Appendix 1.

**Skills supported by positive attitudes.** In formal contexts, facilitators need practical skills to support and encourage the participation of children and young people with disability. This expertise needs to be situated in a surrounding framework of adult attitudes which are focused on children and supportive of their rights and capacities (Knight & Oliver, 2007). When this is the case young people’s participation is viewed positively, supported individually and their perspectives have wider influence because they are promoted in multiple ways.

**Training.** Training and education for children and young people with disability about what participation means (particularly in a formal advocacy contexts), ways in which they could expect to participate (the core principles of the participation model), as well as strategies for working individually and in groups will help make participation processes more meaningful and carry over into other areas of young people's lives. While it is important to have access to this grounding, care needs to be taken to ensure that it doesn't replace participation on matters of substance.

Training and education for facilitators and supporters about the same range of issues as children and young people is important, but clearly with a different focus. For facilitators, additional guidance in making participation engaging, building confidence, addressing some young people's acquiescence when asked their views, and addressing resistance to participation of young people with high support needs and younger children would be particularly valuable. For supporters (such as family members and teachers), information and guidance about the differences between a support 'facilitator role' and their usual relationship would also be helpful in supporting young people's participation.

## Audience — ensuring children and young people's participation is heard

**Knowledge sharing.** While it is important to ensure that young people have opportunities for personal development through their participation, finding and making opportunities for children and young people to share their knowledge and educate others are just as important.

*'(A) challenge I, and many other people with a disability, face on a regular basis is trying to get people to understand these challenges and increase public awareness.'*

**Ariane, 17 years old (Listen Up! CDA National Publication, August, 2010)**

**Relationships which promote participation.** The quality of relationships are important to all children, and we all look for the basic requirements of warmth, empathy, and sensitivity in our relationships (Martin & Franklin, 2010; Thomas, 2012). For children and young people with disability and high communication support needs, the importance of these relationships is heightened, and respectful, reciprocal relationships are shown in several studies as critical in supporting meaningful participation, facilitating communication and helping children and young people with disability to be heard (Knight & Oliver, 2007; Mitchell & Sloper, 2011; Wickenden, 2011).

In regard to formal participation, the development of capability in young people and their ongoing contribution through their involvement in research and advocacy groups was raised by both young people themselves and researchers (Aoslin et al., 2008; Kellett, 2010; Knight & Oliver, 2007). It is also important that organisations continue to build capacity and consultative relationships with young people, rather than see participation as 'a one-off exercise or project' (Commission for Children and Young People NSW, 2014; Franklin & Sloper, 2009).



**Following up.** At the very least, children and young people need feedback about what has happened as a result of their formal or informal participation. As Hill notes, ‘young people are primarily outcome oriented. When asked their views, they expect a response. Many are disappointed or disillusioned when nothing happens afterwards’ (2006, p. 72). Lansdown (2001) likewise discusses how it is important that all children understand right at the beginning the decision making process that will occur and by whom, and states that if this does not happen, and children discover after a project has started that they do not have any decision making power ‘they are likely to feel resentful and cynical about the process’ (Lansdown, 2001, p. 10). Some participation methods outlined in Appendix 1 identify how to conduct follow up action, see in particular the Participation Guidelines developed by the Children’s Commissioner, Western Australia.

## **Influence — acting on young people’s participation**

**Building a rights focus.** Participation in advocacy occurs in a rights based context. To change culture, improved awareness and understanding of rights is needed which will in turn improve participation practices. As young people put it, ‘[P]articipation works best when staff understand that disabled young people have a right to participate...’ (VIPER, 2012).

**Sharing good practice.** Sharing information about what helps young people to participate can spread successful practice. A number of studies note that sharing knowledge and evaluation is important for all involved (young people, families and organisations) to increase understanding of what is needed to better support participation (Aoslin et al., 2008; Franklin & Sloper, 2009).

**Evaluating participation.** Evaluating both the process and outcomes of children and young people’s participation in both formal and informal contexts is important. Evaluating participation allows assessment of how well the experience has worked in gathering the perspectives of children and/or young people with disability, and also how effectively their contributions have been used. There are multiple studies evaluating the process of participation, (Mannion, 2012; McCready, 2011; O’Kane, 2003) but far less common is evaluation of the ways in which young people’s involvement has influenced change. There are real opportunities here to develop an easy to use framework to measure the influence of participation, and to report it back to people who have contributed.

The models discussed in section 2 provide a starting place for evaluating the depth, meaning and influence of children and young people’s formal participation. Broader contextual work around these principles of participation and, particularly understanding how participation emerges in informal contexts needs to be done (by adults) to create a receptive climate in which young people’s participation can have increased meaning and impact, particularly in creating rights based contexts and building policy commitment.

**Skilling adult professionals to facilitate meaningful change.** Improving the skills of adult professionals (such as teachers, community workers, and researchers) through understanding and incorporating the core principles of participation and the related strategies into their practice will make a real difference to the participation of children and young people with disability. This includes ensuring that participation is embedded at the design of programs and learning curricula, and that information sharing and feedback/evaluation is built in to practice.

**Influencing policy.** Organisations that support children and young people's formal participation can work to promote improved relationships with policy makers to ensure that policy informs practice and vice versa. Organisations and agencies, particularly systemic advocacy groups, can actively inform policy makers of the outcome of independent participation initiatives, seek opportunities to contribute to policy development, and promote current practices to policy makers and politicians which have the potential to improve understandings of participation.

It is an important role of peak bodies to represent the views and perspectives of their members. For a peak body like Children with Disability Australia, the participation of children and young people is critical in ensuring their work is informed and grounded. A blend of informal and formal participation measures, (informed by ethical principles, discussed above), would be extremely beneficial to informing the current practices of Children with Disability Australia. To improve the representation of and by children and young people in participatory contexts, CDA is developing sustainable strategies that identify and measure both informal and formal instances, which will ensure a well-informed approach to providing meaningful and appropriate participation opportunities.

**Increasing the responsiveness of policy.** Government (and also non-government) policy makers would benefit from adopting the core principles into their approaches to consultation and the translation of input provided by children and young people, so that the advice of children and young people with disability is firstly gathered creatively, and secondly, incorporated into policy which is better responsive to their needs and aspirations.

*'Does your disability have a name?'*

*'I don't know what it is but I'm certain I have a disability or as my brother calls it a super ability'.*

**Danny, 11.5 years old (Listen Up! CDA National Publication, April 2010)**



## Supporting children and young people's participation

As mentioned, practical strategies are needed to support participation for some children and young people with disability and to make it enjoyable. The methods generally used for consultation can exclude some children and young people with disability, particularly those who communicate in non-standard ways or have higher support needs. Drawing from a range of practical communication tools and strategies to support young people's participation in creative and positive ways has been shown in multiple studies to work well for children and young people with disability (Franklin & Sloper, 2009; Germain, 2004; Lewis & Porter, 2004; Mitchell & Sloper, 2011). The following explores some of these strategies for both formal and informal participation contexts. Other participation methods, including creative communication strategies, are explored further in Appendix 1.

**Positive attitudes.** Positive attitudes from adults are also needed for both formal and informal participation contexts. The impact of a positive and child-focused approach can be seen in Thomas and O'Kane's (1999) matrix of adult attitudes to including children and young people with disability (below), which shows the likely results on children's participation which arise from the attitudes of adults.

	Focus on child	Focus on adult
Positive attitude	'this child can find ways to make herself understood'	'with creativity and determination we can include her'
Negative attitude	'her disabilities are too profound to include her'	'I just can't see any way to find out what she thinks'

**Figure 3:** Adult attitudes to participation by children with disability  
(Thomas & O'Kane, 1999, p. 384)

**Skill development for children, young people and adults.** An increase in knowledge for children, young people and the adults who support them about what participation means (both formal and informal) and how their contribution will be understood and facilitated helps children and young people to feel confident and enabled. It is also important that adults develop responsive and effective structures to support young people's participation.

**Communicating creatively.** A wide range of communication strategies have been developed for working creatively in formal and informal scenarios with young people to support them to express their views and preferences. Young people with cognitive disability can be assisted by using strategies such as scaffolding decision making (Saaltink et al. 2012), using easy read material (Franklin & Sloper, 2009; Mitchell & Sloper, 2011); and providing support people prior to and in meetings to assist with meeting processes and written material (Aoslin et al, 2008; VIPER, 2012).



# Communication strategies

Young people who use augmentative and alternative communication tools contributed to a study about communication, and created a guide for better inclusivity in conversations when talking with young people with ACC (Wickenden, 2011, p. 11). The guide includes:

- Give me time to get my message ready
- Be patient
- Listen to me
- Treat me as someone who has things to say
- Don't look over my shoulder at my screen
- Don't look bored
- Check that you have understood me right
- Don't be scared of me, my brain works fine
- Ask me before you try to guess what I am saying

Experienced participation researchers in the UK with children with high support needs suggest that it is valuable to use informal approaches in addition to more formal participation mechanisms to make sure that children's perspectives can inform in less traditional ways. Observing children's and young people's behaviour and body language in different settings, joining with activities that they are doing, and using play to engage with children can help children to feel at ease and be more willing to express themselves, and provide rich and deep information about the things that are important to them (Lightfoot & Sloper, 2002a, 2002b, 2003; Marchant & Jones, 2003; Morris, 2002, 2003). Franklin (2013, p. 40) helpfully summarises the differences between formal and informal approaches to listening:

Informal listening	Formal Listening
Ongoing dialogue Observation Listening to spontaneous communication Engaging in joint activities	Dedicated mechanisms and activities such as one-off consultations, regular group meetings, suggestions boxes

**Figure 4:** Informal and formal listening (Franklin, 2013)

## What might support and promote participation?

### Space — opportunities for formal and informal participation

- Creating opportunities
- Resources for formal participation
- Equalising power
- Helping children and young people to feel comfortable and welcome in formal contexts
- Ethics

### Voice — facilitating participation

- Skills supported by positive attitudes
- Training for formal contexts

### Audience — ensuring young people's participation is heard

- Knowledge sharing
- Following up
- Relationships which promote participation

### Influence — acting on young people's participation

- Building a rights focus
- Sharing good practice
- Evaluating participation
- Influencing policy

### Supporting children and young people's participation

- Positive attitudes
- Skill development for children, young people and adults on what participation means
- Communicating creatively in formal and informal contexts
- Communication strategies — alternative tools, formal and informal listening





# Conclusion

The benefits arising from children and young people's participation in advocacy and change-making are clear. When young people have meaningful opportunities to participate, their perspectives and experiences bring a unique contribution which can promote their own rights, shape policy, make organisations more responsive to their needs and preferences, and influence positive change in communities.

However, participation remains far from straightforward for many children and young people with disability. For some young people this is due to the nature of their support needs, but more commonly it is lack of opportunity, low expectations, inaccessible processes and structural barriers which discourages or prevents them from contributing.

When these barriers to participation are not addressed, children and young people's participation is either non-existent or ad-hoc and tokenistic, and their needs are not met or are misinterpreted. As a consequence, their contributions are inadequately heard, leaving policy and practice uninformed by the perspectives of the young people it is directed towards.

Pockets of inclusive practice exist, and provide encouragement and guidance on creative and innovative ways in which children and young people have participated in choice and decision-making, research, and advocacy. Creating spaces and opportunities for participation; promoting and facilitating participation with and for children and young people; ensuring participation outcomes are heard; and increasing the influence of young people's participation are all ways to embed and build on existing inclusive approaches.

It is difficult to separate participation for advocacy purposes from participation in the activities of daily life or choice and decision-making, and in many ways, the processes and mechanisms of supporting young people's participation are the same. The purpose of participation may be for personal planning, contributing to research or for advocacy, but the goals remain the same: to promote the contribution of children and young people, build their capability, and create a culture in which these attributes are recognised and valued.

## Where next?

CDA will promote key learnings from this paper to key stakeholders including CDA members, governments, disability sector, youth sector, community sector and schools. This will include the hosting of sector specific workshops to promote, discuss and progress opportunities for participation of children and young people with disability in advocacy and policy development.

Additionally, CDA will develop an online resource which outlines critical components of meaningful participation and specific considerations to enable the inclusion of children and young people with disability. This resource will provide continuous improvement and be an ongoing evaluation tool for organisations so that they can improve and support participation practices with children and young people with disability.





# Appendix 1

## Participation methods — strategies and practices

The following table lists examples of formal strategies through key documents and tools to assist children and young people with disability in developing skills in participating.

Participation resource	Overview of resource/ methods	Link
WeCan2, Devon and Blackpool, UK (2010)	The WeCan2 are a group of young researchers with learning disability who conducted their own research on children and young people's involvement in advocacy meetings. The group attended and reviewed varied youth decision making groups over a year, such as youth councils and anti-bullying meetings, and devised a list of recommendations from their findings as well as an on-line toolkit.	<a href="http://wecan2.open.ac.uk/about.cfm">http://wecan2.open.ac.uk/about.cfm</a>  See 'What support we needed' for participation ideas
'Participation Works' Book — 'Making Ourselves Heard' (2009)	This book reviews barriers, challenges and methods of practice for working with children and young people with disability in a participatory context. The book has 'easily replicable case studies' for organisations (Franklin, 2014, Participation Works website). The resource offers 'practitioners and managers ideas from which to develop their practice and embed disabled children's participation across their organisations' (Franklin, 2014, Participation Works website).	<a href="http://www.participationworks.org.uk/resources/making-ourselves-heard">www.participationworks.org.uk/resources/making-ourselves-heard</a>
Children's Society Parents And Children Together (PACT) project in York, (2010)	A DVD and report was created for the York Council on the findings from the research project conducted by the Time 4 Change research group. See link for details on the project.	<a href="http://archive.c4eo.org.uk/themes/disabledchildren/vlpdetails.aspx?lpeid=147">http://archive.c4eo.org.uk/themes/disabledchildren/vlpdetails.aspx?lpeid=147</a>  A short YouTube on the project: <a href="http://www.youtube.com/watch?v=rP_1URfXldY">http://www.youtube.com/watch?v=rP_1URfXldY</a>



Participation resource	Overview of resource/ methods	Link
Missing Voices: A review of independent advocacy services for looked after children and young people, care leavers and children in need in Wales, Children's Commissioner, Wales (2012)	This report offers a comprehensive review of advocacy services in Wales with related recommendations. The issues of advocacy are reflective of the issues reviewed in this paper. Of particular relevance are the recommendations made in the report in order to improve advocacy on a systemic level (Children's Commissioner, Wales 2012).	<a href="http://issuu.com/childcomwales/docs/missingvoices/1?e=3726591/5774206">http://issuu.com/childcomwales/docs/missingvoices/1?e=3726591/5774206</a>
Two Way Street (Stone, 2001)	Two Way Street is a training video on communication for professionals who encounter children and young people who do not use speech or language through their work (Stone, 2001 cited in Testro, 2006).	<a href="http://www.jrf.org.uk">http://www.jrf.org.uk</a>
'Down Syndrome, NSW' Up, Up and away guide (2009)	<p>A mentorship program for life mapping and goal setting for young people with disability and organisations wanting to implement the program.</p> <p>Launched in October 2009, the DVD and manual document outline the implementation of the Up, Up and Away Project and related guidelines for organisations. The package can be purchased for \$59.95 (+ postage and handling), or the DVD for \$22, from Down Syndrome NSW.</p>	<p><a href="http://www.downsyndromensw.org.au/pages/up-up-away.html">http://www.downsyndromensw.org.au/pages/up-up-away.html</a></p> <p>The above link explains the project and has a link to the 15 minute version of the DVD that provides an overview of the mapping and goal setting process.</p>
Talking Mats™	Is a research tool (a board) that uses symbols instead of words. This provides a tool for conducting interviews and consultancy with people who use assisted communication.	<a href="http://www.talkingmats.com/research-consultancy/free-stuff-communication-disability/">http://www.talkingmats.com/research-consultancy/free-stuff-communication-disability/</a>
Widget™	Widget™, similar to Talking Mats™, is a software platform for communicating non-verbally.	<a href="http://www.widgit.com/about/index.htm">http://www.widgit.com/about/index.htm</a>

Participation resource	Overview of resource/ methods	Link
Making Rights a Reality (2013) Leonard Cheshire Disability	<p>This report is devised by a 'network of over 1200 young people with disabilities from over 20 countries across the globe'. The group 'speak out for the rights of people with disabilities worldwide' (Leonard Cheshire Disability, 2013, p.2).</p> <p>The publication covers 'Young Voices campaigners from across the globe report on how well we think our Governments are implementing the UN Convention on the Rights of Persons with Disabilities' (<a href="http://youngvoices.leonardcheshire.org/about/resources/">http://youngvoices.leonardcheshire.org/about/resources/</a>). The report outlines recommendations for change and case studies on how young people's voices have influenced change to practices around the world.</p>	<a href="http://youngvoices.lcdisability.org/wp-content/uploads/2013/12/FINAL-Report.pdf">http://youngvoices.lcdisability.org/wp-content/uploads/2013/12/FINAL-Report.pdf</a>
Effective practices for engagement, participation and consultation: A resource guide to involving young people with a disability in youth services, Youth Affairs Network Queensland (2011).	The guide reviews issues and barriers to participation then reviews resources and practices, of particular relevance to participation toolkits is Section 3, p.31. The organisations and policies reviewed are Queensland based.	<a href="http://www.yanq.org.au/uploads/1/4/1/7/14174316/ydac_resource_kit.pdf">http://www.yanq.org.au/uploads/1/4/1/7/14174316/ydac_resource_kit.pdf</a>
Toolkit for parents — School issues for students with disabilities, Disability Advocacy, NSW (2013)	This document is a toolkit for parents at school in regard to information and strategies for issues student with disabilities can face, such as bullying. Part three offers advocacy strategies for parents.	<a href="http://da.org.au/wp-content/uploads/A-Parent%E2%80%99s-Toolkit-School-issues-for-students-with-disabilities-v-1.1.pdf">http://da.org.au/wp-content/uploads/A-Parent%E2%80%99s-Toolkit-School-issues-for-students-with-disabilities-v-1.1.pdf</a>
Listen Up and Shout Out, Best practice guidelines for engaging young people in decision-making processes in Alice Springs (2010)	<p>This report reviews best practice guidelines for engaging all young people in decision making. It reviews case studies of projects in the Alice Springs area.</p> <p>Sections 4 'Informal and Formal methods' and 5 'Keys to Success' are most relevant to toolkits.</p>	<a href="http://www.youth.nt.gov.au/documents/Round%20Table/2010/Community%20Based%20Projects/CBP%20Listen%20Up%20Shout%20Out%20Asp%20FINAL%2021%2012%2010.pdf">http://www.youth.nt.gov.au/documents/Round%20Table/2010/Community%20Based%20Projects/CBP%20Listen%20Up%20Shout%20Out%20Asp%20FINAL%2021%2012%2010.pdf</a>

Participation resource	Overview of resource/ methods	Link
Office for Youth, toolkit — consultations with young people (2006)	This is a resource developed by the Office for Youth, South Australia. It covers issues and opportunities for conducting consultations with all young people. Part 5 looks at different methods for consultation (interviews, surveys, forums).	<a href="http://www.officeforyouth.sa.gov.au/resources/toolkit">http://www.officeforyouth.sa.gov.au/resources/toolkit</a>
Carter, J., Pitt, J. and Birac, P. (2010). DIY Reality: Recipes to transform and inspire. Sydney: Youth Action & Policy Association NSW.	This is an online report-like resource for all young people developed by young people and supported by Youth Action & Policy Association, NSW. Of particular relevance to participation 'toolkit' is Section 5 — Speak: Youth spaces, forums and workshops. It provides 'how to' information for young people setting up and running an advisory group forum.	<a href="http://www.yapa.org.au/youth/diy/DIYreality.pdf">http://www.yapa.org.au/youth/diy/DIYreality.pdf</a>
Western Australian Commission for Children and Young People (2009). Caring for the future growing up today: Involving children and young people, Participation guidelines.	This is an extensive document that explores all aspects of participation practices. It provides case studies, advice to organisations deciding to involve children and young people, what works, what does not work, and participation guidelines, such as the importance of feedback and action.	<a href="http://www.hrc.act.gov.au/res/Participation%20Guidelines.pdf">http://www.hrc.act.gov.au/res/Participation%20Guidelines.pdf</a>
YAC Victoria — YERP website, launched 2014	A website for young people and organisations which includes resources and articles and links to methods on ways to involve young people in participation.	<a href="http://yerp.yacvic.org.au/taking-part/involve-young-people/ways-to-involve-young-people">http://yerp.yacvic.org.au/taking-part/involve-young-people/ways-to-involve-young-people</a>



Participation resource	Overview of resource/ methods	Link
NSW Commission for Children and Young People: 'Citizen Me', 'Taking PARTicipation Seriously', and related online resources (2000–2004)	<p>A link to resources for conducting participation with children and young people.</p> <p>Citizen Me: Reviews the issues and benefits of participation for organisations, it offers case studies and tools to conduct (such as consent forms) and evaluate (surveys) participation.</p> <p>Taking Participation Seriously: Based on consultations with children and young people, this document has 'practical advice about how to involve children and young people in activities, events and decision making about issues that affect their lives' (NSW Commission for CYP website). The link has pdf's of resources on how to do participation, including activities and games.</p>	<a href="http://www.kids.nsw.gov.au/Publications---resources/Participation-resources/Participation-resources">http://www.kids.nsw.gov.au/Publications---resources/Participation-resources/Participation-resources</a>
Participation Unit, The Children and Young People's Participation Consortium for Wales Blast Off! Guides to increasing participation of children and young people (2006)	<p>'The Blast Off! Guides are a range of 'good practice' guides developed by the Participation Unit and based on the experiences of workers in Wales.</p> <p>Nine guides were developed originally as paper resources and are now only available to download. More have been developed since as purely downloadable guides with others currently in development' (referenced from website <a href="http://www.participationworkerswales.org.uk/resources.aspx">http://www.participationworkerswales.org.uk/resources.aspx</a>). This links to these participation guides.</p>	<a href="http://www.participationworkerswales.org.uk/resources.aspx">http://www.participationworkerswales.org.uk/resources.aspx</a>
Save the Children and Dynamix (2002). Participation: Spice it up! Practical tools for engaging children and young people in planning and consultations. United Kingdom	<p>'Participation—Spice it up!' is a resource for all 'professionals who work with children and young people—including local authority staff; teachers; play and care workers and health professionals'. It includes a toolkit — an 'easy to follow guide filled with new ideas of how to run 49 practical activities to involve and engage children and young people... and...practical resources — sample timetables and sheets to photocopy, plus contacts and further reading' (referenced from website <a href="http://www.dynamix.ltd.uk">http://www.dynamix.ltd.uk</a>).</p>	<a href="http://www.dynamix.ltd.uk">http://www.dynamix.ltd.uk</a>







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