



# Social Action Partners:

Peer support for children and young people with intellectual disability and their families in Victoria

Never Stand Still

Arts & Social Sciences

Social Policy Research Centre



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**SPRC**  
Social Policy Research Centre

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# Abbreviations

<b>BM</b>	Belonging Matters
<b>IM</b>	Inclusion Melbourne
<b>NDIS</b>	National Disability Insurance Scheme
<b>PWDA</b>	People with Disability Australia
<b>SCU</b>	Southern Cross University
<b>SPRC</b>	Social Policy Research Centre
<b>TAFE</b>	Technical and Further Education
<b>UNCRC</b>	United Nations Convention on the Rights of the Child
<b>UNCRPD</b>	United Nations Convention on the Rights of Persons with Disabilities
<b>UNSW</b>	University of New South Wales
<b>YDAS</b>	Youth Disability Advocacy Service
<b>YMCA</b>	Young Men's Christian Association

# Easy Read Report



## The Social Action Partners Project

## Easy Read Report

This report is an Easy Read version of the following report:

Meltzer, A., Parker, Z., Purcal, C. and Fisher, K.R. (2015) Social Action Partners: Peer Support for Children and Young People with Intellectual Disability and their Families in Victoria: Final Report, Sydney, Australia: Social Policy Research Centre, UNSW Australia.

This Easy Read report was written by Ariella Meltzer, Christiane Purcal and Karen Fisher. The pictures are Photosymbols.





## What is this report about?

This report is about a project called Social Action Partners.

## What was the project about?

The project was about children and young people with intellectual disability and their families.



It was about:

- what they know now about self-directed disability support
- how they might like to use self-directed support in the future

The project included:



- research



- peer support



## Who took part in the project?

The people who took part in the project were:



- Children and young people with intellectual disability (aged 9-22)



- Parents

- Other family members (such as siblings and cousins) were invited to take part, but decided not to



## How did they take part?



Children, young people and parents took part in groups where they talked about:

- what they do in their lives at the moment
- what they want to happen in their lives in the future
- their experiences with self-directed support and other types of support

As well as talking, some people:



- wrote ideas on butcher's paper



- took photos



- watched videos

## Who ran the project?

Three organisations set up and ran the project:



- Social Policy Research Centre



- People with Disability Australia



- Southern Cross University

Another three organisations ran the groups:



- Belonging Matters



- Inclusion Melbourne



- Youth Disability Advocacy Service

## What do children and young people do at the moment?



Many children and young people spoke about studying, working and taking part in activities in the community, such as going to the gym or swimming.



Some children and young people spoke about having friends at the moment. Some people wanted to meet more friends.

## What do children and young people want for the future?

Children and young people wanted lots of things for the future. They wanted to:



- Meet new people



- Move out of home



- Learn to drive



- Find a job



- Travel

## How do children, young people and families use self-directed support?



Most people in the project had not used self-directed support yet.



Only one young person and his parents had used it. They spoke about how the young person was able to have a personal trainer instead of a support worker to help him at the gym.



The other people in the project thought this was a good idea and started to think about how they could use self-directed support too.

## What do children, young people and parents know about self-directed support?

Most people said they would need to know more about self-directed support if they were going to use it.



- Some children and young people were too young to think a lot about different types of support yet, but would start to think about it as they grew up.



- Some of the older young people were thinking about different types of support and starting to make their own decisions.



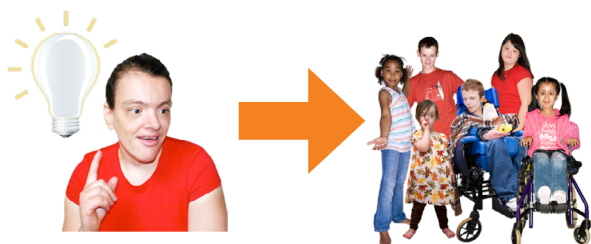
- Parents said they needed more information about what support is available.

## What was it like to take part in the project?

Taking part in the project was good for most people. In the groups:



- Everyone shared information and experiences



- The young people helped the children have ideas about what they could do in the future



- Parents listened to their children and heard new ideas about what their children wanted



## Why is the information important?



The information from the project is important because the NDIS is coming and more people will have the chance to use self-directed support.

The information is important because it shows that in the NDIS people will need:



- The chance to use self-directed support
- The right information about what support is available



- A chance for peer support and to share information with other people



- Control over their own support so that they can do what they want in their lives



# Executive Summary

This project used a social action research approach to establish local groups of children and young people with intellectual disability and their families in Victoria. These groups conducted research and provided peer support about their experiences with self-directed disability support. The project was run as a partnership between children, young people, families, group facilitators and university researchers. The intentions were to build capacity among children, young people and families for the transition to a policy context of self-directed support under the National Disability Insurance Scheme (NDIS) and to build capacity within the disability community for self-direction, strengthen peer support and develop research competence.

Two local groups were formed of children and young people with intellectual disability aged 9-22 and their parents. Twelve children and young people took part and eight parents. Other family members, such as siblings and cousins, were invited to participate, but did not volunteer to attend. Three facilitator organisations ran the groups. They conducted two workshops with each group. Data was generated and collected through discussion, artefacts from the workshops, feedback forms, demographic surveys, notes written by the facilitators and teleconferences with the facilitators.

Primary findings from the groups about experiences with disability funding and support are:

- Most children, young people and parents had not yet used self-directed disability support, but were interested in hearing the experiences of the few who had and in imagining the possibilities it might present for themselves in the future.
- Reflecting their age and life-stage, children had little knowledge of their funding arrangements, but some young people had developed more knowledge in this area as they became older. Parents said they needed more information about funding options.
- Children and young people discussed their participation in school, work and volunteering, the relationships they had and valued or wished to have and their aspirations for the future. For children and young people, funding and support were a means to achieving their goals in these life areas.

Primary findings from the groups about conducting social action research with children, young people and parents are:

- Peer support occurred in the groups through information sharing, mentoring, role modelling and the opportunity for dedicated discussion time to hear each other's perspectives. In particular, the young people were able to mentor the children. The dedicated discussion time allowed parents to hear aspects of their children's experiences and opinions that they had not discussed before.

- There was initially some concern about whether children/young people and parents would be able to speak openly in the groups without feeling inhibited by each other's presence. This was less of an issue than anticipated, possibly due to effective strategies for running the groups by facilitators or due to the actions and perspectives of group members, who were respectful and inclusive in letting each other talk and in listening to each other. While parents were usually more vocal than children/young people, children and young people had the opportunity to contribute perspectives they had not articulated to their parents before.

The project's findings have policy implications for children, young people and parents' access to self-directed support options in the future; their control over managing their support; how to better cater to information needs; the importance of peer support, information sharing and opportunities for discussion in developing capacity for self-directed support; and the need to focus decisions about support arrangements on the aspirations of children and young people.

# 1. Background and Rationale

This project used a social action research approach to establish local groups of children and young people with intellectual disability and their families in Victoria. These groups conducted research and provided peer support about their experiences with self-directed disability support. The project was run as a partnership between children, young people, families, group facilitators and university researchers. The intentions were: to build capacity among children, young people and families for the transition to a policy context of self-directed support under the National Disability Insurance Scheme (NDIS); and to build capacity within the disability community for self-direction, strengthen peer support and develop research competence.

The project built on knowledge gained from the university researchers' previous inclusive studies for the National Disability Research and Development Agenda (Purcal et al., 2014<sup>a</sup> – national adult peer support groups about self-directed disability support; Robinson et al., 2013 – photo research with young people with cognitive disability about belonging and connectedness). These studies found that people with disability value each other as trusted sources of information regarding their opportunities for social inclusion, disability support options and how to organise their support in ways that meet their preferences, including learning about self-direction.

This project extended the approach by examining disability support from the perspective of children and young people with intellectual disability and their families in Victoria. Its findings could be used as a baseline for a repeated study examining service information systems pre and post the introduction of the NDIS. They can also be used to advance disability rights and the sustainable provision of effective, good-quality social support. In addition, the findings can inform the development of self-directed support policies as well as the capacity of the disability community to use the opportunities presented by self-directed support.

The project was led by the Social Policy Research Centre (SPRC) and conducted in partnership with People with Disability Australia (PWDA) and Southern Cross University (SCU). Three local Victorian disability community organisations were partners in the project as they led the peer support groups. These organisations were Belonging Matters (BM), Inclusion Melbourne (IM) and Youth Disability Advocacy Service (YDAS). Brief profiles of these organisations are included in Appendix 1.

## 1.1 Policy context

### National context

Until recently, disability support across Australia has been organised and financially managed by governments and service provider agencies. However, reflecting similar developments in many other nations, Australian disability support is increasingly offered through personalised, individually-focused packages, which allow a person to make their own decisions and self-direct how their funds are spent. There are also in-between ways of organising support, which give people various

degrees of decision-making autonomy about their support and about spending their funding, but also allow them to outsource some of the administrative arrangements to a service provider.

With the introduction of the NDIS, opportunities for self-directed disability support and individual funding are expanding and will continue to expand across Australia, as these are core components of the scheme (Purcal et al., 2014b). This means that more people with disability and their families will have the option to access individual funding, and they will learn the skills and knowledge needed for self-direction in order to decide about whether they want to access an individualised package and how they choose to manage and direct this package. This implies the need for opportunities for information sharing and capacity building.

Currently, little is known about the prevalence and impact of information sharing between children and young people with disability, their families and providers of self-directed support (Prideaux et al., 2009). This project aimed to contribute knowledge about how children and young people with intellectual disability and their families are managing the transition towards self-directed disability support and what further assistance they might like.

## Victorian context

In Victoria – where this project was conducted – disability services are funded by the Victorian Department of Human Services (DHS) and are legislated by the Disability Act 2006, including the 2012 amendments. The act embodies the principles that people with disability should have control over their own lives and access to services that meet their needs and desires. The act is consistent with the type of individualised packages under the NDIS.

Early examples of individualised funding were developed in Victoria in the 1990s and were consolidated in 2008 to create Individual Support Packages (ISPs). ISPs are an “allocation of funding in relation to a person with a disability to purchase supports that will best meet their ongoing disability support needs and achieve their goals” (DHS, 2014). ISPs support the process of self-direction. They consist of three main elements:

- self-directed planning (the person plans the support they need, with help, if required);
- self-directed funding (the person uses funds to implement their support plan and respond to change or preference); and
- self-directed support (tailored services to help the person to achieve their goals) (Victorian Auditor-General, 2011).

Support through an ISP can be self-directed and can be used to access non-traditional, non-centre based activities, independent accommodation and/or mainstream support. Most people choose to allocate funds in a more traditional arrangement to one or more disability service providers (Purcal et al., 2014b). For children with disability, supports are based on the best interests of the child and aim to build the capacity of the family to support their children (DHS, 2014).

The process of applying for an ISP is complicated and many people experience inequities accessing ISPs. There is an imbalance between the supply and demand for ISPs and, as a result, the number of packages are limited (Victorian Auditor-General, 2011, LDC Group 2007). In 2011, ISPs accounted for 19 per cent of DHS disability funds in Victoria (Victorian Auditor-General, 2011).

The context is that individualised packages are available in Victoria, but not necessarily widespread or easy to access, which informs the experiences included in this report. As detailed in later sections, few participants in the project had experience of using individualised funding or self-direction, but many of them expressed interest in it, especially as such options will become more widespread in Victoria and throughout Australia under the NDIS.

## 1.2 Research question and research aims

The project focused on developing capacity of children and young people with intellectual disability and their families, a group that might be less involved in the shift to self-directed support.

The research question for the project was:

How are children and young people with intellectual disability who have high support needs and their families managing the transition towards informed decision making about self-directed disability support?

The aims of the research were to inform the processes and cultural change necessary in Victorian communities so that children and young people with intellectual disability and their families can transition effectively to self-directed support. There were six aspects to these aims:

- create 'social action partners' through developing peer support groups of children and young people with intellectual disability who have high support needs and their families
- enable peer support for decision making and enhance the capacity of individuals and groups to act on their preferences about disability support
- use peer support to develop steps towards self-directed learning and reflect on any steps taken to implement them
- share information about opportunities for social inclusion, support options and how to manage support
- learn about practical experiences with person-centred approaches to disability funding and increase understanding of the mechanics, choices and implications of self-directed support
- extend peer support guidelines, tools and dissemination methods between children and young people with disability and their families during their younger years in preparation for future choices.

## 2. Methodology

The methodology for the project is summarised in this section. All participation was voluntary, consensual, recompensed and approved by the Human Research Ethics Committee at UNSW Australia (approval number HC14165).

### 2.1 Social action research

The project used a social action research approach: children, young people, families, group facilitators and university researchers worked together as 'social action partners' to develop knowledge and research capacity, to provide peer support to each other and to create change. Based on a participatory action framework in this application of social action research, children, young people and families were seen as experts in their own lives, able to act on social issues and feed knowledge back into the research framework and findings (Balcazar et al., 2004). The facilitators and the research team contributed research skills and knowledge in disability funding and support policy.

In practice, the social action research approach meant forming local groups of children, young people and family members. Group facilitators from the three Victorian disability community organisations ran the groups, and PWDA and university researchers provided support with organisation and data collection. The groups had four functions:

- to stimulate reflection and discussion about self-directed approaches to disability support
- to increase local information sharing and research capacity
- to increase social inclusion through social action partnerships between people with shared interests
- to collect data about group members' preferred methods of information sharing and capacity development.

### 2.2 Recruitment

#### Group participants

Initially, the project aimed to include children and young people aged 19 years or under with an intellectual disability, but this was extended to 25 years or under to respond to the interest. Family members of participating children and young people were also invited to the groups, including parents, siblings, grandparents and cousins. Together, the child or young person and their family members were seen as a 'family unit' participating in the project.



## Recruitment method

Recruitment was conducted at arm's length from both the researchers and the group facilitators. The first approach to potential participants was made through other staff from the facilitators' organisations, but not through the facilitators themselves. This was to ensure that children, young people and families felt able to make a free choice about whether or not to participate. The approach was made by the staff member sending an email or flyer about the project to the organisation's contact and mailing lists. Once a potential participant indicated their willingness to be involved and be contacted about it, the facilitator arranged their participation. Where children and young people were under 16 years of age, the first approach was made to parents, who then assisted with contact with their children.

## Recruitment difficulties and solutions

There were several difficulties in recruiting to the project. Some problems were around finding children and young people as well as a family member who were available to attend a workshop together. In some cases, this difficulty was because children and young people did not like changes to their usual routine; sometimes because parents were unavailable at the same time as their sons or daughters due to work or other responsibilities; and sometimes because other family members, such as siblings, grandparents or cousins did not volunteer to attend. Sometimes families were interested in participating, but lived far away and could not travel the distance to attend. In one group, the facilitating organisation supported many culturally and linguistically diverse families, and families did not expect to attend these types of events, preferring instead to leave the interaction between the young person and the organisation.

There were also difficulties recruiting participants with intellectual disability. Group facilitators knew that many people with intellectual disability did not identify as having this type of disability, so it was difficult to advertise the project specifically to this group. Further, some parents who initially expressed interest in the project ultimately decided not to participate once they realised that their children would also attend the workshops. These parents said that managing funding and support was their responsibility alone.

In addition, the workshop format may not have been perceived by children and young people as interesting. Some facilitators reflected that framing it as a fun activity or skill development experience may have achieved better success in recruiting people to participate.

Successful aspects of the recruitment were:

- extending the age range from an upper limit of 19 years of age to 25 years
- providing compensation for travel expenses and time
- approaching organisations who specifically worked with young people with intellectual disability to assist with recruitment
- recruiting through existing groups of young people with intellectual disability
- condensing several shorter meetings into fewer longer workshops.

## 2.3 Group structures

The way the groups operated changed in response to what they wanted to do. The plan had been to form three groups of six families who were using self-directed support and six families whose support was organised through an agency or who did not receive specialist disability support (Purcal et al. 2014c). The plan was for each group to meet approximately six times for a series of short workshops, as well as organise a public event during the project, such as a play day,

information workshop, art exchange or photo activity. However, in practice, the group membership and meetings were quite different.

Two partner organisations, YDAS and BM, combined to facilitate one larger group. The combined group included seven families, each with a child or young person (age range 9-22) and one or both parents. The combined group met twice for a longer meeting of four to five hours because this suited the participants best. It also enabled group members to come late or leave early if they had other commitments. The group met on weekends at a local library. There were approximately 16 people at each meeting, plus four facilitators.

The other group, organised through IM, included five young people (aged 18-19) who were all part of the same school leavers' program. Their family members, including parents and siblings, were invited to participate, but declined. The expressed reason for this was time constraints; however, the facilitator felt it was also possibly due to language barriers and cultural reasons. Like the combined group, the IM group met twice, each time for two to three hours at IM's premises. The workshops were attached to routine meetings of the school leavers' group.

## 2.4 Consent

Consent was required from all group members to take part. An Easy Read consent form was provided for children and young people with intellectual disability and a standard form for family members. Where legally necessary due to age or guardianship, parents also provided guardian consent for children and young people to participate. The continued contact of the facilitator with the group members allowed discussions regarding informed consent to take place and for group members to make a considered and informed decision about whether or not to take part.

## 2.5 Data collection

Data collection occurred within the groups. The university researchers provided initial resources, and the facilitators guided the data collection process.

### Discussion topics

Five discussion topics were suggested by the university researchers to guide data collection in the workshops. Facilitators could use these topics to stimulate discussion among group members. The topics are summarised below, with a full copy included in Appendix 2:

- **About you**

About participants' values, activities and what they wanted other members of the group to know about them. This topic also included what type of funding participants' had and how they chose to use it.

- **About what is important to you**

About what was important to the participants with regard to their activities at home, school or work, after school or work, with their family and friends and in the community, and how they used their funding to support what was important to them.

- **Access to information and having a say**

About what information about funding and support participants had access to, how they used that information and what other information they would like to have.

- **Arrangements with workers**

About participants' arrangements with support workers, including how the workers helped

or assisted them and what they would change about their arrangements with support workers.

- **Reflection and future planning**

Reflection on participation in the project and what should happen next or what support they would like or need in the future.

These topics were a guide only and, consistent with the social action research process, the group members sometimes determined the subject matter of the workshops. For example, children and young people chose to talk about their aspirations for the future more extensively than suggested in the discussion guide. Similarly, one parent asked about how they could access more information on the NDIS, and this became a topic for discussion at the next workshop. Some facilitators also developed their own sets of supplementary or explanatory questions to better assist their coverage of the topic areas.

## Data types

The workshops were conducted with a flexible format that allowed the groups to collect data in ways that suited them best. Different types of data were collected, including:

- **Artefacts from the workshops**

Data was provided as artefacts from the workshops – for example, butcher's paper notes, drawings and photos. These were produced by the children, young people and parents and collected and returned to the university researchers by the facilitators, with group members' permission.

- **Feedback forms**

The facilitators of one group designed a feedback form about the workshop, which they completed in conversation with each of the participants. They collated the responses and returned these to the university researchers.

- **Demographic survey**

A short demographic survey was used for collecting consistent demographic information from all group participants. This was designed by the university researchers and filled in by group members with assistance from facilitators, where necessary.

- **Notes from the facilitators**

After each workshop, the facilitators wrote notes about what had happened, what had been said and about their own perceptions and reflections on the workshop. They sent the notes to the university researchers, and the notes were used as the basis for teleconferences (see below).

- **Teleconferences with the facilitators**

After each workshop, teleconferences were held between the facilitators and the university researchers, with notes and recordings compiled by the university researchers to document the facilitators' feedback and to be used as data.

In the YDAS-BM group, all group members completed most or all surveys and activities, either in written form or on butcher's paper or both. In the IM group, the majority of surveys were filled in and other data was collected, including butcher's paper notes and drawings by the children and young people. The teleconferences between the university researchers and the facilitators were an important additional data source for the project.

## 2.6 Data analysis

The data was analysed by the university researchers against the research question for the project: *How are children and young people with intellectual disability who have high support needs and their families managing the transition towards informed decision making about self-directed disability support?*

The findings were compared between the YDAS-BM and IM groups, across children/young people and parents and across experiences with different types of support and funding. The analysis was conducted thematically, with some themes coming inductively from the data and others being informed by the questions and topics considered in the workshops. The analysis drew on a conceptual framework based on themes and principles included in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2008), the National Disability Strategy (Commonwealth of Australia 2011) and the NDIS. Examples of these themes and principles include participation, growing and learning, social relationships and autonomy. The findings below demonstrate that these principles were relevant to the group participants.

The following sections describe the characteristics of the the group participants, followed by their experiences with disability funding and support and with the research process.

## 3. Participant Profile

The groups consisted of people from diverse socio-demographic, cultural and geographic communities. Whilst most of the participants shared some commonalities, each child or young person with disability and his or her family had a unique experience with disability funding and support and with the life opportunities they had experienced or wanted for the future. The characteristics of the children and young people and family members included in the project are outlined in the sections below.

### 3.1 Children and young people

The children and young people were at different stages of their lives, with the youngest being nine years old and the oldest 22 years old. Their demographic characteristics are listed in Table 3.1.

**Table 3.1 Children and young people's demographic characteristics**

		YDAS-BM (n=7)	IM (n=5)
Gender	Male	4	3
	Female	3	2
Age	12 and below	-	-
	13-18	-	3
	19 +	-	2
Born in Australia	Yes	7	2
	No	-	3
Language other than English spoken at home	Yes	2	5
	No	5	-
Aboriginal or Torres Strait Islander	Yes	-	-
	No	7	5

Some of the children and young people had attended mainstream schools and others had attended special needs schools. Two young people were continuing their education post-school at mainstream TAFE and at a registered training organisation. Both studied with other people with disability. Four young people had attended adult day services since finishing school, including two who had stopped day services and transferred to TAFE. Several participants were also involved in a school leavers' program, which was aimed at developing their skills, plans and aspirations for the future.

Two of the young people were employed. One worked twice a week while attending a mainstream school. Another person worked part-time on a supported wage in hospitality and retail. Further, most participants were involved in group or community activities such as sport, drama and volunteering,

either at school or within their local community. Often these activities were with other people with disability; however, some children and young people also played mainstream sport or volunteered within mainstream community organisations. In the IM group, many young people were engaged with community groups servicing disadvantaged communities rather than people with disability.

## 3.2 Family members

The family members who participated were parents, although other family members were also invited to participate but did not volunteer to attend. The YDAS-BM group included five mothers and three fathers. All but two were born in Australia and all but one only spoke English at home; none were from an Aboriginal or Torres Strait Islander background. Mostly one parent participated, but in one family both parents took part. No family members took part in the IM group.

Several children and young people with disability had other family members living in the household apart from their parents, including siblings, grandparents and cousins, but they did not attend the workshops. Particularly in the IM group, where there were several families with culturally or linguistically diverse backgrounds, participants were living in multi-generational households.

## 3.3 Types of funding and support

The combined YDAS-BM group included people who received funding from DHS and/or Centrelink, and people who received no funding. Types of funding included:

- Disability Support Pension
- specific program funding
- respite funding
- unspecified funding.

Only one YDAS-BM family used self-directed support. Three families used disability support organised through an agency; two families received no specialist disability support; and one family received only the Disability Support Pension.

In the IM group less information about the young people's funding arrangements was available, due to the absence of family members in the group and the young people being less aware of the administrative details. All participants in this group were receiving some funding, and the information provided by the facilitator suggested agency managed funding arrangements were in place for all of them. No one specifically described self-directing, but many felt comfortable that they had some control over their plans and arrangements. The types of funding and support are summarised in Table 3.2.

**Table 3.2 Types of funding and support**

		YDAS-BM (n=7)	IM (n=5)
Using formal services	Yes	4	5
	No	3	-
Type of funding	Direct payments	1	-
	Agency managed	2	5
	Other funding	1	-
	No funding	3	-

## 4. Experiences with Disability Funding and Support

This section summarises the groups' findings about disability funding and support. At the group meetings, participants reflected on their experiences with funding packages and other disability support; they discussed what information they had about support options and what they needed; and the children and young people talked about life goals they wanted to achieve with their funding and support.

### 4.1 Funding packages and other support

The groups discussed their experiences with different types of disability funding packages and support. Due to the limited experience among the group members of using self-directed support, much of the discussion focused on current experiences with other types of funding, how they might like to use self-directed support and their perceptions of other people doing so.

#### Self-directed support

People in the groups had limited experience with using self-directed support. One family in the combined YDAS-BM group was using it, which was interesting for the other people in that group. The family gave examples of how they had self-directed their support, and this was an impetus for the group to discuss how individual funding and self-direction might offer them increased flexibility and choice and 'better value for money'.

A good example from this family was that the young man wanted to go to the gym and required a support worker to attend with him. However, the family's support agency required that workers be hired for a minimum of three hours, which was too long for a gym visit. Under a self-directed support package, the family, however, found that they could hire a personal trainer, instead of a support worker, to assist the young man to attend the gym. They highlighted this as a beneficial example of the flexibility available under self-directed support.

Based on examples like this, the participants in the YDAS-BM group who did not receive self-directed support expressed interest and enthusiasm in receiving it in the future. It sparked a conversation in the group about 'thinking outside the square' and the possibilities available when using self-directed funding.

#### Other types of support

Although few participants had experience using self-directed support, many had used other types of support with varying degrees of satisfaction. In some cases, participants were satisfied with their support. For example, participants who received a Disability Support Pension (DSP) were generally satisfied with the amount of money they received. The DSP was used to pay for expenses such as telephone bills, gym memberships, support workers and personal purchases. In comparison, a



family who received respite was unhappy with the limited amount of respite they could afford with their package (three hours a month).

In other cases, where children and young people received a more substantial funding package, their experiences were mixed depending on how the funding was used. Some had achieved outcomes they were happy with by using the funding to pay for skill development, support programs and support workers. These young people were now engaged in the community through work experience and/or volunteering. Another participant who used the same funding package to attend a day centre was bored, had no work experience and few opportunities for skill development, and felt that she had missed life opportunities as a result. Some other participants who used funding to attend day centres were also negative about their experiences. Two found the day centre 'boring', another did not 'get anything out of it' and another 'hated' it. These examples highlight the key importance of not only whether one is receiving funding, but also how it is used.

All participants who received funding felt that they had some control over how it was used. The participants who wished to use it differently did not articulate that this change was restricted due to how they received their funding or the type of funding they received. Rather, the primary restriction was not receiving enough funding to afford the changes.

The families who did not receive any funding received disability support through schools, community groups or youth organisations. They all expressed the need for additional support. One parent specifically stated the desire for respite support and a support worker to assist with sporting activities. One family who did not receive funding managed to find support through community programs and volunteers. Their child was involved in a community swimming program and received help with homework once a week from a volunteer. Both programs were found through the parents' own investigation.

In many cases, children and young people's type of disability support was unclear as they were more interested in talking about their lifestyle, interests and aspirations than they were in linking this to a particular type of funding and support structure. Particularly in the IM group – where young people participated without their parents, who might otherwise have added these administrative details – it was unclear what funding and support packages young people received. Instead, they spoke about attending and leaving school, future aspirations to work and/or volunteer, their desire to have friends or partners and to travel. According to the facilitator of the IM group, rather than talking about funding and support packages, the young people's language was 'more individual, more everyday world, this is who I am'.

## 4.2 Access to information and decision-making

The groups also discussed how they organised disability support, what they knew about funding, where they found information either about funding or about opportunities for the child or young person to do activities they valued, and shared what information they needed to know. The experiences of children and young people were different to those of parents and are reported separately below.

### Children and young people

In general, the children and young people in both the YDAS-BM and IM groups had limited knowledge about the funding and administrative arrangements for the support they received. The level of knowledge they had was often related to their age. The children were generally unaware of having funding. However, some who had support workers or aides knew that they were hired to assist them. Young people were generally more aware that they received funding and were sometimes able to identify what their funding was used for; however, they did not know the

administrative details. One young person was aware of all the details of their funding.

The facilitator of the IM group commented that she felt that the young people in her group generally had a notion that they received money, but that she was unsure if they knew that this came from the government as a funding package. She had observed that the immediate concerns of most of the young people in the group appeared to be developing their decision-making and aspirations around what they wanted for the future and developing their relationships. The facilitator felt that once the young people saw how others lived, had more ideas of what they could do themselves and made more decisions about what they wanted, they would naturally become more interested in how those new aspects of their lives might be paid for and thus learn more about funding.

The children and young people typically did not decide how their funding was used although some made smaller financial decisions, for example about spending money on entertainment. The money they had control of was generally more like an allowance or pocket money. One facilitator felt that many of the young people in her group, aged 18 to 19 years, did not have an appreciation of how money was spent to facilitate all aspects of independent living, e.g. rent. In general, young people felt that despite not managing their funding themselves, they still had choice about their lives and how some of their money was spent. They mainly emphasised choice about buying items such as DVDs, video games and clothes. In another case, one young person, aged 20, was beginning to be included in family decision-making processes about the use of funding.

It is important to acknowledge that where children and young people did not have knowledge about or control of their funding and support arrangements, it is not clear whether this was due to their disability or their age. It would, for example, generally be unusual for children to be fully informed of the type of administration involved in using funding, to have full control over their schedule within the family or to hold substantial financial responsibilities. Young people do, however, move into more of these responsibilities as they grow towards adulthood. People with disability commonly experience barriers in managing their own funding and support arrangements, but for the group of children and young people in this project, these barriers interact with their age and life-stage. It is possible that they will grow into more knowledge and control of their funding and support over time. The example of the young person aged 20, cited above, who was just moving into further decision-making responsibility suggests that in some families this happens.

Some young people mentioned receiving information they wanted on a range of topics, not just related to their funding, through their parents, extended family members and friends. They also mentioned developing skills for information-seeking, for example, learning how to do research on the internet (including using websites such as SEEK to find jobs) or being assisted to join the library to gather information.

## Parents

In general, the amount of information parents had about funding and support was related to the age of the child or young person with disability. Generally, the older the child or young person, the more comprehensive was parents' knowledge about funding. However, overall, parents wanted more information on funding and support options, now and into the future.

Most parents mentioned that they received information on funding and support through seminars, workshops, support groups and conversations with other parents of children with disability. Some expressed that it was important to join disability groups and organisations. Some were engaged with other families through the internet and Facebook groups and used these forums as a source of information. There was a general consensus that parents needed to be proactive and 'keep knocking on organisations' doors' in order to be heard and to gain knowledge.

Perhaps as a result of this engagement, all parents were aware of what funding was. However, they were not necessarily aware of what types of funding were available, how to apply for different types

of funding and how to access information in general. In fact, two families were entirely unaware that they might be able to receive funding. One participant who received no funding did not know whether to attempt to access funding now or to wait until the NDIS. A facilitator noted that there was 'a sense of hope and expectation' that the NDIS might make further funding available. Several participants wanted to know more about the NDIS, about different funding options and about where they could get a comprehensive guide to the different types of funding and the options that were available to them.

Even the parents who had more information about funding and support wanted clearer and more detailed information. Five parents were not aware of funding facilitators, and three were not aware of self-directed packages or direct funding. One family was particularly frustrated that they had not been informed about the different types of funding that might be available to them. Only one family was self-directing their funding. They were adept and knowledgeable regarding disability support, mainly due to one parent working in the disability sector.

All parents gave recommendations as to how information and guidance could be provided in the future, for example:

- a personal assistant to help navigate pathways and funding options by giving impartial advice and information
- a resource outlining information about organisations, training and workplaces to help children with disability
- a mentoring program for parents to guide and support them
- improved access to information about post-high school options, such as TAFE
- improved access to information about employment opportunities and options.

### 4.3 Life experiences and goals

Children and young people were most interested in talking about their life experiences and the goals they wanted for the future. They discussed their participation in school, work and volunteering, the relationships they had and valued or wished to have, and their aspirations, including how they envisioned future independence for themselves. For the children and young people, funding and support were a means to achieving their goals in these life areas.

#### Participation in work, education and community

Many children and young people spoke about their participation in a range of areas. Some attended school or TAFE and others worked, mainly in retail or hospitality. Further, several young people had volunteer positions. For some, this was to gain work experience, mainly in retail, while for others, their volunteering was targeted to their interests, such as volunteering with animals. Many young people were preparing to work in the future; for example, one wanted to work in fashion and others in retail. As noted in Section 4.1, some young people were attending day services and were not happy with the opportunities for participation that these services offered. One young person noted an example where her day service had travelled to an animal park but never left the bus to see the animals up close.

Most children and young people were involved in group and/or community activities such as sport or drama, or they attended community locations such as the gym. Often these were with other people with disability; some also played mainstream sport or volunteered in mainstream community organisations. In some cases, the support and funding they received was important in facilitating these activities, for example, the young man mentioned earlier who used his funding to pay for a

personal trainer at the gym.

Occasionally, young people experienced barriers to their participation that had not been addressed adequately by their funding or support arrangements, for example, they had limited access to transport, which restricted their activities. The young people who were most independent could travel alone by bus, bike or skateboard, but this was not possible for everyone.

## Personal relationships

Relationships were important to the children and young people. Some mentioned concerns around bullying, cyber-bullying and other forms of social exclusion. More commonly, they emphasised (both through what they said and how they acted in the workshops) their desire to meet new people, including new friends without disability and older people with disability as role models or mentors. Some young people also wanted to meet boyfriends or girlfriends and worried about how they could organise dates and meet people with whom they might develop intimate relationships.

There was a general consensus, among both the participants and the facilitators, that many children and young people would benefit from establishing more relationships outside their families. One facilitator reflected that funding and different styles of support could be used to facilitate young people meeting new people.

Particularly in the IM group, the children and young people with the most contacts with peers and friends had siblings of a similar age or slightly older. These siblings often introduced them to friends and/or went with them to age-appropriate locations; for example, one participant went with his older sister to a nightclub, and others mentioned that they went with their siblings to parties, the movies and concerts. The facilitator commented that the participant who went to the nightclub appeared to have more life experience and a more sophisticated worldview and social interests than others in the group. She felt this was because of the sister's influence as a peer, but also a family member who knew the young man well and therefore knew how to support him to broaden his life experiences. Beneficial relationships with siblings were often mentioned by those who came from families of a non-English speaking background, where young people with disability often had a high level of involvement with family, perhaps as this was appropriate culturally.

## Aspirations and independence

Young people also spoke about their aspirations and goals for the future. Some saw funding and support as ways of working towards or achieving these aspirations. Common aspirations included:

- meeting new people, including people without disability and mentors with disability
- moving out of the family home, either by themselves or with friends or a partner
- addressing transport barriers by learning to drive and/or owning their own motor vehicle
- finding work experience and/or meaningful employment in an area they were interested in or valued
- travelling, both in Australia and overseas and both with and without family.

Embedded in these aspirations were various visions of independence. The IM facilitator commented that the young people in her group varied in their views regarding their future lives. Some envisioned an independent future, citing jobs, plans to move out and friends beyond their family as well as a desire and ability to make independent choices. Others based their choices around their family's views and the location of their family home. The facilitator was unsure whether the latter young people were happy about this or not. Some talked about restrictions within their families – 'My family wouldn't let me do that!' – but the facilitator found it difficult to know what some of the others thought about remaining closely connected with their families in adulthood, because 'if someone doesn't

know the alternative, they don't know if the alternative will make them happy'.

There was also a group of young people who spoke about how they 'get help to get help', showing inter-dependence while also knowing what they wanted to do and choosing the help they needed.

# 5. Social Action Research with Children, Young People and Families

The project used a social action research approach (Section 2.1), which was intended to provide peer support among participants and to create social change. The project aimed to achieve these goals by including children, young people and their families together in the research. This section presents the project experiences with regard to this methodology.

## 5.1 Peer support and social change

Providing opportunities for peer support and social change were important functions of the groups. In the YDAS-BM group, the facilitators observed that participants had two main motivators for being involved: firstly, learning from others and sharing experiences, and secondly, the opportunity to have their opinions and experiences heard by the organisations that ran the workshops. In the IM group, the participants already knew each other and were part of an established school leavers' program, but valued the opportunity to have more unstructured discussion time than usually happened in the program and to talk with a new person, the facilitator, who came from outside the program's usual staffing.

This section describes how peer support and social change were achieved in the groups. This happened through sharing information and experiences among participants, mentoring and role modelling and developing decision-making autonomy as a result of participating.

### Sharing information and experiences

The YDAS-BM group provided an opportunity to share information and ask questions about funding and support options with new people who the group members had not necessarily met before. The YDAS-BM facilitators and participants appreciated discussing one family's successful experience of self-directing and the thoughts about future possibilities that this inspired in other group members. The facilitators felt that hearing another person talk about their life goals, achievements and success with navigating self-directed funding had greater impact than reading materials or participating in forums run by the government or organisations. This was also reflected in the feedback from some parents. The opportunity to speak about these issues was particularly important for some participants who felt that otherwise they were not being heard and were isolated.

In comparison, the IM group provided the opportunity to share experiences among group members who already knew each other. The facilitator said that while it would have been beneficial for the young people in the group to meet new people, the structure of the workshop as it was gave them the opportunity to strengthen their existing relationships and share more than they might have with people they did not know. She felt that the rapport they already had made them comfortable discussing personal topics such as relationships with boyfriends or girlfriends.

The workshops also strengthened the sharing of information between the facilitating organisations



and the children, young people and parents who took part. By running the group workshops, YDAS and BM were able to find out more about what the participants needed and to form continuing relationships to support them in developing future goals and achieving them. In the case of IM, the workshops were run by a different staff member to the one who usually worked with the school leavers' program. This allowed the participants contact with a new person in the organisation, who had a new perspective. The young people commented at the end of the second workshop that this had been one of the most beneficial aspects for them; it brought a different energy and tone into the room and extended the number of people in the organisation who they were familiar with.

## Mentoring and role modelling

The wide age range of children and young people in the YDAS-BM group (ages 9-22) allowed mentoring and role modelling to take place. While it was initially anticipated that younger and older participants would be separated for part of the workshops to enable age-appropriate discussions, the age diversity proved to be a benefit, and the whole group stayed together throughout the workshops. One facilitator observed that the younger participants were highly interested in the life experiences of the older participants; the older participants' stories seemed to inspire the younger group members. A younger person stated that listening to an older group participant describe what he had achieved was 'so awesome, and if it's all I get out of this then that was more than enough'. The parents of younger children also expressed verbally and in survey responses that they benefitted from hearing the experiences of the young adults in the group.

For the older participants and their parents the meetings were also beneficial as they affirmed their life choices and encouraged them to continue on their life paths. For example, one young person worked in hospitality on a supported wage and studied related skills at TAFE and YMCA. The group commended him for what he was doing and encouraged him to move beyond a supported wage to open labour market employment.

A drawback of the age diversity of the group was that there was little interaction and socialising between the children and young people in the group, with many preferring to interact with the facilitators. This was perhaps because children as young as nine and people in their early twenties who do not know each other have little in common that might encourage conversation.

## Developing autonomy

It appeared that some parents in the YDAS-BM group became open to the idea of giving their children a more active role in decision-making about funding and support. This happened because parents saw that it had been successful in other families. For example, a young person in the YDAS-BM group was involved in the community and worked a couple of different jobs. He had got these jobs after expressing his desire to work in them to his parents, who, in response, actively sought the relevant opportunities for him. A facilitator of the group said, 'He had a voice. He had a say. His parents were listening and acting on what he had to say'.

The other parents in this group listened and were receptive to the family's experiences; some mentioned in response that they would focus more clearly on their children's 'goals', 'visions' and 'needs' in the future. In this way, the peer support aspect of the groups opened some participants up to new possibilities around decision-making autonomy for the child or young person with disability.

## Continuing the groups

The YDAS-BM group decided not to continue meeting after the project was over, and the facilitators thought the families were unlikely to keep in touch with each other. This may be for several reasons,



including living in geographically disparate areas, the age diversity of the group and a lack of commonality between the children and young people. Additionally, the group had met only twice, allowing limited time for establishing rapport. Further, one of the facilitators observed that in previous projects he had been involved in, networking was usually maintained where the participants were involved in some sort of shared fun activity or collective action rather than peer support, as had been the purpose of the groups in this project.

In comparison, the IM group was recruited from an existing school leavers' program that continued after the project finished, and thus the participants maintained their relationships with each other.

## 5.2 Including children, young people and parents together

Only the YDAS-BM group included children, young people and other family members (parents) together, while family members did not participate in the IM group. One of the initial considerations regarding the project was effectively managing the inclusion of children, young people and families together in the workshops. The project's aim was to ensure that everyone had an opportunity to speak and express their experiences. Children and young people on the one hand, and family members on the other, both needed space to express their views without feeling inhibited by each others' presence. It was anticipated that these issues could be addressed through having a mix of activities where children, young people and families participated sometimes together and sometimes separately.

In practice, however, the YDAS-BM group found it most appropriate to run all activities together. This was because the younger participants, aged nine to thirteen, relied on their parents to help them communicate with the group. As such, it was necessary for parents to be involved in all activities to enable the younger children to participate.

The facilitators used various strategies to ensure that everyone in the group was engaged and able to communicate:

- The group was set up in a horseshoe arrangement and every question and activity went around the table. This provided everyone an opportunity to have their say and to build off the responses of others.
- All questions and activities were directed at and involved the children and young people. Questions were personalised, rather than general. For example, many of the activities involved brainstorming about the interests, likes and dislikes, dreams and goals of the children and young people.
- Many of the activities could be completed on butcher's paper or on a written survey. The children and young people preferred to use the butcher's paper and appeared to take more control over these responses. For example, one child did not offer information about his aspirations verbally to the group, but drew them in great detail on butcher's paper, allowing his parent to learn for the first time what his aspirations for the future were.
- Videos were used to generate discussion. The videos were about young people with intellectual disability who had successfully found work or were living out of home. The facilitators found these videos were effective at engaging the group, especially the children and young people.
- The room was spacious and allowed for the children and young people to move around and have discussions with the facilitators one-on-one. The facilitators noted that some of the young people were more comfortable communicating in this context than in the group discussion setting.

With these strategies in place, the facilitators of the YDAS-BM group observed a respectful

and inclusive environment in the groups where children, young people and parents expressed themselves and listened to each other. This may have been due to the strategies and also due to who was involved. The facilitators observed that the parents in the group were encouraging and facilitated their child's participation.

The facilitators also commented that parents were generally more vocal than their children, however, that to some extent 'that's to be expected' as parents commonly speak on behalf of or together with their children when they are young in age regardless of whether or not they have a disability (Harden et al., 2010). However, this may become more accentuated where the child or young person has a disability (Abbott, 2012). The facilitators tried to ascertain whether parents were more vocal due to the children's age or their disability, acknowledging that the answer was complicated and unclear. Facilitators reflected less on whether parents appeared to feel restricted in what they could say in front of their children.

Involving parents and their children together in the YDAS-BM group created space for beneficial dialogue between children and parents which, for some parents, resulted in an improved understanding of their son or daughter's aspirations. Feedback from some parents was that they got to know their children better as a result of the workshops. One facilitator suggested that the workshops may have exposed some parents to hearing more about their children's opinions and thus led them to have a better understanding that their children had 'a strong voice' and 'know who they are'. The best example of this involved a young boy who was keen to work with animals. The boy was passionate about helping animals, and it was clear in his responses to the activities that this was a future career goal for him. Yet his parent had previously been unaware of his interest in this field. The opportunity for dialogue in the group thus furthered the parent's understanding of the boy's aspirations.

# 6. Implications

This section presents implications of the project findings for the methodology of similar projects in the future as well as for self-directed support policies and the NDIS.

## 6.1 Implications for future projects

The experience of developing, applying and evaluating a methodology of social action research with children, young people and families yields implications for future projects, including in the areas of data collection, participant recruitment and group activities.

### Researcher involvement

A researcher could be directly involved in the groups and assist with data collection. In this project, all group data was collected and reported through the facilitators, and the research team had neither direct contact with the participants nor direct responsibility for recording the data. While this was a strength of the project in drawing on the skills of the facilitators, data could be more comprehensively collected, classified and archived in future projects if a researcher was present at the workshops. This would also free the facilitators to concentrate exclusively on running the workshops.

### Group activities

Given the recruitment difficulties described above (see Section 2.2), one facilitator supported the idea of running workshops focused not just on peer support but also skill development and fun, for example, the group together developing a media or radio show, podcast or recorded TV-show style program. This facilitator said that in his experience, such activities were the most effective method of attracting participants and were particularly successful in attracting young people and developing their skills. Another facilitator similarly emphasised that creating networks through social media or creating the workshop around an enjoyable activity that is attractive to young people (e.g. share boards, flash mobs) might be more effective for including not only young people with disability, but also a broader range of family members such as siblings.

Another recommendation was that future projects could be advertised as teaching a skill in relation to self-directing funding and support (e.g. how to hire your own support worker, how to apply for disability support funding) as opposed to advertising as a peer support group, thus seeming more practical and less emotive.

Nevertheless, future projects would still need to overcome the primary barrier to participation in this project, which was arranging a time when everyone was available.

## Recruitment avenues

Future social action research with children, young people and families could explore whether different recruitment avenues might more successfully recruit a balanced mix of children, young people and family members. This project focused on recruiting through organisations primarily servicing people with disability and, perhaps as a result, was successful at recruiting children and young people with disability. It did not, however, always manage to recruit family members. Other research that has focused on including family members both with and without disability together has used a mixture of recruitment avenues, focusing on a mix of organisations, some primarily servicing people with disability and others primarily servicing family members and carers, and has recruited a reasonably equal balance of family members with and without disability (Meltzer, 2015). Experimenting with a mixture of recruitment avenues in future projects may thus hold potential to include a more even mix of children, young people and family members.

## 6.2 Implications for self-directed support policies and the NDIS

The project's findings have policy implications for people's access to self-directed support options in the future, control over managing their support, information needs, participation in peer support and information sharing, and focusing decisions about support arrangements on the aspirations of children and young people.

### Access to support

Participants in the groups had little experience with using self-directed support. Only one young person and his family had a self-directed package. In this regard, the group participants were similar to a wider population of people with disability as self-directed funding was still rare at the time of this project. However, it will become more widespread under the NDIS. The group discussions gave participants an opportunity to learn from the experiences of peers about how to use self-directed support effectively. Participants welcomed this, and it appears good preparation for the rollout of the NDIS when more people will be able to access a self-directed package.

The policy implication is that planning processes for the NDIS and other self-directed support will need to take into account that people who are eligible for and access the funding will have limited experience with what self-direction actually means and how it might benefit them. Planners or other supporters will need to be sensitive, respectful and patient in exploring children and young people's goals as well as possibilities for achieving these goals, so that funds can be used effectively. In addition, children and young people will likely need high flexibility in planning as they try new things and want to change their plans as they gain life experience.

### Control over support

All participants who received funding felt that they had some control over how it was used. However, people's choices were restricted by insufficient funding amounts, limited flexibility in how funding could be applied and lack of experience in structuring their funding and exploring the possibilities of their package.

Consistent with the ages and life-stages represented in the groups, the children had little knowledge of the administrative details of their package, while the young adults generally knew and understood what funding they had and what it was for. While children and young people were clear about the goals and aspirations they wanted to achieve, the funding packages were usually managed by parents.

The implication for the NDIS and similar support options is that children in general and young

people in the majority will need support to manage their funding package. In most cases parents will be involved. While parent involvement will often be appropriate, this research shows that children and young people – consistent with the UNCRPD and United Nations Convention on the Rights of the Child (UNCRC) – have the right and capacity to make decisions about their support, or at least to be involved in the decisions, and that this capacity evolves over time. Therefore, there is a need to support the evolving capacity of children and young people to make their own decisions about their funding packages and support arrangements. This may include support to develop over time the skills to think through options, consider consequences and make informed decisions. Children and young people may also need independent decision making support.

## Information needs

Most parents in the groups had actively sought information about funding and support options through seminars, workshops, support groups and interaction with other parents of children with disability. However, the information they were able to get was incomplete. Parents were not necessarily aware of what types of funding were available, how to apply for different types of funding and how to access information in general. Even the parents who had more information about funding and support wanted clearer, more detailed and more easily accessible information.

The implication is that parents of children and young people with disability need additional information to access and make effective use of new types of funding. Parents in the groups suggested what types of information they would find useful, including impartial assistants, written resources, mentoring for parents and better access to information about education, training and work for their children post-school. Some aspects of this information and guidance may already be available, but the parents' experience highlights that it is not easily or widely accessible to all families. Some may benefit from better information about existing resources.

## Peer support and information sharing

The children, young people and parents all appeared to benefit from participating in peer support and information sharing during the project, including among the families, with the facilitators and between parents and children. The project enabled some mentoring and role modelling between children and young people, and it appeared to increase some parents' understanding of their son or daughter's aspirations. Peer support and information sharing occurred around key issues, such as identifying strengths, interests and passions; following inclusive pathways; and building capacity for self-direction, rather than following traditional options. The implication for the NDIS and similar approaches is that various opportunities for peer support and information sharing are important for building capacity to navigate self-directed services.

## Children and young people's aspirations

The children and young people in the groups shared their aspirations and life goals. Like any child or young person, either with or without a disability, they commonly aimed to form relationships outside their families, work, travel and live independently. Some saw their disability funding and support as ways of working towards these aspirations. Some parents had not been aware of their children's aspirations before the children revealed them in the group. The implication is that planning processes for the NDIS and other self-directed packages need to ensure the voice of the child or young person is heard, so that funding can be directed towards achieving their individual life goals.

# Appendix A

## Facilitator organisation profiles

### Youth Disability Advocacy Service (YDAS)

[YDAS](#) is a service of the Youth Affairs Council of Victoria (YACVic) and is funded by the Office for Disability. It is the only advocacy service in Victoria with a specific focus on the needs, interests and rights of young people with disabilities. YDAS works alongside young people with disabilities aged 12 to 25 in order to raise awareness of their rights and to support them to achieve their goals.

YDAS is engaged in one-on-one support through individual advocacy services as well as broader social issues affecting young people with disabilities through systemic advocacy. This systemic work is directed by the YDAS steering committee, which is primarily composed of young people from across Victoria with disabilities.

### Belonging Matters (BM)

[Belonging Matters](#) is a small, not-for-profit community education and advisory service developed by families who believe in social inclusion. Belonging Matters aims to assist, inspire, and build the capacity and knowledge of people with disability, their families and other allies to enable people with disabilities to have opportunities similar to those of other citizens in the community – lives that are personally fulfilling, unique, socially inclusive and empowering.

### Inclusion Melbourne (IM)

[Inclusion Melbourne](#) provides personalised support for people with an intellectual disability. Inclusion Melbourne was founded in 1948 by a group of concerned parents who sought to provide a more inclusive, respectful alternative to the institutional model of care then available.

Inclusion Melbourne has a vision that people with disability should be able to live in an inclusive community, supported by people who genuinely care for them, and have the same opportunities as others to participate in community life. Inclusion Melbourne is the only disability day service in Victoria which has completely transitioned from a centre-based model to offer fully personalised support for people with intellectual disability. This means the support provided takes place in the community, based on an individually tailored life-plan.

# Appendix B

## Discussion topic guide

### Topic prompts for children with disability and families

\*\* This is intended as a guide to the facilitators of the type of information we are interested in knowing from children with disability and family members. The intention is not to ask these questions verbatim, but to, in general, gain insight into these sorts of topics.

The questions are written from the perspective of children with disability, but could also be adapted to family members. Some notes are included on each section about how the questions might be adapted for family members. These types of adaptations should be easily made in the context of group discussion.

After session one, please use the responses of children to individualise and personalise further sessions (for example, asking about how workers 'help you to get to judo' rather than 'with community activities' and rather than talking about 'workers', use their names).

### About you

<i>About you</i>	<i>About your funding</i>	<i>About how you decide to use your funding</i>
<ul style="list-style-type: none"><li>• What would you like the group to know about you?</li><li>• What do you do on week days?</li><li>• What do you do on weekends?</li><li>• What is important to you?</li><li>• Who is important to you?</li></ul>	<ul style="list-style-type: none"><li>• What funding do you have to help you?</li><li>• What do you know about your funding? For example:<ul style="list-style-type: none"><li>- Where does it come from?</li><li>- How is it organised?</li><li>- How long have you had it?</li><li>- What can you use it for?</li></ul></li></ul>	<ul style="list-style-type: none"><li>• How do you use your funding? For example, do you use your funding for:<ul style="list-style-type: none"><li>- Workers</li><li>- Equipment</li><li>- Therapies</li><li>- Appointments</li><li>- Help with activities</li><li>- Help at school</li><li>- Help at home</li><li>- Other help or support</li><li>- What else?</li></ul></li><li>• Who decides how you use your funding?</li></ul>
<ul style="list-style-type: none"><li>• What would you like to try out between now and the next group meeting, about your funding or your support?</li></ul>		



**Notes on adapting questions to family members:** These questions could easily be asked of parents or siblings as well. The first column could be asked unadapted. The second two columns could be asked phrased as “What funding does XX [name of child with disability] have?” (column 2) and “What is XX’s funding used for?” It will be interesting to note if different people from the same family have the same or different knowledge and perceptions of the funding.

## What is important to you? [Social participation]

<i>About what is important to you</i>	<i>About how you use your funding for what is important to you</i>	<i>About what you would change about using funding for what is important to you</i>
<ul style="list-style-type: none"> <li>What is important to you? For example, you could talk about:               <ul style="list-style-type: none"> <li>Home</li> <li>School</li> <li>Other activities you do on the weekend or after school</li> <li>Family</li> <li>Friends</li> <li>Other people who are important to you</li> <li>Taking part in your community</li> </ul> </li> </ul> <p><b>NB: Facilitators, please personalise this question according to interests and information from session 1.</b></p>	<ul style="list-style-type: none"> <li>Do you get help to do any of the things that are important to you? Who/what helps you?</li> <li>Do you use your funding to help with those things that are important to you? If so, how?               <ul style="list-style-type: none"> <li>For example, does the funding give workers, equipment or the chance to join groups?</li> <li>What is helpful/good or unhelpful/difficult about using funding for that?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>What would you change about using your funding for those things that are important to you? Why?</li> <li>Can you already make changes if you want to? If so, how? If not, why not?</li> <li>Who decides about making changes?</li> </ul>
<ul style="list-style-type: none"> <li>What have you tried since the last group meeting, about your funding or your support?</li> <li>How did it go? What have you learned?</li> <li>What would you like to try out between now and the next group meeting?</li> </ul>		
<p><b>Notes on adapting questions to family members:</b> Both children with disability and family members will have areas of life that are important to them that the funding potentially helps with. The questions in column 1 could be asked of all family members, with references to ‘school’ changed to e.g. ‘work’ or ‘household responsibilities’ for adults. In column 2, the question for family members could be “How does XX’s funding help with those things that are important to you?”, with a similar adaption in column 3. It will be interesting to see how the areas of importance to different people from the same family do or do not fit together and are or are not similarly influenced by the funding. It will also be interesting to see participants’ reflections on whether and how the funding can simultaneously address what is important to multiple family members.</p>		

## Access to information and having a say

<i>About the information you have and how you have a say</i>	<i>About how you use that information or chance to have a say</i>	<i>About the information you want or what you would change about having a say</i>
<ul style="list-style-type: none"> <li>• What information do you have about how you can use your funding?</li> <li>• How do you decide how to use your funding?               <ul style="list-style-type: none"> <li>- Who gets a say in deciding?</li> <li>- What do you do to decide?</li> <li>- What makes a difference to what you decide? (e.g. what you want, need [aspirations and plans])</li> <li>- Who organises it once you've decided?</li> <li>- Who helps if there is a problem?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• How have you used information or a chance to have a say to use your funding the way you want to?</li> <li>• What do you think of:               <ul style="list-style-type: none"> <li>- How you use the funding</li> <li>- Whether you spend it on the right things</li> <li>- Whether there is enough funding to do what is important to you</li> <li>- Whether you can use the funding in enough different ways to do what is important to you [flexibility]</li> <li>- Whether you can use the funding so that it also helps with what is important to other people in your family</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• What do you still need to know?</li> <li>• What do you want to have more of a say about?</li> <li>• How could getting information or having a say happen better?</li> </ul>
<ul style="list-style-type: none"> <li>• What have you tried since the last group meeting, about your funding or your support?</li> <li>• How did it go? What have you learned?</li> <li>• What would you like to try out between now and the next group meeting?</li> </ul>		
<p><b>Notes on adapting questions to family members:</b> These questions could easily be asked of all family members, just changing references to “your funding” to “XX’s funding”. It will be interesting to note the balance between the extent of different family members’ information and chance to ‘have a say’ here.</p>		

**Arrangements with workers/ characteristics of disability support. *Facilitators: Please personalise and differentiate between individual workers.***

About your workers	About how your workers help	About what you would change about your workers
<p><b>Arrangements with workers</b></p> <ul style="list-style-type: none"> <li>When do your workers come?</li> <li>Why do they come then?</li> </ul> <p>If not already clear from previous sessions, please find out:</p> <ul style="list-style-type: none"> <li>What do you do together?</li> <li>What do they help you with?</li> <li>Who decides?</li> </ul> <p><b>Relationships with workers</b></p> <ul style="list-style-type: none"> <li>What are your workers like?</li> <li>What is good about them?</li> <li>What makes you cross with them?</li> <li>What makes a good worker?</li> <li>What makes a difference to how you get on with them?</li> </ul>	<p><b>What the workers do</b></p> <ul style="list-style-type: none"> <li>What do your workers help with?</li> <li>What do your workers <u>not</u> help with?</li> <li>When do you want a worker to be there and when not?</li> <li>Which things do you want a worker to help with and which not?</li> </ul> <p><b>Making sure workers are organised</b></p> <ul style="list-style-type: none"> <li>Do your workers come from a disability organisation?</li> <li>What does this organisation do for you? <i>[Prompt for things like: organise the workers; provide information; resolve complaints]</i></li> </ul>	<ul style="list-style-type: none"> <li>What would you change if you could have more of a say about your workers? For example, would you change: <ul style="list-style-type: none"> <li>What they do</li> <li>What they are like</li> <li>The type of worker who comes</li> <li>How they are organised</li> </ul> </li> <li>What would you change it to?</li> </ul>
<ul style="list-style-type: none"> <li>What have you tried since the last group meeting, about your funding or your support?</li> <li>How did it go? What have you learned?</li> <li>What would you like to try out between now and the next group meeting?</li> </ul>		
<p><b>Notes on adapting questions to family members:</b> Everyone in the family may potentially have opinions of or perceptions about workers, especially where the workers come to the family home. These questions could easily be asked of all family members by replacing references to “your workers” with “the workers” or “XX’s workers”. It will be interesting to see if different people in the family have similar or different perceptions of what they want workers to help with and about what makes a good worker.</p>		

**Reflection/some sort of future planning activities**

About taking part in the group	About what you would change about the group	About what should happen now / next
<ul style="list-style-type: none"> <li>What did you think of taking part in this group? <ul style="list-style-type: none"> <li>What was good or fun about it?</li> <li>What was difficult or hard about it?</li> <li>What was useful and not useful about it?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>What would you do differently to make the group better? Why?</li> </ul>	<ul style="list-style-type: none"> <li>What do you want to happen to the group now?</li> <li>What do you want to do next?</li> </ul>
<ul style="list-style-type: none"> <li>What have you tried since the last group meeting, about your funding or your support?</li> <li>How did it go? What have you learned?</li> <li>What would you like to try out in the future?</li> </ul>		
<p><b>Notes on adapting questions to family members:</b> These questions could easily be asked of everyone without any adaptations.</p>		

# References

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