

Submission to the Productivity Commission

Inquiry into Disability Support and Care

Family Governance

I am writing in my capacity as the Coordinator of a Family Governed project called Getting A Life. This group was formed in 2005, by three Canberra families and works for, and on behalf of, Ben Pattrick, Jackson West and Daniel Connaughton. Each of these young men has a disability but they believe that this should not prevent them from living a full, valued and meaningful life. It is their vision, and the vision of their families, that they will enjoy meaningful employment, chosen leisure activities, warm and caring relationships, relevant and respectful paid and unpaid support and an inclusive, rich and interesting life in a community where there are opportunities for them to contribute and community members are interested in, and value this contribution.

These families, and in particular the mothers of these young men, Cheryl Pattrick, Karen Connaughton and Sally Richards, have been working to create good lives for their sons since the inception of Getting A Life and they continue to do so on a daily basis.

The Getting A Life Group is based on a three-way partnership between the families, a host agency; Hartley Lifecare, and the Department of Disability A.C.T. This innovative response has allowed the families a level of control and autonomy that would otherwise have been impossible. These families are still obliged to operate within the available disability service providers and other government funded programs, however, they have had the capacity and drive to be more creative and innovative and to plan for the future of their sons in collaboration with these young men.

I believe that a huge amount of what has been made possible is due to the alternative focus that these families have. Above all else, they absolutely see the abilities and capabilities that their sons have. They acknowledge that the talents and contributions that Ben, Daniel and Jackson have, may be unconventional and traditionally devalued, however, they firmly believe that all individuals have a contribution to make and that opportunities can be found, or created, to allow this to happen. These families are committed to supporting and encouraging these young men to achieve what they dream of and aspire to.

My experience in working with people with disabilities was limited when I commenced this role. Since working on this project I have been astounded at the lack of services that are available for those who live with disabilities, and their Carers. I was shocked to discover that aids and equipment, that can drastically improve the quality of life of those living with disabilities, is not always provided in a timely and straightforward manner. Previously, I gave little thought to the fact that those with disabilities are expected to live in a parallel universe where

they have extremely limited control and choice over their own lives, where their human rights are regularly dismissed and where people with disabilities and their carers live in a constant state of stress with regard to what the future might bring.

Because of this, I believe an essential measure to introducing a National Disability Insurance Scheme must involve a component of community education to ensure it is supported by all members of the community who have been lucky enough to remain oblivious to the struggles of those who live with disabilities.

It is difficult to have anything other than the utmost respect and admiration for the families and mothers of these young men around whom this project is focused. They are highly principled and hold strongly to the simple belief that all members of our community are of value and have something to contribute. They are an inspiration and a positive example of what can be achieved when the focus is on ability and not on disability.

It has been stated that the current goal of government disability policy is to enhance the quality of life and increase the social and economic participation of people with disabilities. It appears that a major difficulty around achieving this goal is that people with disabilities are not involved in either the design or the implementation of this scheme, yet it is expected to meet their needs and do so in an inclusive way. It is generally service providers and government administrators that make these decisions and this sends a strong message about the inability of those with disabilities to make a worthy contribution.

I strongly support the introduction of the NDIS or similar scheme and have outlined the points below in response to some of the questions in the issues paper.

Eligibility

I believe that all people living with a disability should be eligible for this scheme, whether that disability is acquired or congenital. The current system is focused very much on the Poor Law concept of those who are deserving, versus those who are un-deserving. A new system based on the concept of entitlement has the ability to send a message about the value that is placed on the well being of those living with a disability.

I do not believe that this system should be means tested as it is contradictory to the concept of entitlement, there are significant bureaucratic measures involved in means testing and it is an obvious disincentive to employment.

Which groups are most in need of additional support and help?

It is not always the case that those with similar disabilities have similar needs. If we work from the premise that all people with a disability deserve to have an opportunity for a good life, then those who are most in need of service can be identified as those who have the greatest potential for social isolation, exclusion and marginalization. I understand that all those with a disability are marginalized to some degree but some suffer significantly more than others.

I feel that there are times when additional support and help may be required but that this does not always have to be put in place as a permanent measure. For example, when a diagnosis is initially made, whether that be at birth or when a disability is acquired and during times of transition or crisis, a coordinator should be immediately available to assist the person with a disability and/or their family to educate and guide them about all of the possible services/options/assistance that they may need or benefit from. To hear that people are unaware of the limited services that are available is simply unacceptable. There should *absolutely not* be waiting lists for this. It is a time of extreme uncertainty and distress and should be recognized and supported as such

Assessment

Needs to be designed and completed by an independent and objective party that does not have a vested interest in either funding or service provision. Could most likely be most effectively designed by those with disabilities.

Should focus on the abilities and capacities of the person with a disability, their concept of what a good life would look like for them, the current barriers to this and how this could potentially be overcome.

Should only have to be completed once. These assessments should be held electronically and centrally and accessed by other services as necessary. The person with a disability/carer should have the capacity to update this when necessary.

The duplication of assessments is a shameful waste of resources across the board as well as creating a high level of frustration and humiliation for those who are continuously subjected to these assessments. The process of having to retell one's story over and over and over whilst being in the position of begging for limited and insufficient assistance is humiliating, degrading and shaming.

Power and Decision Making

Given the obvious benefits that have been experienced through the family governance project, I strongly support the introduction of a self-directed approach. I believe a huge step toward achieving this would be through the introduction of individual funding.

Ultimately, this funding should be attached to the person and not an agency, allowing it to be portable. Services, funding and guidelines should be simplified and uniform which would result in improving and simplifying choice and should reduce costs significantly by reducing the high levels of bureaucracy that currently exist.

Flexible and individual funding packages would allow people with disabilities and their carers to access the care that is most appropriate to meet their needs. Ultimately those who require the service can make the decisions about

when a service is provided, what that service will look like, who will provide it (i.e. there is capacity to employ their own support workers), and in what priority it is accessed. This has multiple benefits in that it:

- Allows for high levels of flexibility and creativity
- Allows for independence, control and choice, autonomy and a sense of dignity
- Encourages people to build on their abilities and strengths and the resources that can be accessed for them to build a good life
- There is more effective use of limited resources
- Gives those with disabilities consumer power which encourages a much greater level of transparency and responsiveness from service providers
- Where this system is in use, evidence shows that people with disabilities report higher levels of participation and community contribution, improved health –both mental and physical and increased satisfaction.

Accountability

A system with a high level of monitoring should be avoided. A highly bureaucratic system that attempts to monitor all of the individual funding packages is probably less economically viable than requiring an annual or bi-annual reconciliation of accounts and allowing for a small amount of roting that *may* take place.

Capacity building for people with disabilities and their families

Coordination assistance should be provided if required, and/or other measures that can assist people with disabilities and their carers to build the capacity necessary to manage their funds. As is the case with the Getting A Life group, where possible, the person and/or families could employ the coordinator. If this is not appropriate, it is essential that a person centered and self-directed approach is upheld. There are many examples of case managers and other professionals dictating the boxes that must be ticked and the hoops that must be jumped to accommodate the requirements of the service providers.

Little support currently exists around developing and maintaining informal supports, about creating and maintaining other support networks and about the concept of self-directed/ managed funds. As stated below, all of these concepts are difficult to put in motion unless the basic supports and stresses of living as a person with a disability have been addressed

Families, carers and the community need to be educated around the ability that exists for people with disabilities to plan for the future and to build a good life. There needs to be education around the capacity for all to contribute. To date the system has been crisis driven and creativity and initiative has been rewarded – this needs to be reversed.

Community education is required to ensure that those who do not have an insight into these issues are willing to support and assist to fund a scheme for ongoing care and support of people with disabilities.

Sufficient, appropriate and planned support and respite

To allow people with disabilities to plan for the future and to develop good lives it is essential that their basic needs are met. For many with a disability and their families the future is extremely uncertain. Lack of services means that it is impossible to plan for life independent of, or only partially dependent on, the family unit, in relation to housing, self care and support.

As well as these basic services it is essential that Carers are provided with appropriate and timely respite – not just crisis driven respite, and other resources that allow the Carer to have a good quality of life and good mental health. Too many carers are prevented from contributing to society through employment because of the lack of basic consistent supports.

Service providers and Support workers

Service Provision needs to be focused on supporting the creation of a good life for the person with a disability. The current economically driven business model that providers operate from, focuses purely on a quantitative outcome, which is the complete antithesis of achieving a quality of life for an individual.

Further to this, it appears that many service providers have minimal focus, knowledge or experience of creating a meaningful and valued life for people with disabilities. Support workers are not always encouraged to be creative in this area, resulting in ongoing lists of monotonous and mindless activities for the person with whom they work.

The role of disability support work is one that can be highly rewarding although it is a very physically demanding. Although there are many support workers who have a high level of respect and value for those they serve there are many stories of support workers who believe it is ok to treat people with disabilities without any level of dignity or respect.

This role needs to be one that is more highly regulated and Care Agencies should have an obligation to provide trained and competent staff. Support workers should be encouraged to be more proactive in creating valued roles for PWD. They have many opportunities and a responsibility to make those with disabilities more visible and to assist them in developing relationships

Accommodation

One of the major areas of concern for people with disabilities and their parents and carers is that of suitable and appropriate accommodation and support. This should be an entitlement and as such would be a powerful statement about the value that our society places on this group of people.

Congregated and segregated accommodation models are highly detrimental to the people who are expected to live in them. Generally it is those with intellectual disabilities who are subjected to these accommodation models. As

well as having no control over where and how they live, they may be subjected to abuse, neglect and disrespect from other residents or paid support workers.

Examples of alternative and individual living arrangements for people are emerging worldwide. These models have generally been developed through the creativity, initiative and hard work of parents and people with disabilities who have rejected the above outlined model. Their focus is one of freedom and choice. People with disabilities and their families need to be educated about these alternative options and practically and financially supported in their efforts to achieve these, if they feel they are appropriate.

To alleviate the extreme stress that people with disabilities and their carers live with because of the uncertainty of the future it is essential that they are encouraged and supported to move into a home of their own in a planned and timely way.

“Adequate planning...can avert the crisis of an ill prepared transition from parental care (and) ensure long-term security and stability of those with a disability” (Bigby, C; P14).

The Getting A Life group is planning now so that Ben, Jackson and Daniel will each have a quality home with security of tenure. The vision is to develop an intentional community with the necessary paid supports and the potential of unpaid supports through the relationships and networks that will hopefully be fostered and built. A significant number of meetings have been attended but to date there are no definite developments.

Conclusion

After three years, Ben was able to make his dream come true by securing a position of employment that is both desirable and enjoyable for him. Ben was not assisted to achieve this through any of the government programs designed to assist him, because he did not fit their criteria. If anything, attempting to navigate the system and access assistance was extremely frustrating and time consuming, where conflicting and incorrect information was regularly supplied. Eventually, Ben has been able to secure the support needed for him to start his job and is currently working toward independence. Ben is incredibly proud and happy with his new job but this was an opportunity that was created and supported with a tremendous amount of hard work. Individual funding would have saved a huge amount of time, energy and money in this case.

Jackson would never have been deemed as being appropriate for employment. In fact, Sally was advised that Jackson would *never* make a contribution to society and would *always* be dependent. Jackson is now the public face and key worker of a successful courier company, JACKmail, which was thought of, created and established, maintained and grown by Jackson's mother, Sally Richards.

JACKmail was specifically planned and developed around the needs, likes and abilities of Jackson.

Daniel continues to work in a voluntary capacity in an office because this is his dream job. In the past, his mother, Karen, has privately funded a support worker to assist on the job training, as Daniel was not eligible to receive funding for this. Daniel also works two other part time jobs. His mother has worked hard with Daniel to secure these positions. She was successful in accessing some assistance via a support worker, again privately funded, when he commenced work at the restaurant.

Without the hard work of their families and the vision for, and commitment to, a "good life" that they all share, the alternative for each of these wonderful young men does not amount to much. It would involve attending a daycare program or working in a sheltered workshop/supported business or some other alternative where those with disabilities are segregated and congregated. Ben, Daniel and Jackson would not know about the experiences of choice, independence, creativity, satisfaction and dignity. The lack of control and the limited and disheartening choices that are available for employment, training, education, accommodation, support, respite and leisure activities for people with disabilities and their carers, make a clear statement about the value society places on them. The focus needs to change from one that is crisis driven and unresponsive to one that looks at and expects, encourages and supports a contribution from people living with a disability.

I am grateful for the opportunity to provide this information regarding the benefits of a family governance/self directed model. We are very hopeful that the outcome of this review will result in a revolutionized scheme for the support and care of people living with disabilities and their families.

Regards,

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Further information about Getting A Life is available at www.gettingalife.com.au and Jackson West also has his own website www.jacksonwest.org where his achievements and contributions to the community are documented