

Association for Children with Disability

Snapshot: Families' experience of the Disability Inclusion Profile process

May 2024

Background

Association for Children with Disability (ACD) is the leading advocacy service for children with disability and their families in Victoria. We are a not-for-profit organisation led by, and for, families of children with disability. Our vision is an inclusive community where children with disability and their families thrive.

In March 2024, ACD held two online sessions with families of children with disability to hear about their experience with Disability Inclusion Profiles, which are currently being rolled-out and implemented across government schools.

These sessions gave families the opportunity to share their experiences, connect with other families and have their voices heard on issues that affect them.

Disability Inclusion Profiles are part of the Victorian Government's \$1.6 billion Disability Inclusion investment. The profiles are designed to be strengths-based process to help schools and families identify the student's strengths and needs, and what educational adjustments schools can make to help students with disability.¹

This snapshot highlights families' experiences of the Disability Inclusion Profiles including what worked well, and how the process could be improved.

For more information contact

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ACD acknowledges the Traditional Owners of this land. We recognise their continuing connection to land, waters and community. We pay respects to Elders past and present.

¹ https://www.schools.vic.gov.au/disability-inclusion

Disability Inclusion Profiles

1. Strengths-based approach

The most common thing families talked about when asked what was good about the Disability Inclusion Profile (DIP) meeting was that it was strengths-based and that they had the opportunity to talk about their child's needs holistically. Many families felt unjudged and that the advocacy they undertook for their children was acknowledged.

Several attendees shared examples of the Department or principals stepping in to make sure the discussion remained strengths-based. For others, hearing their child's teacher talk about their child's strengths contributed to a positive environment. When meetings were strengths-based, it built trust between families and the school. Families reflected positively on seeing that their child's teacher knew their child well.

'While we felt a lot of pressure ... We had a very positive experience with the people we dealt with. I felt scared and like I was going to be judged for my parenting but I wasn't and it was nice.'

'At one point my daughter's teacher was focusing on a deficit, rather than me having to pull her up, the people from the Department said I'm going to have to interject to say that's not the purpose of the meeting and helped reframe it for the teacher.'

'Then it went to teachers and they were able to identify the strengths and it was really good because normally you get the phone call about something that's happened in the classroom, that's probably the feedback you'd get throughout the term. So to hear the teachers speak so highly about my son it was really good to see.'

2. Setting families up for success

Families who received information about the process and breakdown of domains prior to the meeting spoke about feeling prepared. These families had an opportunity to reflect and make notes in advance, supporting them to feel ready to engage in the conversation.

Families reported that the meetings were complex, long and had a lot to cover. Families shared they felt rushed and that there was some confusion for both families and schools about the details of the domains. Families talked about feeling pressure to get the best outcome for their children, feeling like they couldn't take a break in the meeting and finding it stressful and intense. They felt this meeting was the one chance for their child to get the support they needed.

Some families felt 'steam rolled', many weren't given information about the domains or the process in advance, and some found the DIP meeting to be deficit focused. For these families, it took an additional emotional toll and complexity increased. Families noted there was no easy read information for parents, limited support for parents with an intellectual disability, the use of acronyms made the language unclear, and there was often an underpinning assumption that all parents were capable of advocating for their child. Families said a one-page infographic showing the process from start to finish from a parent's perspective would have helped, as well as info packs about the process. Being able to provide written responses to the domains and additional information after the meeting if needed would have improved the process for many families.

'We had some preparation from the school. I did have to ask for it but we ended up with the school's preparation document. I would have been quite terrified by that document if I hadn't had time to read through it and adjust to it, and it did help in going into the meeting. We already had levels circled and we knew why.'

'Beneficial how they looked at my child in a holistic way. Things were broken down in the domains and looked at every aspect of my child's education needs.'

'We found the experience totally deficit focused. We found ourselves having to clearly quote deficits to establish levels in every domain.'

'There was confusion about what the domains covered eg mobility is only one that talks about difficulty with travel but my child is a runner and that affects all transitions and supports needed.'

'We had three staff from government present. Did feel intimidating. Felt that a lot of the pressure was on me to advocate and provide evidence.'

'Not being clear what evidence was needed and not being able to follow the inside chat between department staff about what was needed, and whether the therapy team can help.'

3. Gaps in the process

While many families found positives in the DIP meeting, many raised concerns about the process.

For many families, the wait time for a DIP had been extensive. Families reported waiting between 8 months and 2 years for a DIP meeting.

Families were concerned that meeting discussions were restricted to adjustments that had been made in the last 10 weeks. Where families felt their child's teacher had limited understanding of their child, where the wrong adjustments had been made, or none had been made at all, families felt let down by the process and as though it wasn't set-up to get the best outcomes for their children. This was heightened if their child had school refusal, or absences due to illness or extreme weather events, which meant there were limited adjustments made in the previous 10 weeks. When children started prep, families were concerned about the 10-week observation period and whether their children received support during this time.

Families raised concerns that children with significant learning support needs but fewer behavioural support needs received inadequate adjustments and therefore funding. This resulted in poorer educational outcomes which at times led to disengagement and escalating behaviour.

In addition, some concern was raised about the disability knowledge and expertise of the facilitator. This highlighted the importance of providing more proactive information to support their understanding of the process in advance, including how decisions are made and by whom, and what happens when there is disagreement between parties.

Families wanted more support to cover the costs of reports, or to be allowed to submit older evidence. For other families, they saw no evidence the reports made an impact on the DIP final report, adding to frustration over the time and cost to compile evidence.

While some families were given information about timelines and next steps during their DIP meeting, many weren't aware they should have received a final report, and others were still waiting despite following-up with their school.

'If the school didn't make adjustments in the last 10 weeks, they couldn't include it in the discussion, even if really relevant or needed.'

'I felt at times in the meeting that sometimes my son's needs didn't match what the school have done in the previous 10 weeks.'

'Timelines involved so you know when you expect things.'

'That the department actually trusts the reports and opinions of experts and educators, when they say they need support and funding, trust them that they need it.'

'I actually had to reach out to [ACD] and the local Regional office in order to have to fast track [for a DIP meeting] after waiting 2 years.'

'Unclear follow up – Had to ask the principal after the meeting when we needed to have the documents spoken about in the meeting submitted and to clarify if I needed to do anything.'

4. Transparency

Families shared experiences of being told by their school their children weren't eligible or wouldn't receive funding to justify the school's decision not to apply. This created challenges for families who ultimately believed their child was in scope and would benefit from a DIP.

Similar occurrences have been reported through ACD's Support Line. Families spoke about their children being denied a DIP meeting, even where they are currently receiving support from education support staff (through school-level funding decisions, not through the Program for Students with Disabilities or Disability Inclusion).

Families also reported that they did not know the outcome of the DIP because they weren't provided with a final report. Families were concerned there was no transparency about the level of funding their child received and that there were not avenues to appeal. Concerns about appeals applied to accessing a DIP and the outcome of a DIP.

'Had to fight to get a DIP meeting.'

'[I wanted] more information and understanding of the DIP and level of funding you are entitled to and what that means and looks like.'

5. Student voice

Half of families reported their child participated in the DIP meeting. Of the families whose child did participate this was a combination of attending the meeting, having a say prior to the meeting or that their input was provided through an Individual Education Plan.

Some families were unaware that their child could have a say until they were in the meeting. Families said they'd like to see the option of their child sharing what kind of support they'd like via video, and others noted that student voice can sometimes be relayed via parent-advocates.

'I didn't find out about the student voice aspect until I was in the meeting.'

'At no point was my child asked to be in the meeting, he's in grade 3 so probably quite capable of attending.'

'They did ask if my son wanted to participate but he was in prep, non-speaking and minimal receptive language and he couldn't sit still so it would not have been his scene and he was not at that time capable even with supported communication to participate in that.'

'They brought him in towards the end, so he could have his say not only in writing the response but verbally and for the team to meet him. Because it's interesting to hear what he has to say in his own words.'

6. School, student, and family partnerships

Student Support Group (SSG) meetings are an important tool to continue collaboration between schools, students and families beyond the DIP process.

Most families whose children had a DIP had an SSG meeting each term, but what the meetings were used for, length of time and how collaborative they were differed. Some families reported SSG meetings taking place only twice per year for 15-minutes, while others spoke about lack of planning and preparedness for meetings which undermined their effectiveness.

Similar occurrences have been reported through ACD's Support Line. Some families had SSG meetings for 15 minutes for the sole purpose of the school providing an update to the family, rather than engaging in a discussion or planning to support the student. Many families are being told by their school that they don't have the time or resources to run SSGs, particularly for students who don't receive individualised funding, leaving limited avenues for families to ensure their child is being proactively supported.

'Find the SSG meetings are generally tooth and nail having to drag the school to make appointments for one.'

'The first year I didn't even have an SSG meeting, the first school year I didn't know what one was. It wasn't until grade 1 and looking at DIP so I didn't even know what one was. I'm getting them now.'

'It is nice to reflect back on milestones that have been achieved, especially when end of semester reports can often deliver challenging news.'

'I'm also trying to break it to the school that they're meant to have an agenda and take minutes, which I'm currently doing. They're pretty supportive so I try to work with them on those things.'

'Meant to be each term, but prob only twice a year. It also often seems like a hassle and rush to book in and only 15mins each child. Often IEP are not prepared prior or even drafted.'

Final comment - interface with the NDIS

While there were no specific questions about the NDIS as part of the consultation it did get mentioned by families.

Families reported the DIP gave them an understanding of functional domains and that this was helpful when talking to the NDIS. Families shared the DIP report as part of their child's NDIS plan reassessment, and they reported it was good evidence of their child's support needs.

Families who participated

17 parent/carers attended the session. Their children were aged between 5 and 14 years old. Autism was the most represented primary diagnosis. Their children attended both mainstream and specialist schools. Almost one quarter of attendees identified as being from a culturally and linguistically diverse background. One attendee identified as Aboriginal and/or Torres Strait Islander. Most participants lived in metropolitan Melbourne (65 per cent) compared with regional Victoria (35 per cent).

Additional insights were provided (where indicated in the snapshot) through information gathered by ACD's Support Line, which offers free phone advocacy to Victorian parents raising children with disability.