

# Work pathways and employment experiences of young people with Cerebral Palsy and opportunities to improve outcomes.

## White Paper Submission to the NDIS Review





the national voice

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## **About Cerebral Palsy Australia**

Since 1952, Cerebral Palsy Australia (formerly known as CP Australia and the Australian Cerebral Palsy Association) has provided a national voice for cerebral palsy awareness.

Furthermore, Cerebral Palsy Australia has positively contributed to the community through research and service development for children and adults with cerebral palsy.

Cerebral Palsy Australia focuses on the promotion and advancement of the rights, interests, welfare and social inclusion for people with cerebral palsy by:

- Assisting in obtaining appropriate funding
- Supporting and encouraging innovation and improved service practices
- Encouraging, conducting and supporting research concerning cerebral palsy
- Working with governments in developing policies for services and support of organisations working with people with cerebral palsy and the people who support them

Cerebral Palsy Australia is a wholly owned subsidiary operated of Ability First Australia and is overseen by a Working Group of CP focused organisations and individuals with lived experience:

- Ability WA
- Cerebral Palsy Alliance
- Cerebral Palsy Support Network
- CPL – Choice, Passion, Life
- Novita
- The Australasian Academy of Cerebral Palsy and Developmental Medicine
- Scope
- 3 people with lived experience of CP

## **This paper**

This submission speaks to two of the key questions identified in the 'What we Have Heard Report' prepared as part of the NDIS Review, which are a **complete and joined up ecosystem of support** and **achieving long term outcomes**.

The paper has a specific focus, which is the work pathways and employment experiences, primarily of people with Cerebral Palsy (CP), also incorporating a perspective of young people with Intellectual Disability who do not have CP.

The important insights that follow are evidence based and reflect the lived experience of people within the disability community. The paper is informed by qualitative research undertaken and other resource materials prepared by or sourced through Cerebral Palsy Australia, Ability First Australia, CPA (Cerebral Palsy Alliance) and CPSN (Cerebral Palsy Support Network).

The source documents are listed in *Appendix 1*.

## **Context**

It is widely accepted that having productive and meaningful employment is a basic human right. Many people with disability who aspire to employment face considerable challenges and barriers along their journey to preparing for, seeking employment and when they enter the workforce.

The fundamental role of work readiness development along the pathway from secondary school to employment is to equip and empower young people with disability with workforce aspirations to realise their goals. When working effectively, it does this by enabling and supporting them to identify and refine their goals and develop the skills, expertise and self-belief to achieve these in ways that align with their needs, capabilities and capacities. Effective workplaces for those with disability who require supports require employers with the willingness to provide inclusive workplaces and who back up their commitment by providing conditions and workplace environment that enable people with disability to become productive employees.

## **The Issues**

### **Work Readiness & Transition to Work**

The quality of work readiness training and development programs, services and supports and how influential adults such as parents, teachers, and/or others support and encourage a student with disability can have a profound effect on an individual's chance of successfully transitioning into employment<sup>3</sup> and achieving positive longer-term outcomes through adulthood. In the interests of fairness, quality work readiness and transition to work should be available to people with disability who aspire to employment—whether they are in or outside the NDIS.

To optimise the chances of successful outcomes, the employment journey starts in the formative years well before a student with disability leaves secondary school. Ideally, work readiness accessed at

secondary school provides a crucial foundation which can be built upon in further education, programs and/or supports in post-secondary years,<sup>1</sup> and should therefore be part of a complete and joined up ecosystem of support.

Effective work readiness works on formulating goals, developing skills, building confidence, self-belief and resilience, as well as serving as a starting point for exploring employment possibilities and opportunities.<sup>3</sup> These skills are also the basis for self-advocacy, which is often a crucial skill down the track when an individual is demonstrating employability and negotiating supports and accommodations with employers at the applicant stage and when in employment.<sup>7</sup>

Hallmarks of effective work readiness programs, including foundational programs in secondary school as well as those accessed post-secondary school in further education or School Leavers Employment Supports (SLES), depending upon the needs of individuals, include one or more of the following:<sup>1</sup>

- Consistent with, or part of life goals and other skills development such as independent living
- Incorporate aspirations, dreams and goals as well as soft skills such as confidence, leadership, work ethic and hard skills such as resume writing and interview preparation and practice
- Include practical experience, such as through volunteering, mentoring and/or work experience to complement hard and soft skills development programs. Some research participants had exposure to these in secondary school and this was a positive
- Involve partnerships between one or more types of organisations such as secondary school, post-secondary education, disability service providers, Disability Employment Services (DES) and employers

**Work experience** gives young people with disability exposure to employers, industries/sectors, work routines and tasks. Benefits include shaping future work goals, building confidence, resume development and contributing to realistic expectations of working life. For some, a further benefit was that work experience undertaken in secondary or early post-secondary years was a precursor to ongoing full or part time employment.<sup>1,7</sup>

**Volunteering** can be a means of connecting with local community (as can work experience). While it can often be seen as a means of 'giving back' or being community minded, it can be also be a valuable component of work readiness and transition to work for young people with disability. Some research participants saw their volunteering as akin to work experience (albeit unpaid); benefits included learning new skills transferrable to employment and resume building as well as assisting with confidence building and self-belief. While many volunteering placements were accessed through family and reflect individual skills and interests, opportunities were accessed through secondary school programs or at the suggestion of a DES<sup>1</sup> and were often part of well-rounded work readiness and transition to work programs.

**Mentoring** can be a powerful experience for young people on their pathway to work. Mentorship models with strong benefits to research participants<sup>1</sup> include mentors with disability who role model what is possible and peer-to-peer mentoring.

One example of peer mentorship was the experience of one young person with CP who had been mentored in Year 9 as part of a secondary school work readiness program and was invited to return as a mentor to younger students with disability in Years 11 and 12. As a mentee, this helped shape his early work readiness goals and skills and as a mentor it provided exposure to leadership. This mentorship was a positive example of a collaboration between the secondary school in which it was accessed, a disability

service provider which delivered the service and a large corporate employer which sponsored the program.<sup>1</sup>

### Research participant comments

*"Work skills development was really helpful...we did mock interview. It was good to see what they were like."<sup>1</sup>*

*"For my job, actually, my school helped me because when I was at school, I had work experience where I work now, and now I work four days a week part-time"<sup>3,7</sup>*

*"I was lucky because I had a mentor with CP...it was very important. She was a role model who helped me see what I could do"<sup>1</sup>*

*"Skills I gained in the mentorship program were the personal development side. I attended every two weeks and would go through a guided session. Activities included sessions on personal brand, leadership and how to stand up for yourself if bullied"<sup>1</sup>*

Finding the **'right' work readiness and transition to work programs, supports and services**, particularly those outside secondary school and disability services more generally, is problematic and a challenge faced by many. The 'right' services, supports & programs were those that are high quality, met the often complex and highly individualised needs of young people, were accessible and affordable<sup>1</sup>.

Higher barriers identified in the research<sup>1</sup> were experienced by people with multiple disabilities. Some people have complex and highly individualised needs due to multiple diagnoses such as CP and/or intellectual disability together with one or more disabilities such as autism, ADHD, PTSD, vision or hearing impairment. The experience can be that available services and programs suit some but not all their needs and at worst can have negative cross-impacts. There was a perception among some that more services are available for those with intellectual versus physical disability. For some, the most effective services were tailored to the individual and delivered in a one-on-one rather than group setting.

Another barrier was the design of programs based on the assumption (stigma also experienced with employers and the general community) that people with CP have cognitive issues and are therefore pitched to those with intellectual as well as physical disability.

### Research participant comments

*"They (SLES) are moulding to what we need them to be."<sup>1</sup>*

*"Connecting with the right services is largely a matter of luck."<sup>1</sup>*

*"Because I need a lot of physical support but am not intellectually impaired...there is not a lot out there for people like me."<sup>1</sup>*

*"Group sessions are often targeted to people with intellectual disability...I didn't get as much from the group ones."<sup>1</sup>*

## Work Search

**Disability Employment Services (DES)**, not surprisingly were seen as effective when employment outcomes were successful<sup>1</sup>. For those with CP, this often rested upon Disability Employment Service providers' knowledge about the condition and how best to identify the right type of role to meet applicants' physical requirements whilst showcasing their strengths<sup>3</sup>. Positive experiences were with DES personnel who took the time to learn about the individual's needs, skills and interests and worked collaboratively with the applicant to achieve effective outcomes<sup>4</sup>.

An example of a beneficial experience with a DES was with a case manager who also had CP and understood its impacts and was therefore better placed to make appropriate recommendations for their client<sup>3</sup>.

The research also identified examples of effective outcomes when Disability Employment Services worked in partnership with employers and/or suggested other work readiness skills development<sup>1</sup>. When focussed on the interests of individual, partnerships were more likely to operate as a joined up or seamless ecosystem of support.

Disability Employment Services were considered ineffective when their services were not person-centred<sup>1</sup>. Themes in reports of sub-optimal experiences with Disability Employment Services were<sup>3</sup>:

- Poor understanding of disability
- Lack of understanding of interests and skillsets of applicant, often as a result of making assumptions about what they want and need
- Putting applicants into short courses which were often irrelevant to applicant interest and skillset when they were unable to secure employment
- Staff that are ill-equipped, inexperienced or lack interest<sup>4</sup>

While personal experience of candidates around Disability Employment Services and Career Agencies were many and varied, there were many suggestions from our research participants on how the services could be improved.

Suggestions, which are listed below, mostly centred around coordinated education of staff, promotion of services and the need to fill more positions in agencies with staff with lived experience of disability<sup>3</sup>.

### Research participant comments

*"Improve the profile and funding for advocacy and affiliation and actions from Disability organisations"<sup>3</sup>*

*"Use Government funding, and taxpayer funding, for public campaigns, advertising, and higher profile interviews, postings with people who have success, their stories. Represent the people with CP"<sup>3</sup>*

*"Front line advocacy from general organizations"<sup>3</sup>*

*"RecruitAbility scheme helps (govt)"<sup>3</sup>*

*"More information to inform of resources out there, i.e DES providers, I had no idea these places were out there, normalizing the fact that being unemployment just happens, it's not something to be ashamed"*

*or embarrassed about. A DES who understands the disability I have, my case manager DES, Had CP as well, having a provider understand is important”<sup>3</sup>*

*“DES should support individuals trying to develop their own business as well as placing people in the workforce”<sup>3</sup>*

*“Employment services being available regardless of if you have a job or not”<sup>3</sup>*

*“The under-utilisation of people with disabilities in the workforce is clearly a multi-faceted issue and addressing it will require significant shifts and changes in policy and ethics on the part of government, tertiary education and training institutions and employers. Advocate, advocate, advocate!”<sup>3</sup>*

**Advocates** were a valuable resource for many exploring employment opportunities and therefore are a part of a complete and joined up ecosystem of support. These could be other people with disability who had successfully gained employment sharing their experiences, professional services such as career counsellors or employment services, and family, friends, and mentors<sup>3</sup>.

Choosing if and when to **disclose their disability** to a potential employer was a way of exercising control for some<sup>7</sup>. However, a consistent finding through the research was the belief, based on experience, that an applicant’s application would not be considered in a fair and unbiased manner if they did disclose. The research indicated this was more keenly felt by those with CP who were ambulant<sup>3</sup>. As a result, many applicants made strategic decisions about when and if to disclose their disability in the application process<sup>1, 2</sup>. There were examples cited with online application processes for large mainstream employers, with online applications where applicants who had disclosed their disability received immediate rejections without explanation. Without any other obvious reason, the disclosure of the disability and immediate rejection led applicants to suspect that their disability was the reason and they had been subject to discrimination<sup>1</sup>.

Some felt that they missed out on a position after they disclosed their disability, or it was observed by the employer, even when it would have no impact on the applicant’s ability to perform the role<sup>3</sup>.

We note that there is also a potential downside to non-disclosure which is that applicants with disability may miss out on roles with employers who are actively seeking employees with disability as part of their inclusive employment goals.

### Research participant comments

*“I declared my disability on the online application form but it throws potential employers off”<sup>1</sup>*

*“If I leave it (my disability) off, I have got a 2nd and 3rd interview.”<sup>4</sup>*



## **Employment**

Many mainstream organisations have targets for people with disability and say they are inclusive, but not all “walk the talk”. Some don’t have any targets in place while others have targets but don’t implement practices to make these a reality. Research participants recounted experiences with potential employers at interview stage who were reluctant or unable to provide appropriate work environment or conditions<sup>1</sup>.

Some employers have a poor understanding of the physical limitations associated with CP including fatigue, which meant that there was also limited knowledge of ways these might be accommodated with shorter or flexible working hours and special equipment. Together with physically inaccessible workplaces, this was a significant barrier encountered in acquiring or remaining in employment<sup>2, 3</sup>.

Some applicants did not have the confidence and/or knowledge of the types of accommodations they could access. Some who did and raised their required accommodations were denied by the employer<sup>3</sup>.

A common experience for many (as noted above with respect to work readiness and transition to work programs and services) was an assumption that, if a candidate had a physical disability, then they must also have cognitive issues<sup>1,3</sup>. Furthermore, those with CP who are successfully employed found that decisions were still regularly made for them by their employer without consultation<sup>3</sup>.

Some applicants who had applied for roles with some components beyond their capabilities were able to self-advocate and arrive at mutually satisfactory solutions such as swapping tasks with another colleague and/or using adaptive equipment/techniques to complete tasks<sup>2</sup>. The need for self-advocacy highlights the value of building confidence and other skills needed in the formative years of all young people with disability who aspire to the workforce, irrespective of whether they are on the NDIS or not. Furthermore, over the longer term, reducing employer stigma and discrimination toward people with disability should reduce the need for, or reliance on self-advocacy to obtain fair outcomes.

People with CP who obtained employment reflected that there were several ways to prepare oneself to improve their likelihood of a successful appointment. CPSN has provided practical tips for self-advocacy in their employment journey guide resource for job-seekers with disability as a further support<sup>5</sup>. Preparations include self-awareness of passions and interests, support from close networks, external advocacy, career advice and mock interviews, and a clear understanding of transferrable soft and hard skill sets<sup>3</sup>. These all reinforce the importance of sound work readiness and transition programs in secondary school and early post-secondary years together with providers who understand and cater to their needs.

There were instances of positive experiences recounted by research participants with employers who provided workplaces and employment arrangements which incorporate the supports needed by an employee with disability<sup>1</sup>. These positive examples reflect employers who have a genuine commitment to inclusiveness and practice this commitment by providing flexibility and supports that are responsive to an individual’s needs and circumstances.

### **Case studies:**

- Accommodations provided for an employee with CP included a support person (funded under the NDIS) to assist with reading lengthy documents, taking notes and tasks requiring fine motor skills, flexible working hours and paid time for attending medical and other appointments to manage their CP<sup>1</sup>
- The manager of an outlet with a fast-food chain worked with a DES case worker to modify work tasks to suit the needs and capacities of a young person with mild intellectual disability. This involved induction and learning tasks at a slower pace than other employees, fewer hours per week and rostered on the same shifts as the manager who oversaw the employee, with the intent to build up in ways that suit the employee. This approach was described as job carving, whereby elements of a role are carved out to suit the individual<sup>1</sup>. It is also an example of a partnership between an employer and DES that worked together
- A young adult with moderate intellectual disability and hearing impairment had a three-week placement washing wheelchairs at an aged care facility, with his wage supported by government. The opportunity was identified through family after the failure to secure employment through a DES. The placement has evolved into more permanent employment with expanded tasks which now include supporting the maintenance manager, washing equipment, tidying storage areas and interacting with residents. The facility has adjusted hours and tasks in line with the employee's capabilities and preferences, particularly his desire for variety, and arranged for assistive technologies such as an app on his phone that converts written maintenance instructions to speech so that his low functional literacy is not a barrier to performing tasks<sup>1</sup>. This approach illustrates the 'place and train' approach versus the traditional 'train and place' approach discussed by Kavenagh et al<sup>6</sup> in their evidence review of strategies to increase employment and economic participation of people with cognitive disability. It is also an example of an effective role created to accommodate the employee in a sector experiencing workforce shortages

Some of our interviewees aspire to be employed, in mainstream roles, with service providers in the **disability sector** from an early age, while for others, it becomes an option over time. There were both pull and push factors at play in the choices to seek mainstream employment in the disability sector. Positive or pull factors included familiarity with disability services and desire to leverage skills based on their lived experience<sup>1,2</sup> as well as the altruistic desire to 'give back' to a sector from which they had benefitted<sup>1</sup>.

Push factors included negative experiences with mainstream employers and an assumption that the disability sector offers an inclusive and flexible work environment<sup>2</sup>. This assumption may not always be correct given the experience of one research participant with a disability sector employer who was unwilling to provide the necessary supports for a mainstream role.

Some choose the disability sector due to a lack of confidence and/or the belief that they will be accepted despite their disability, which stems from feeling the need to constantly prove themselves, or to work harder because they had a disability, and is seen as a common theme in the CP community<sup>3</sup>. Building self-belief in work readiness programs and inclusiveness in mainstream employment not only opens up the range of opportunities and better outcomes for people with CP, but also potentially reduces the sense that mainstream roles in the disability sector are a secondary option for some young people.

### Research participant comments

*"Early assumptions about a person's capability (or lack thereof) coupled with and unwillingness to look outside the box sets a very negative tone." <sup>4</sup>*

*"There is always discrimination with disability. I am sure I have been prejudiced against. My peers from school all got jobs. I applied for more than 25 and didn't get any. The only one I got was through a friend of my mum's" <sup>1</sup>*

*"Assumptions made by employees regarding capability including that a physical disability MUST indicate cognitive impairment therefore tasks assigned accordingly." <sup>3</sup>*

*"I am only happy to apply for jobs in the disability workforce now as they are mostly more accommodating and flexible." <sup>4</sup>*

*"My current employer is fantastic. I love my job. I have fantastic support." <sup>1</sup>*

## The NDIS

The NDIS was an important enabler when it supported young people to access to work readiness and transition to work services and programs, and funded supports that make employment accessible.

There were examples of where the services of therapists such as OTs or psychologists funded by the NDIS had a positive role in the journey to employment, particularly when they dovetailed with other work readiness transition to work programs, services and supports. Ways they did this included helping their clients to shape goals, suggesting courses, building self-awareness and belief, suggesting areas to research and/or identifying potential avenues to explore.

### Case studies:

- An occupational therapist funded by the NDIS who provided career guidance that was considered useful by the young person in contrast to that provided by a careers counsellor whose advice was based a view that did not incorporate input from their client<sup>1</sup>
- Funding workers to drive a young person to attend their SLES program<sup>1</sup>
- Funding for a support person in the workplace<sup>1</sup>

There were also perceived limitations of the NDIS, including that it is geared more toward major physical disabilities than non-physical diagnoses. It was also seen as less oriented to the needs of those with multiple disabilities by operating on the primary diagnosis and not taking account of secondary or tertiary diagnoses.

### Research participant comments

*"The NDIS can help break down the barriers." <sup>4</sup>*

*"The NDIS makes accessing programs a lot easier." <sup>4</sup>*

*"The OT/speech therapists funded through the NDIS have helped...they put in a lot of hard work." <sup>4</sup>*

## Parents & families

A complete and joined up ecosystem of support for Australians with disability in relation to work readiness, transition to work, acquiring and maintaining employment should incorporate availability of the right mix of natural (parents and families) as well as paid support<sup>7</sup>. A recurring theme in the research feedback from young people and parents was that the role of parents and families can be critical if journey to employment pathway is to be successful<sup>1,2</sup>.

The positive parental/family role, particularly for young people involves providing moral support, confidence building, encouragement and education, and practical support in terms of goal setting, identifying and accessing programs and supports and finding ways around or through barriers. It also involves stepping back as the young person becomes more independent.

Family contacts and networks often come into play as back-up when the system failed. Opportunities in work transition such as volunteering, part-time work or casual work in secondary years and post-education employment opportunities were often identified through family networks and personal contacts. The aged care sector employment example cited above illustrates this point.

On the flipside, parents/families who were unwilling or unable to provide supports and/or had low expectations present significant barriers to effective work readiness and transition to work<sup>7</sup>.

**Case study:** A research participant who is eighteen years old, has intellectual disability and mental illness and whose parents were not able to provide support for a range of reasons. While she has some extended family support, she appears to be largely reliant on her own resources, has limited access to support programs and services beyond a public health psychiatrist, won't apply for the NDIS because she fears rejection and feels daunted by her prospects. Arguably, the absence of sound family support substantially contributes to her overall sub-optimal situation and may affect her opportunities to achieve great outcomes over the longer term.

### Research Participant comments

*"Mum always does my research. She is my everything."*<sup>1</sup>

*"My parents have been a huge help. I have great parents."*<sup>1</sup>

*"Dad is helpful...but not about work. Mum has severe mental health issues and is not in a position to help."*<sup>1</sup>

## **Improvement Opportunities**

The following recommendations are a direct result of the research conducted with young people with cerebral palsy. These improvement opportunities relate specifically to people with cerebral palsy but may also be applied more generally – however that is not within the scope of this paper.

It is recommended that the NDIS acts on the following recommendations, working with participants, families, circles of support, providers and employers to co-create better long-term outcomes within an integrated and complete ecosystem for young people with cerebral palsy.

- Strengthen foundational work readiness programs in secondary school and making them universally available, irrespective of whether young people are in the NDIS or not.
- Incorporate volunteering and work experience in secondary and post-secondary programs given their benefits in providing practical experience to complement hard and soft skills development. Volunteering and work experience are also ways that people with disability can connect with the community and can lead to better long-term outcomes.
- Identify how mentoring programs involving peer-to-peer mentoring and role modelling can be more broadly applied for people with disability who seek employment.
- Identify the extent to which the barriers associated with multiple disabilities and physical versus intellectual disability reflect systemic limitations or failures. Develop policy responses with respect to the NDIS and more broadly.
- There is still progress to be made with respect to employers' attitudes, workplace culture and institutional barriers to inclusive employment. This finding reinforces the need for, provides evidence for strengthening ongoing initiatives to educate and motivate employers to improve their recruitment and employment policies and practices.
- Identify and implement opportunities to communicate the positive examples of flexibility and commitment demonstrated by some employers – show what is possible and how motivation, creative thinking and person-centred approaches can have effective outcomes for employers as well as employees.
- Develop policies and other ways of motivating employers in sectors such as aged care that are currently experiencing workforce shortages.
- Identify ways that partnerships between schools, employers and DES providers can be fostered, given the evidence presented in this paper of the role of partnerships in the effective delivery of work readiness programs and employment opportunities.
- Parents should be included in the debate, formulation of improvements and supports. They play a pivotal role for young people embarking on pathways to employment and are critical in navigating barriers and improving outcomes. Their lived experience can be a source of learning and more effective policy.



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## **Source Documents**

1. Reflections Research, 26<sup>th</sup> July 2023, "*Work Related Research Report*" Prepared for Ability First Australia
2. CPSN (Cerebral Palsy Support Network), 10<sup>th</sup> August 2022 "*Employment Strategy: Preliminary Data Findings Draft 3*"
3. Sue Harris, CPSN (Cerebral Palsy Support Network), October 2022, "*Employment Experiences of People with CP*"
4. CPSN (Cerebral Palsy Support Network) Human Rights Committee, "*Employment and the CP Experience*"
5. CPSN (Cerebral Palsy Support Network), CPA (Cerebral Palsy Alliance), "*The Employment Journey Guide for People with CP: My CP Guide*"
6. Kavanagh A, Brown D, Dickinson H, Mallet S, Marck C, Weld-Blundell I (2022) "*Evidence Review: Strategies to increase employment and economic participation for people with a cognitive disability.*" The University of Melbourne
7. Cadeyrn J. Gaskin, Christine Imms, Gavin R. Dagle, Michael E. Msall, and Dinah Reddihough (2021) "*Successfully Negotiating Life Challenges: Learnings From Adults With Cerebral Palsy*" Qualitative Health Research 1–18, [journals.sagepub.com/home/qhr](https://journals.sagepub.com/home/qhr)