YOUTH DISABILITY
ADVOCACY SERVICE

Productivity Commission
GPO Box 1428
Canberra City ACT 2601

To the Productivity Commission,

Re: Inquiry into a Life-time Disability Care and Support Scheme

“We all have a right to freedom and for people with a disability that’s getting the support we need to do what we choose to do” Samantha, 25

The Youth Disability Advocacy Service (YDAS) is a Victoria-wide advocacy service of the Youth Affairs Council of Victoria. YDAS is funded by the Victorian government to provide individual and systemic advocacy for young people with disabilities between 12 and 25 years of age.

In preparing this submission, YDAS consulted with a range of young people with disabilities. We asked young people about their experiences as recipients (or potential recipients) of disability care and support and what aspects of the current system they believed most needed to change. We have identified and illustrated some of the major issues experienced by young people with disabilities and their families under the current system and outlined ways the disability care and support system needs to be reformed.

In summary, with reference to a new life-time disability care and support scheme, YDAS recommends the following:

1. **The Australian Government implements a new, comprehensive, life-time support scheme for people with disabilities.**

2. **This new scheme should provide supports for everyone who is born with or acquires a disability before the age of 65, regardless of the cause of their disability.**

3. **People with disabilities should remain eligible for supports under the scheme across their lifespan.**

4. **There should be a focus on early intervention and supports to facilitate life transitions.**

5. **Supports and services should be individualised, flexible and adaptive to peoples changing needs, choices and circumstances**

6. **Supports should be timely and comprehensive. People should be able to access all the supports they need, when they need them.**

7. **Assessment processes should be transparent, respectful and easily navigated.**

8. **Eligibility for supports under the scheme should not be subject to means or asset testing.**

9. **Funding arrangements within the scheme should be flexible, individualised and controlled, to the extent that is desired, by the person with a disability and/or their family.**

10. **Key areas in which support should be provided under the scheme include:**

- **Aids and Equipment**
- **Personal Care**
- **Allied Health**
- **Preventative Therapies**
- **Community Access**
- **Leisure and Recreation**
- **Home and Vehicle Modifications**
- **Assistance with Transport**
- **Employment Support**
- **Sexuality and Relationships**
- **Support for lifelong learning and**
- **Mental Health Services**

11. **Significant workforce issues need to be addressed including particularly those related to the provision of reliable and flexible attendant support.**

12. **There should be an independent advocacy program which exists to protect and promote the rights and interests of people with disabilities and their families who are recipients, or potential recipients of supports under the scheme.**

1. The necessity to implement a life-time care and support scheme for people with a disability

A life-time care and support scheme is a necessary entitlement for people with disabilities in Australia. Such a scheme is desperately needed to enable people with disabilities to contribute as active and valued citizens and facilitate our full economic, social and cultural participation. Providing timely, on-going, individualised support across the lifespan of a person with a disability would address the significant disadvantages, inequality and unmet need that exists in the current system. The guaranteed provision of personalised, consumer controlled support would contribute to a vital sense of empowerment, control and personal security for people with disabilities, families and carers.

Having ratified the United Nations Convention on the Rights of Persons with Disabilities (including its optional protocol) in July 2008, the Australian Government now has a legal obligation to protect and ensure the rights and equal participation of people with disabilities in all aspects of Australian life. Providing a life-time of comprehensive supports under the Scheme would be a significant and necessary means to realise the rights and freedoms outlined in the Convention and would achieve far greater equality for people with disabilities.

2. A new scheme should provide supports for everyone who is born with a disability or acquires a disability before the age of 65, regardless of the cause. Those who are living with a more severe disability should be entitled to more support, however there should be some entitlement to support for all, based on level of need.

Currently, there is often considerable discrepancy in terms of the amount of support that people are entitled to, depending on the cause of their disability. For example in Victoria, someone who acquires their disability in a traffic accident is likely to be entitled to comprehensive long-term supports and services. In comparison, someone who sustains the same injuries through a non-compensable occurrence, such as a stroke or congenital disease, is faced with waiting lists and an inadequate service system where they are unlikely to receive the supports that they need.

YDAS would like to emphasise the need for a fair system which allows all people with a disability to be able to access the supports they need. However, we would also like to stress that the with introduction of a new scheme, no-one who is currently receiving supports and services under existing schemes (such as the Transport Accident Commission Compensation Scheme) should be ‘worse off’. Regardless of whether a new scheme replaces existing avenues for compensation or exists alongside them, no-one who receives support under an existing compensation scheme should have current supports or entitlements reduced.

3. People should remain eligible for supports under the one system over their lifetime.

The benefits of a lifetime support scheme are significant. It would allow people to ‘age in place’ and maintain their existing support networks and lifestyle. Furthermore, it would facilitate continuity of support provision which is important for well-being and quality of life. It is likely that throughout life, the person with the disability will have developed strong informal support networks and effective means for meeting their support needs. This should not jeopardised by forcing the person into aged care.

Current lack of support continuity across the lifespan for people with disabilities

Currently, many aspects of disability support are fragmented and there is a lack of service continuity. There are changes in what supports and services can be offered to people with disabilities across their lifespan, (for example, as they move from secondary school to university, after they reach a certain age, or once they are living independently from parents) This creates stress and uncertainty for young people and families and many people face the very real prospect of having necessary supports withdrawn because they no longer meeting some arbitrary criteria for eligibility.

> ***“When I was at primary and high-school my integration funding paid for physio and I was able to have this regularly. Now I can only have it irregularly because my family can’t afford it and (now that I am at University) I am no longer able to get this paid for”.***
>
> ***“Bits of services coming in and out. They do their bit and go. You need things that are on-going to be worthwhile”.***

Lack of service continuity makes it extremely difficult to successfully plan for new stages of life and is detrimental to the ability of the young person and their family to feel confident about the future.

> ***“I wouldn’t want to move out of home because I would need 24hour support and my parents are too good (at supporting me) . If funding was unlimited it would be a maybe.”***
>
> ***“Yes there is a real problem, every system is different, primary, secondary, university, then TAFE and now work.”***
>
> ***“Up till now, we have been doing quite well in terms of supports, but I don’t know what kind of road bumps we are going have when I leave school – it’s scary”.***

Young people and families should have consistent, clear and accessible information available to them (in a range of accessible formats) about what supports and services are available to assist them. This information should be provided *pre-emptively* where it would help young people and their family make good decisions about new stages of life such as commencing university, getting a job or moving out of home. People with disabilities should not be subject to losing supports because they move to a new stage of life, rather supports should be there to facilitate life transitions.

Provision of supports for the person with a disability in later life is also important. Being able to age ‘in place’ and continue to have supports provided under the one system, (rather than having to transfer to an aged care support system) would be essential to promote continuity of services and supports and create greater security for the person with the disability and their family.

4. There should be a focus on early intervention and supports to facilitate life transitions such as getting a job or moving out of home.

YDAS strongly supports the need for effective early intervention measures to be provided as part of the scheme, these should be flexible and individualised. The wishes and needs of families and children with disabilities should remain central to all early intervention processes. Timely and accessible information should be provided about the range of interventions and services that are available and how and why they may be beneficial.

> ***“I think services should tell people much more clearly what they are entitled to. This would be one of the best ways for me to find out what services I can get”***

Counselling and mentorship, (both for the young person and family) should be available as a central part of early intervention and as an on-going support. Intervention should include a central person who has a holistic understanding of the young person and their family situation and can provide on-going guidance and support.

Early intervention is crucial in picking up difficulties relating to a persons disability and finding ways that families and young people can manage these. Establishing effective supports and strategies early helps build a child’s self confidence and allows them to move forward to reach their potential.

> ***“A learning difficulty does not have to be a big deal but without the early intervention – it can become (a) “severe” (disability). Debilitating actually”.***
>
> ***“If I had had early intervention – I don’t think I would suffer from the anxiety that I have (now) that voice in my head that says you are really pretty dumb and you are doing everything wrong. The system tells you directly and indirectly that you are no good it constantly hits you down.”***
>
> ***(With more early intervention) “I would have been a lot more ready for further education and employment. In early TAFE I was playing catch-up. At the same time as trying to learn the course I was learning how to use adaptive software, literacy skills, etc.”***
>
> ***“I was diagnosed at TAFE! (With a learning disability). Lucky I was stubborn. I’m sure there are people who give up before they get to TAFE!”***

> ***"I had a scribe during year 12, you had to have a test to have that scribe, but they never told me I had dyslexia. They just put me in the dumb class all the way through primary and secondary school."***

5. Supports and services should be individualised as well as flexible and adaptive to peoples changing needs, choices and circumstances

YDAS strongly believes that supports for people with disabilities should be individualised and flexible and enable them to work towards achieving their goals and living the life that they want. Victoria has been most progressive in moving towards an individualised model for the delivery of disability supports and we would like to recommend that supports under a new scheme are developed **according to a similar model**.

New individualised support arrangements in Victoria mean that disability services funding is allocated to each person with a disability for support to meet their disability-related needs. Funds may be used to buy a range of supports that are chosen by the person. An individualised planning process is undertaken to help the person and their family to consider how they may want to spend funding and what supports they want to access. Unlike previously, where funding has been allocated to service providers, funding is attached to the individual, meaning that people with disabilities can 'shop around' for services that best meet their needs. We strongly urge the Commission to examine the disability service reforms that have taken place in Victoria (specifically, the Individual Support Package Guidelines).

Enabling people with disabilities to choose the services and supports they access would create a new accountability to people with disabilities as service users and provide a significant incentive for service providers to offer better-quality services. Adoption of an individualised model also allows for services and supports to be offered in innovative ways and for young people to use their funding for things that are not 'traditionally' considered disability supports, but are the best services to meet their needs. Preventative healthcare services (such as Chiropractic care and massage) are just one example of a 'non-traditional' disability support services, now accessed by some people with disabilities in Victoria as part of their individualised support package (ISP).

> ***"My massage and osteopath (treatments) are covered by my ISP. "This makes moving around easier, I am not in so much pain. If that stopped, it would be a real crisis in terms of my pain and not being able to move around as freely".***

Meaningful and flexible supports for people with disabilities

Young people made the following comments about the importance of meaningful, flexible supports and having control over these:

> ***"I am with a good day service and they mostly let me choose what I want to do. I have good communication with Marcella (day program Manager) and I can tell her***

> ***if things are not working. Marcella and I have a good rapport they are open to feedback and changing things if they are not working for me.”***
>
> ***“They (day service staff) are in support of the career development I want to do – they are happy to support me in doing my public speaking. The service is helping me to develop a website for my public speaking and they help me with my speech writing. They are behind me doing the things I love and especially because it is also helpful of the community.”***
>
> ***“The more control you have over things, the better”.***

Frustration was expressed when supports were seen as inappropriate or tokenistic and not helpful for young people in reaching their goals.

> ***“It seems at the moment DHS are trying to get me into a day program, which I think I would be bored, and seems like the easy way out. You don’t learn anything, you just play games, and do things that don’t help you learn real things.”***

6. Supports should be timely and comprehensive – people should be able to access the supports they need, when they need them

Under a new scheme, people with disabilities should have timely access to the supports they need. In particular, people should be entitled to a sufficient amount of paid attendant support and young people and family members should be able to access respite when needed.

The costs of all aides and equipment that are needed on account of a persons' disability should be covered *in full.*

An entitlement to these basic services and supports would curtail the considerable physical, financial and emotional stress that is currently being borne by families and/or people with disabilities themselves.

> ***“We’re applying for more funding through the Disability Support Register and have found that it is a long process. We applied for extra personal care funding at the start of the year and we have not heard back yet. I need an increase of 28 hours a week (attendant support). I’m getting married in Feb next year and want to have everything in place before then.”***
>
> ***“Everything just happens way too slowly. It took over 2 years from when It became pretty clear I needed a motorized wheelchair to when I finally got one and then yet longer to get transport training. This held me back unnecessarily from gaining personal freedom and greatly impacted on my self-confidence."***
>
> ***“I have been told that it might take up to 4 years or longer just to find accommodation, and that they can’t just stick me anywhere. I know they can’t just stick me anywhere, but I am sick of waiting and really had enough with the time it takes to get things done just because I have disability.”***

Insufficient entitlement to paid attendant support and lack of respite

Not being entitled to a sufficient (or, in many cases, sufficiently flexible) paid attendant support was a common concern of young people with disabilities, that often leads to an unsustainable reliance on informal support from family. In the majority of situations, particularly where the young person has high support needs, family members continue to provide an immense amount of care and support for the young person with the disability.

Young people spoke about the many issues this created for them, including the compromise to their independence and the development of unhealthy family dynamics. As evidenced with some of the advocacy cases YDAS has undertaken with young people, lack of attendant support can also mean that a persons ability to get on with even the most basic tasks in daily living (for example getting out of bed or going to the bathroom) is compromised.

> (Not having enough attendant support hours means that) ***"my parents have to take up the slack in taking care of me. They have been doing this for 20 years and it has had a negative impact on them."***
>
> ***"I pay for attendant support for an outing once a fortnight or so. This is at a cost of $100 -$200, Just for an evening out. If I was living on my own and surviving on the Disability Support Pension I would not be able to afford this I would need to prioritise basic living costs like food and rent."***
>
> ***"Sometimes you don't have enough hours. Sometimes you want to be able to go out with friends and you can't because you have already used up your allotted hours."***
>
> ***"There is annoyance there – that I have to rely on (my parents) so much. I'm 25 now and I should have an adult relationship with my parents, but I don't, it feels like a patient/carer relationship – not what other 25 year olds have!"***
>
> ***"I would be worried if dad wasn't around to assist. if I decide to move back to SA, while I have friends there, I have no family, or anyone there I feel could assist me."***
>
> ***"We all need to have a life independent from our families, some privacy from our loved ones. Plus families shouldn't have to carry the burden of care."***
>
> ***"I call on my parents (now) but I won't be able to do that for the rest of my life because they won't be able to do it for the rest of my life and I won't want them to. I wouldn't want to sit in my own apartment that I am sharing with someone and call my parents and say hey mum, can you come and get me out of bed because I haven't got a carer today. "***
>
> ***"I have a fight with one of my parents and then five minutes later I have to ask them to help me have lunch."***

> ***"It would make me happier doing what other 18 year olds do, and not just being stuck in the house, and not getting to seeing new things. Other 18 year olds wouldn't be just stuck at the house like I am most of the day".***

Lack of respite was also highlighted as a particular issue for parents, carers and young people with disabilities, particularly those in rural areas.

> ***"I've never really used respite services – takes time to arrange it. There should be 'spontaneous respite' services that can be arranged quickly."***
>
> ***"Family emergencies are a huge issue for me and something that I think of often. There needs to easy and quick access to extra funding when needed to assist during a family emergency"***

A new scheme should be adequately funded to provide sufficient attendant support. This would assist the young person to have an active, high-quality of life in their community.

Unmet supports and services costs currently absorbed by families of people with a disability

People with disabilities/families often have significant out of pocket expenses for various supports, and equipment. This financial burden generally comes about due to funding caps, or families being forced to purchase equipment outright, when long waiting lists became untenable.

> ***"My family have had to access two different buckets of funding to be able to afford the chair I need and will have to cover a significant gap in funding. I am still waiting for the new chair and am in more pain now because the current chair is no good."***
>
> ***"I can only access funding for a new chair every seven years it needs to be sooner than this."***
>
> ***"Most of the money that pays for the chair comes out of family pockets anyway, the funding I get does not cover the chair I need."***
>
> ***"I have to go private for my psychology sessions - that's $260 for first session and follow-up sessions are $160. I also access massage therapy which I have to pay for myself."***
>
> Financial hardship is a reality for many young people and families
>
> ***"I have absolutely no money left at the end of the week. I pay for food and medical bills and that is it."***

7. Assessment processes should be transparent, respectful and easily navigated

Assessment for support under the scheme should not be unnecessarily intrusive or repetitive. Where a condition is expected to remain stable, assessment should not need to be repeated unless the person with the disability or family acknowledges changes to their needs or circumstances. People should be able to request re-assessment if they have a change in their life circumstances or to gain the supports which will facilitate a life transition.

Assessment should not be about having to 'convince' assessors of a persons need and portray the person with the disability or their family situation in as dire state as possible in order to 'prove' the need for support. Assessment should recognise people with disabilities and families as experts on their conditions, circumstances and the supports and services they need. It is important that people with disabilities and families have a good understanding of the assessment processes. This can be enabled through the provision of accessible information and clear communication about assessment processes and outcomes.

Where an individual's disability may undergo change – degeneration or improvement, reassessments and reviews should be available as needed. Where family or the person with the disability does not agree with an aspect of assessment, there needs to be an accessible, effective and transparent appeals process available.

8. Eligibility for the scheme should not take into account peoples income and assets

People who receive supports under the scheme should not have their entitlements effected by their income level or assets. Means testing would create both a barrier and disincentive to participation in the workforce. Many young people with disabilities, like other young people view employment as an important part of their lives and many aspire to achieve success in their chosen careers. Means testing of the support scheme will result in a perverse conundrum for people with disabilities who will fear losing their supports if they earn a decent income and become successful in their employment. Asset testing will also make it difficult for young people to save which is essential for future planning, especially with increasing costs of accessible housing.

> ***"It definitely should not be means tested. Although we are making money we still have more costs than the average person, just so we keep fit and well."***
>
> ***"No, I shouldn't be means tested! If a person with a disability gets into a really good job – then they should be able to earn good money and not worry about loosing supports. Means testing would be basically holding you back. I shouldn't be punished because I am good at a job."***
>
> ***"What we need is equality, if able-bodied people don't have to pay the costs for a disability why should we have to? It would discourage us from become a valuable***

> ***part of the work force if anything we manage to earn just disappears into our disability needs."***

9. Funding arrangements within the scheme should be flexible, individualised and controlled to the extent that is desired by the individual and their family

Funding administration options under the scheme should include the full spectrum of control to enable people with disabilities to access the level of assistance and/or independent management of funding that they desire. Where a young person or their family want to have more control over funding and supports, they should have access to information and support that would enable them to do this. Options should include a financial intermediary model, as well as direct payments, where people with disabilities can have maximum control over their own funding and service arrangements.

Accountability guidelines need to be clear and accessible and not onerous. Appropriate support with respect to accountability processes also need to be available. These things will be necessary to enable the successful operation of these varied funding arrangements.

> ***"Whenever I have requested changes to my Individual Support Package, I have only had to ring them up."***
>
> ***"I can choose where I want to spend money on supports – having that choice is handy."***
>
> ***"You might not want to take control of your funding, but you should have the option if you want to."***

10. Key areas in which support should be provided under the scheme

Reflecting the generally broad impact of having a disability on a person's life, the range of services provided within a life-time care and support scheme should also be comprehensive, including supports in the following areas:

- Aids and Equipment
- Personal Care
- Allied Health
- Preventative Therapies
- Community Access
- Leisure and Recreation
- Home and Vehicle Modifications
- Assistance with Transport
- Employment Supports
- Sexuality and Human Relationships
- Support for lifelong learning
- Mental Health Supports

YDAS would like to highlight some specific areas of service gap that need to be addressed as part of a new Lifetime Disability Care and Support Scheme. What has been outlined below certainly does not constitute all ‘service gaps’ that should be addressed in the scheme, however, we have touched on the areas below because they have particular relevance to young people with disabilities and/or feel some of these issues may not be highlighted in other submissions.

- **A new scheme should include increased access to physiotherapy and occupational therapy assessments and services. Allied health professionals need to have a better understanding of issues faced by people with disabilities**

There are often long waiting lists for allied healthcare services such as occupational therapy (OT) and physiotherapy. People with disabilities need to be able to have access to therapy assessments and services when needed, particularly as they are often a means of discovering underlying issues or determining eligibility for equipment. Allied health professionals (including OT’s and physiotherapists) need to have a better understanding of the issues related to various disabilities.

- **Mental health professionals need to have a good understanding of the issues faced by people with disabilities and the difficulties associated with specific disability types. Professionals in the disability services field to have more awareness of mental health issues**

Mental health issues are a common experience for many people with disabilities. Young people spoke about a double-bind that saw them rejected from mental health services, which were ill-equipped to support their needs in relation to their disability and then turned away from disability services because they were ‘too unwell’ to be taking part in various programs or crucial support planning.

> ***“I am having some mental health issues and really need some supports. But my plan was put on hold because of mental health issues. The disability agency said I was too unwell to be supported by them – Psych services said that they did not have expertise in disability”.***

- **Supports for people with disabilities to express their sexuality**

The sexuality of young people with disabilities has traditionally been ignored (and often, any form of sexual expression discouraged). A new scheme should support and acknowledge the right of people with disabilities to sexual expression. There needs to be more avenues available for people with disabilities to get support to express their sexuality in ways that they choose.

- **Occasional/flexible daytime support services for teenagers and young people with disabilities**

Currently there is a lack of flexible/occasional daytime supports available for people with a disability, particularly before and after school hours. A range of ‘day services’ are available, however this type of support is generally offered as an on-going placement. There is a need for more flexible programs that can be accessed occasionally, such as on weekends, student-free days, as well as before and after school. Such programs should operate to hours that would be useful for parents who are working. These placements should provide a range of care and supports that may need to be utilised by people with various disabilities, as well as a range of activities that would be enjoyed by teenagers and young people.

- **Improved supports in education for people with disabilities. Education supports that should be well-planned, comprehensive and on-going and are in line with a young person's needs as well as educational and vocational goals**

Like in other areas of life, supports offered to people with disabilities throughout their education should be individualised and centred on the needs, wishes and educational/vocational goals of the young person. Planning for young persons support needs in education needs to occur early and support provision needs to be flexible and *on-going* throughout primary, secondary and (where applicable) tertiary education. Young people with disabilities should not be 'forced' to attend a special school setting because they are unable to access appropriate supports in a mainstream school. Through better links with mainstream schools, educational opportunities in a special school setting also need to be improved.

> ***"TAFE was too difficult due to lack of carers, no one was around for assistance with nutrition and toileting. I went to a special school though I didn't have many friends and the educational side wasn't very good. If it were up to me I would prefer to go to the local mainstream school but didn't have the supports."***

Specific recommendations related to supports in education

Based on the feedback from the young people we consulted, YDAS would like to recommend a number of additional education related supports in under a new scheme.

- Additional training for teachers in supporting students with Autism Spectrum Disorder and Learning Difficulties. Including training for teachers in recognising the behaviours/difficulties associated with these conditions.

- A range of remedial supports for students to assist with areas of difficulty associated with their disability such as maths, reading, social skills etc as well as training in the use of adaptive technology where this is applicable.

- The consistent implementation of learning plans for students (such those who have learning difficulties) who may benefit from these. Such plans should be developed in partnership the student with the aim of creating a sense of empowerment for the person they are designed to assist. As well as providing clarity and direction for the implementation of useful, comprehensive and timely supports.

- More funding for integration aides.

- Access to counselling and mentorship for people with disabilities including training for student welfare officers in supporting students with a disability.

- More provision of interpreters in schools, TAFE's and Universities. Including provision for these students to access university extra-circular activities such as workshops and social events and student support services, such as counselling and career guidance.

- Live remote captioning provided at University for people who are deaf and hard of hearing (where a Stenocaptioner records lectures and this is made available electronically for deaf and hard of hearing students).

- The provision of flexible and individualised attendant support at University and TAFE for students with a disability. People providing attendant support at Universities or TAFE should be able to perform a range of duties to support students' needs. Including personal care and study related support.

  "All the uni supports worked well because they were comprehensive and complementary. I had a note-taker, I was taught to use assistive technology, there was some work on my literacy skills and I had some mentoring through the NDCO project. It wouldn't have worked to have just one or two of the supports I had".

- **Improved employment and pre-employment supports for people with disabilities. These supports should focus on young people with disabilities gaining skills and preparing for, finding maintaining meaningful work**

As for the rest of the population, it is very important for young people with a disability to be able to find and maintain employment. Although some employment supports for people with disabilities are currently provided, performance measurement and funding allocation that is based on placing clients in 'a job' (in many cases, 'any job') results in many people with disabilities being pushed towards work that is not in line with their skills or interests. YDAS would like to advocate for more individually tailored pre-employment and employment supports under a Life-time Disability Care and Support Scheme that will assist young people with disabilities to find and maintain meaningful and fulfilling employment and pursue their employment goals.

Specific recommendations related to supports in employment and pre-employment

YDAS would like to recommend the following in relation to employment supports under the scheme:

- More on-the-job supports should be provided for people with disabilities, these should be available on an on-going basis for the person with the disability *as long as needed*.

- Effective career counselling needs to be available offered for young people with disabilities who access disability employment providers.

- There needs to be more supports for people with disabilities to undertake employment-related activities such as volunteer work, work experience, training and apprenticeships.

  "I did an Industry-Based Learning placement at University it helped me set my sights high and feel like I was able to work for somewhere like ANZ – where I am now. Work experience was crucial in terms of my beliefs about what I could do for work in the future – it was life-changing! Luckily I had some supports to find this. Uni was very helpful in working to help me find workplaces that were accessible. I sat down with the Uni and employer I told them what some of my disability related needs were they were very receptive."

  "It's not very easy for anyone, let alone people with disabilities to find jobs. If there is good supports for people disabilities to get work experience, that is such a good start."

- Employment support providers should have training in recognising people with disabilities who may be dealing with undiagnosed learning difficulties. Providers should have good links with assessment centres where young people can be diagnosed with learning difficulties and access related supports.

- People with disabilities should be able to access flexible, reliable attendant support for work settings. These people should be able to perform a range of work-related support duties as well as attendant support duties.

  "I want to have a career in film or TV but the hours are irregular. I worry about how this will fit in with getting supports. …..The workplaces are unlikely to be able to pay for carers."

  "People often end up working in the disability sector (because employees are more accommodating of support needs)– I am thinking about going into that field – but this is more about getting my (support) needs met."

11. Significant workforce issues need to be addressed including particularly those related to the provision of reliable and flexible attendant support.

Young people with disabilities raised a number of concerns related the characteristics of the disability care and support workforce:

- It is extremely important for young people to be able to access support from people who they can relate to and feel comfortable with.

  "They are helping us with very personal things, becoming part of our personal life. It's so important that we can choose and trust who's working with us to have any quality of life."

Many young people prefer support workers who are of a similar age to themselves, (especially when support was being provided for social outings). It is not always easy to find younger support workers as many employees currently in the workforce are of an older age.

"I had issues with the Council sending older carers even when I had told them that I didn't want (older people supporting me)."

- Increasingly stringent Occupational Health and Safety regulations are having an impact on the provision of care for young people. They indicated it is becoming more difficult to find carers who are willing/allowed to perform all tasks related to their care and support.

  "What is the point of having a carer from the Council if your parents aren't getting a break because they are having to do the transfers?"

  "I had four assessments for manual lifting in two years. Once instance they would say 'yes, I can do the transfer' and the next instance no I can't"

"There are a lot of crazy rules for things carers can't do – this creates real problems for me."

"One of my carers agency does not allow her to give medication, change dressings or cut toenails."

- The shortage of people in the disability support field was also impacting negatively on young people.

  "I don't feel like I have enough control over which carers we employ because there is such a shortage of carers. If you feel like you have choice – it decreases anxiety about having to employ a crap carer."

  "The problem is that they don't have many (carers) to cover (vacant shifts) if one goes away, say for holidays. My dad covers the shifts if they cant find anyone."

  "It's hard to get carers to go away for a weekend, without them I can't really do anything. I want to be staying out later and not have to rely on my parents to put me to bed."

Specific recommendations relating to the disability support workforce

Based on input from young people with disabilities YDAS would like to recommend the following in relation to the disability support workforce:

Support staff who assist young people with disabilities should be:

- Someone who was chosen by the young person with the disability.

- Subject to the young persons/family/carers feedback and comments about the ways they are providing support or how this may be changed or improved.
- Flexible in the ways they provide supports and able to provide assistance when and how it is required (although not to be detriment of their own health and safety).
- Dependable and skilled in providing supports, as directed by the young person.
- Able and willing to communicate with the young person (about their needs and wishes and more generally).
- Committed to enabling and supporting the young person with the disability.

YDAS would also like to highlight the following:

- Being able to decide who provides personal support should be seen as a fundamental right of a person with a disability who has direct support needs.

- Individualised funding with the option of direct employment arrangements are necessary for young people with disabilities to have maximum control over who provides their support.

- More needs to be done to attract younger workers to the field of disability support.

- Support workers need to receive higher rates of pay however this should be accompanied by increases in support funding for people with disabilities so they are not effectively ‘penalised’ for this increase.

- Formal qualifications should not be a requisite for people to work in the industry. Positive attitudes towards people with a disability should bare greatest weight in choosing candidates to work in the disability field.

12. The need to establish an independent advocacy program which exists to protect the rights and interests of people with disabilities and their families who are recipients, or potential recipients of supports under the scheme.

YDAS strongly supports the establishment of an independent advocacy program that can be accessed by all those who are eligible for supports under the scheme. This program must be funded and operationalised independently from the scheme itself, but needs to be easily accessible to those who are seeking, or may benefit from independent advice or assistance relating to any aspect of the new scheme. As part of such a program, YDAS would also like to call for advocacy support that is specifically available to young people with disabilities and designed to protect and promote their rights and interests.

Conclusion: What young people with disabilities said a lifetime care and support scheme would mean to them.

We asked young people what it would mean to them if they could have all the supports they needed, when they needed for their whole lives. These where some of their responses:

> ***"It would be great; It would make my life, my families life a whole lot easier. It would be like just like living life like a regular person which I don't feel like I can do that at the moment, which sucks."***
>
> ***"That would be absolutely fantastic; it would take away the stress. It would enable myself, my fiancé and my family to live the life they want to live."***
>
> ***"It would make my life easier, easier to manage. Everything would be set up, and I could live like everyone else does and that is all we can ask for. We didn't choose to have a disability; we should get the assistance (we need)."***

YDAS would like to thank the Government for undertaking the Productivity Commission Inquiry into the Life-time Care and Support Scheme for people with disabilities. We wholeheartedly support a new comprehensive, long-term care and support scheme which will create equity, security and possibility for people with disabilities.