

NATIONAL COUNCIL ON



DISABILITY

Incorporated in the ACT

Disability Assistance Package - Supported Accommodation

Response to the discussion paper

Currently there is a huge demand for accommodation for people with high support needs. The options are limited and they are often very distressing for families to consider – for example, long term care in nursing homes, hostels and disability institutions.

Australian Government (2007)

October 2007

26 October 2007

The Hon Mal Brough
Minister for Family, Community Services and Indigenous Affairs
Parliament House
Canberra Act 2600

Dear Minister

In responding to the Disability Supported Accommodation Discussion Paper National Council on Intellectual Disability is very conscious that the Discussion Paper does not address core issues that will have a profound impact on people with intellectual disability and their families.

While the additional funds under the Disability Assistance Package for accommodation support and respite were welcomed by NCID, the funds do not substantially address the amount of unmet need that exists in the community. In addition, unless the Commonwealth is prepared to assume responsibility for all disability support funding then it must work with the States and Territories (through the Commonwealth, State and Territory Disability Agreement) to deliver not only the funding necessary to eliminate unmet need but an administrative system that does not duplicate the number of assessments, etc that people needing support have to negotiate.

For people with intellectual disability and their families to get any substantial and real benefit from Commonwealth initiatives the Commonwealth must re-think its current policy and commit to:

- i. a CSTDA that fully funds all the support needs of people with disability on a 50/50 basis.
- ii. a CSTDA that provides for a single administration of funds in each State and Territory.
- iii. a CSTDA that has outcomes-based, evidence-based research that demonstrates what an 'ideal' support structure is for families and individuals living with disability.
- iv. a CSTDA that fosters positive and cooperative relationships between all levels of government.

Yours sincerely

Rob Allen
President

Currently there is a huge demand for accommodation for people with high support needs. The options are limited and they are often very distressing for families to consider – for example, long term care in nursing homes, hostels and disability institutions.

States and territories are introducing changes, in response to the needs identified by people with disability and their families, to provide more appropriate options for people with disability. There is no ‘one model fits all’; the best way is to provide a range of accommodation options to suit each person’s individual needs. These options include independent living with some advocacy; sharing with another person, with or without disability, with support as needed; independent accommodation with each state/territory Department of Housing with individual 24-hour support; or remaining in the family home with advocacy and support as needed.

Planning for the Future, p 21, Australian Government, 2007

The National Council on Intellectual Disability (NCID) was established over 30 years ago by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with intellectual disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

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Attachments

1. Interaction Volume 19 Issue 3; Presenting the Evidence: Accommodation and Support for People with Disability.
2. Interaction Volume 21 Issue 1; Deinstitutionalisation: a Review of Literature and Lifestyle Supports.
3. Housing and Support for People with Intellectual Disability and High, Complex or Changing Needs; proceedings of the Second Roundtable on Intellectual Disability Policy.

Supported community living is not only for people with low support needs ...

Brian

Brian's parents have seen many challenging years with his health presenting them with concerns and worries but neither of them can imagine their lives without Brian being an integral part of it. They consider him a blessing and see the family home as his home.

Brian is a young man of 19 years who lives at home with his parents. Brian has a long history of seizures which despite an implant and medication can occur up to 3 times a week, 3 times on a 'bad' day. The seizures require Brian to be constantly watched and for at least one of his parents to be in close contact so that they can administer the required medication.

Brian uses a wheelchair and has scoliosis of 85 degrees, he has severe gastric reflux and is PEG fed. Brian needs suctioning to keep his airways clear and has nocturnal oxygen.

Brian goes to a day service on the understanding that one of his parents will be on call if he has a seizure to give him his medication. His seizure management is difficult and for this reason Brian is unable to have respite support.

Brian and his family receive \$90,000 to support him in his home and his day service.

At his birth, Brian was not expected to live for more than a couple of years and, over the years, he and his family experienced many highs and lows, but at this stage of life his parents know that he is content and at peace despite his many difficulties.

1. Introduction

Vision

NCID is an organisation that is committed to ensuring that people with intellectual disability enjoy the full entitlements of living a good quality lifestyle. This includes access to all the diverse cultural norms that other Australians enjoy and participating fully in education, work, recreation, having a home and social supports of friends and family. Therefore, people with intellectual disability need supported living arrangements as opposed to supported accommodation, based on what each individual wants to do to live a fulfilled life.

Principles

The work of NCID is guided by the principles that:

- › We actively seek to hear, understand and represent what people with intellectual disability are asking for, ie. to live a 'good quality life'.
- › We work in partnership with people with intellectual disability and their families in promoting that they *can* and *want* to live a 'good quality life', acknowledging that this will be different for each person.
- › We focus our efforts on removing the systemic obstructions to people with intellectual disability gaining a 'good quality life'.
- › We advocate that any funding spent by Australian governments must be allocated according to best evidence-based practice and person-centred models and standards as the pathway towards achieving 'good quality lives' for people with intellectual disability
- › While we acknowledge the primary role of parents in the lives of people with intellectual disability and support this relationship, our concern is that people with intellectual disability live in accordance with the broad community notion of what constitutes a good quality life for all Australians.

Being supported to live a good quality life

People with intellectual disability are as diverse as all other Australians. Each person has their own hopes and dreams, goals and aspirations which change over their lifetime

as they grow and develop. A supported life is one where a person says what they wish to do and is assisted to do it. It is a constantly evolving, dynamic process that weaves and flows with the individual choices, desires and needs of the person. It is more than a roof over your head! What does the research evidence tell us about what a good support life is?

2. Learning from the research evidence

NCID has researched from international journals the literature over the past 10 years in the field of accommodation for people with intellectual and developmental disabilities. There are some key features of the research that need to be exposed. Academics writing in this area predominantly come from the theoretical position of psychology and psychiatry, as the dominant discourse, which has the outcome that the success of a service is measured by changes of adaptive behaviour of participants in the studies. The dominant participant groups used in this style of research are people defined with Challenging Behaviours, not the wider range of people with an intellectual disability known in the community.

In Australia, the research draws upon quantitative information in the Disability Census on accommodation from the current CSTDA funding that supports people in institutional accommodation models - both large (over 20) and small (under 20). It is acknowledged by researchers in the field that people who are not in such accommodation are not counted in this population – ie. those who currently live at home (alone, partnered or with parents) or in a boarding house/nursing home and do not receive accommodation support from a CSTDA funded service (Young et al, 1998; Stancliffe, 2002; Australian Institute on Health and Welfare, 2005). This leaves an unclear picture as to what is happening in their lives. Most research is undertaken in institutions and group homes as these populations are accessible and easy to observe from a research perspective. There is only now an emerging literature on the individual funding models used in Canada and the UK; most information is in the form of stories by people with disability and their families and advocates, but it already reveals evidence that people live a better quality of life under this policy and program provision. The experience and voice of people with intellectual disability and their parents is not commonly heard in other literature. Blackman proposes that:

the reasons why the perspectives of people with disabilities are routinely ignored or disregarded are multiple and complex, but they have their roots in unquestioned and ubiquitous ideologies of disability and impairment. Normative ideas of what constitutes authoritative, credible knowledge also tend to diminish the value of consumers experiential knowledge as does the dominant position of "experts" in interpreting and constructing credible knowledge. These ideologies all act to devalue and marginalize the knowledge of people with disabilities.

(Blackman, 2005: 26)

Westcott (2003) provides an extensive and important commentary on the disability industry and how it imposes a life of clienthood onto people with intellectual and developmental disabilities. Part of his contribution is an outline of direction for future services. Westcott argues that the disability industry is a poor substitute for loving and caring relationships, and the freedom and autonomy that are typical for non-disabled Australians. He advocates for the person with disability being at the heart of all decision making and policy formation — in so doing, the professional ownership and their dominance in the disability industry will achieve the required balance between professional knowledge and personal experience and thus develop a good service.

In adopting Foucault's recommended strategy, the 'low ranking' knowledge of [clients] staff members and mothers need to re-emerge as forceful and legitimate. The client needs to become a person with a name, his life must become *his* life, his family and his other helpers must be enabled to assist him and the professional voices and their papers must be denied dominance. The professional message is important, but not absolute. Its 'truthfulness' is directly proportional to the power the professional experts wield. In other words, if their influence is reduced it will soon become apparent that their view of the world, which once seemed inviolate, is but one of many.... Truth and reality is in the eye of the beholder.

(Westcott, 2003: 296)

Increasingly, there is a movement to include the voice of men and women living the "dis"abled experience that is emerging in sociological journals like *Disability and Society* and the *British Journal on Learning Disability* (the English term for intellectual disability). With the increase in self-advocacy movements internationally, people with intellectual disability have expressly stated that academics and policymakers should not make decisions 'about' us 'without' us (Charlton, 2000).

Stancliffe (2002) establishes that the trends of style of accommodation is similar in the USA, England and Australia in that people in accommodation services live in large or small residential settings and there is a gradual growth in group and cluster housing and semi-independent living arrangements. Young et al (1998) reveals that the catalyst for moving people out of large institutions and into smaller community institutions (group homes) was that the research showed an increase in people's adaptive behaviour living in the community and there was a perception that people would be free from abuse and neglect in the community. Other benefits include more contact with family and friends and the local community. These findings dominate the literature – that living in the community promotes improvements in adaptive behaviour, better quality of life and more community involvement (Stancliffe and Keane, 2000; O'Brien, Thesing and Tuck, 2001; Reinders, 2002; Emerson, 2004; Duffy, 2005). Reinders (2002:2) argues that living in the community is an experience and that a good life means being welcomed and accepted for who you are.

Emerson (2004) found that there was no overall evidence of the benefits of deinstitutionalization between the group and cluster models of housing, with the cluster model providing poorer levels of quality of life. He argues that the essential feature of group and cluster housing is that they are not homes and thus the benefits of independent community living do not flow to people in these accommodation models. 'Home' is a concept not examined widely in this literature. However, Martin (2006) indicates that the key feature of a home is that you have freedom – to do what you want when you want, wear the clothes you want, live where and how you want and work where you want. In also considering notions of home, Annison (2000) critiques that 'home' and 'home-like' have been terms used in the disability sector when discussing institutional care and this has had the result of perverting the understanding of 'home' when we consider accommodation for people with intellectual disability. One feature of this distortion of 'home' is evidenced in the language used by providers who talk about having a "place", not a person in a group 'home'. She argues that, for most of us, a home provides us with a sense of place, that we are in control of the home and our support networks and that there is a sense of security of tenancy (O'Brien, 1994 in Annison, 2000). These are not the features of large or small group homes, neither of which can provide 'home' or 'homelike' environments when they are workplaces and the staff typically control the life of the person with disability.

Cummins and Lau (2003) examined the literature on community and community participation of people with intellectual disability and found that most of the literature in the field talks about physical presence rather than a sense of social belonging. Mansell

(2006) states that better outcomes cannot be universally applied to leaving the institution and argues for better staff training and for services to adopt quality of life measures to evaluate any accommodation service. The importance of well-trained and quality staff was also linked to a better quality of life for people living in group homes (Holburn et al, 2007). In the UK, Forrester-Jones et al (2006) undertook a study on the social networks of people who had moved out of hospitals 12 years ago. These participants now live in cluster or group housing models. They found that the nature of group housing continues the congregation of people with intellectual disability with other people with intellectual disability and this lessens their social inclusion in the local community. They advocate that staff in such services need to attend more to supporting people to create networks in their local communities. Conversely, O'Brien et al (2001) found that the people, staff and parents involved in their study in New Zealand 22 years after leaving the institution showed that people had lived varied and normal lives in homes of their own and had had more involvement in the community with friends and family, living an improved quality of life and that people had improved in their skill level. Abbot and McConeky (2006: 275) examined what people with intellectual disability in the UK saw as barriers to their social inclusion, finding four factors:

...lack of necessary knowledge and skills; role of support staff and service managers; location of house; and community factors such as lack of amenities and attitudes. Participants were able to identify a range of solutions for these barriers. Most of their proposals were in line with the aims of current government policy and good practice. These findings reinforce the contribution individuals could make to the planning of local services for themselves and others. This advocacy has been an essential element in reducing the social isolation of other marginalized groups.

In considering community involvement, Felce and Emerson (2001: 75) state:

Ordinary housing stock and normative architecture and standards of material enrichment are to be preferred. The use of normative housing constrains group living to relatively small scale, but there is little evidence that smaller size within this range is to be preferred to larger size. There is little evidence to suggest that higher staff-to-resident ratios lead to uniformly better outcomes, but staff orientation, working methods, and performance are important influences. Little is known about what precise characteristics of community location give rise to greater community integration.

Stancliffe and Keane (2000) looked at the costs and outcomes of community living and found that people living in independent settings showed significant improvement in the 29 measures used in the study. People and staff reported that they preferred semi-independent/independent living arrangements. Additionally, people living independently showed greater levels of empowerment and self-determination. The participants living in group homes in the study stated that they did not like living in the group home and therefore spent most of their time staying in their own room.

In their research, O'Brien et al (2001) self-determination was seen as one of the benefits of community living experienced by people now living in their local area. Bleasedale (2001) claimed that people in the USA and Canada felt that the self-determination they gained in an independent funding package was so important that they were prepared to sign exemptions of duty of care, so that a service would not have to bear the cost of potential legal cases of neglect of duty of care litigations. The importance of individual funding is seen as central to self-determination :

- Individualized funding enables the person to direct supports in ways that the person wishes – assistance will be given IN the community;
- Individualized funding arrangements encourage “natural” circles of support with family and community members;
- The choice provided by individualized funding will render institutional and congregate care redundant;
- People with disability will use their supports to engage with the societal institutions of family, education, employment, politics, religion and social life.

(Bleasedale 2001: 17)

Rans and Green (2005) draw on the importance of self-determination in their workbook on community development that tells seven stories of community building, using John McKnight's research as the basis for the model. They argue that the less a person is seen as a client, the greater is the change of their social inclusion in their community.

In the current policy of the UK government (Valuing People), self-determination is established as the third of seven key principles to success in supporting the In Control model (Duffy, 2005; Forbat, 2006). Martin (2006) argues as a self-advocate that being able to make the choices you want in life is vital for people with intellectual disability and one that has been denied them for many years. Self-determination is seen by Nerney (2000) as the foundation for building future services for people with intellectual disability that establishes them as equal citizens and that this will lead to the end of placing a

person in an involuntary congregated setting with other people with intellectual disability in human service programs and organizations, call an end to group homes, day programs and sheltered workshops, and deny that quality is present in human services where there is no freedom. He argues that people need to have individual funding and a budget so that they can plan for their own hopes and dreams. He also advocates that people with intellectual disability need to be involved in the development of policy affecting their lives.

Neumeyer and Bleasedale (2001) in asking 30 people with intellectual disability about their personal lifestyle preferences found that self-determination was linked with a positive quality of life measure. As parents of a child with significant cognitive disability, Turnbull and Turnbull (2001b) urge caution in applying the notion of self-determination to all people, arguing that it is reliant on the range of individual experience and carries many assumptions of value.

Finally, in the literature there is an emerging critique of the model that has emerged in the UK following the 'Valuing People' policy document. As mentioned throughout this submission, the *In Control* model is based on this policy direction. Forbat (2006) suggests that the four principles – choice, independence, rights and inclusion – present considerable challenges for the service providers that are based on the old model of care and containment. She argues that people and providers are excited about the positive changes that can be created in the lives of people with disability. This finding was supported by Dowling et al (2007: 65) who found that the enthusiasm of professionals and families for the plan combined with options for greater access to mainstream services and a quality of life.

The analysis found that implementation is often described as partial or slow and characterizes reasons for this at a number of levels, including the slow pace of change in service culture and power relations, immutable funding structures, services' inflexible infrastructures, high levels of staff turnover and lack of training, inexperience among service management, inadequate staff supervision, and ambiguity among some stakeholders.

(Dowling, Manthorpe and Cowley, 2007: 65)

Simon Duffy (2005: 11) states of the new UK model:

Many of these initiatives are being piloted by *In Control* or by other authorities at present and it is too early to speak definitively of success. But the direction of travel seems clear and the possible advantages enormous. Certainly we have already shown that there is a realistic

alternative to the present system, one that promises a different kind of contract between disabled people and the public authorities that have been funded to support them.

The last word must rest with a person being supported by In Control telling his own story (one of many on the In Control website). While not an academic paper, it offers much insight into the qualities that contribute to a good quality of life.

Ken

After years of being moved from one institution to the other, Ken is now able to organise his life in a place of his own. He moved from an institution into his own flat 200 miles away in Essex, his home county, and he is thrilled. The saga of how he got to where he is today:

Ken moved to the institution six months ago, which was only supposed to be a temporary stay, after spending three years at another institution in Devon. Ken's long-time friend and advocate, Tony, describes how he moved to the institution until a place in Essex could be found. Ken was going to move into his own flat in 2002 but, the day before he was due to go there, the staff at the assessment unit he was living in had been instructed not to work with him. So Tony and Ken stayed together in the flat for a week before moving to the establishment in Devon as this was the only place the social worker could find for Ken.

It would seem that Ken has had a life of being moved around without having any control over where or when he went. Ken is now forty-three. He has been in just about every hospital in East Anglia. He had his first experience of the long-stay hospital system when he was 15. He also says he was kept in hospital on a section under the Mental Health Act. It is true that Ken has lost his temper with staff in the hospitals he has lived in. But, in all the years that Tony has known him, he has never done anything like that outside the hospital. Whilst he was living in Devon, Ken said he was not allowed to go to the toilet alone. He had to ask for toilet paper and wasn't allowed things like razors, batteries, bottles and beakers at night. 'If I was dry, I could not get a drink', he says. The light switch to his room was outside the door, but staff said that Ken could turn it on or off whenever he liked! Nor could Ken go out without an escort. It would seem that going out was a rare event. When he needed new clothes for his move to Essex, a staff member went to buy them for him as there were not enough staff to take him.

His care at the institution cost almost £3000 per week. To stay in the Savoy Hotel for a week costs £2800! Ken's mood becomes sad when he describes the 'Odd's Room'. It was really the observation room, but Ken misheard it and thought you went there when you were behaving 'odd'. This, he explains, is where he had to go if he had a disagreement with staff. It is an empty room with one chair in it. Most people who had to endure these circumstances would probably be inclined to lose their temper. It was Tony who came up with the idea of Ken being part of the In Control project, with a view to moving to supported living and a place of his own. Everyone they spoke to said that this was a great idea. But where would the £3000 a week come from for Ken to move into his own place? Anxiety amongst staff mounted. They had never done this before. It would all take time to sort out. Meantime, Kenny was desperately unhappy where he was living. He longed to move to Essex. So a half-way plan was decided upon. When Ken was on holiday in a cottage with Tony in Essex, he invited Nicola, a social worker, for a cup of tea. She read the report about Ken but couldn't match what she had read with the person she saw in front of her. She was undeterred by the report and started looking for somewhere suitable in Essex.

This is how Ken came to be where he is now – in his own flat, able to organise his life as he chooses.

3. Responding to the themes of the discussion paper

Principles – good foundations for living a supported lifestyle

- The first principle of living a quality supported quality lifestyle is that it is the life that you choose at any given time and that you are safe. There has been a tendency to fund accommodation services in the disability sector which has led to a focus on bricks and mortar but this has restricted the capacity to think about the range of ways that people may choose to live and this will be different for each person. A good life has many components beyond the bricks and mortar:
 - Being in control of your life and responsible for the choices - good and bad - that you make.
 - Owning your own home – be that a room, unit, house (rented or purchased).
 - Living in a place where you have friends and family and living life to the fullest of your capacity – going to work, having fun and doing the things you enjoy.
 - Being safe and free from violence and abuse.
 - Being supported to make good quality decisions.
 - Having financial security.

- The principle that supported lifestyle is based on evidence-based practice and uses the principles of person-centred practice:
 - Individual-based funding models would allow people with disability in partnership with families and allies to have more control on selecting how and where they wish to access supported accommodation. Individual Funding Packages have allowed many people with disability and families around the world to access a good life and gain control of their daily life. Examples are:
 - In Control <http://www.in-control.org.uk>;
 - PLAN Canada <http://www.plan.ca>;
 - Canadian Association for Community Living <http://www.cacl.ca/>

- The Institute on Disability (University of New Hampshire) has been providing an innovative range of housing options and social programs over a number of years with a focus on people with autism in their research centre. <http://iod.unh.edu/>
- Circles of Friends is not a program but rather a strategy of how to create ongoing natural networks of support for people with intellectual disability throughout their lifetime. It undertakes to provide a team that fully engages with a person and protect their life and build upon their hopes and dreams. In SA, Circles of Support is a project run by the Community Living Project and the Julia Farr Centre that creates natural networks of support in the lives of people who have been institutionalized in an effort to create better lives for them by having people involved in their lives (based on Forest, Pearpoint and Snow in the 1980s) (<http://www.inclusion.com> and at <http://judyanddavid.com>).
- In the disability sector, one of the ongoing difficulties has been a lack of innovation and a rigid conceptual framework about what accommodation is appropriate for people with intellectual disability. Predominantly, the accommodation is an institution, group home or boarding house, with a smaller number of people living alone in the community. The New South Wales report on supported accommodation in 2006 attempted to develop a range of suggestions for new ways to provide supported accommodation to people with disability (<http://www.dadhc.nsw.gov.au>).
- The Canadian government has a scheme (Home Buyers Plan (www.cra-arc.gc.ca) that allows low-income earners and people with disability to withdraw \$20,000 from their pension fund to purchase a home of their own. This could be useful to consider but would only be appropriate for people who undertook mainstream work and therefore paid into a superannuation fund.
- Ensuring that people can access local mainstream services, groups and activities of their interest is also a part of being able to live a good quality life. People also need programs that are rewarding, enjoyable and developmental. Many people living alone need help with house cleaning and ordinary daily activities via Domiciliary Care and Personal Support Programs.

- › Person-centred practice has a sound literature that can provide a template for the Government in developing supported lifestyles. O'Brien (2004) indicates that Individual Funding or Person-Centred Practice has been funded in the USA since the 1970's and has been central to achieving good lives for many people with intellectual disability. The essential elements important in person-centred practice are:
 - A focus on the aspirations and capacities expressed by a person with disability with their families and allies rather than a priority focus on needs and limitations.
 - The person is at the centre of all planning and plays the role of senior partner in all aspects of intervention and assessment, based on acknowledging that the old service models of supported accommodation and respite services have often failed people.
 - Acknowledging that sometimes services provide constructed obstructions that prevent a person achieving the life that they wish to lead and that these barriers can all be overcome (Mansell and Beadle-Brown, 2004).
 - In the past, people were restricted from living the life they wanted to lead by having to fit within the disability accommodation and respite service industry which limited where and how they lived. Person-centred planning assumes that people with disability are **ready** to do whatever they want as long as they are adequately supported. The readiness model is replaced by the support model which acknowledges that everyone needs support, some more than others (Sanderson, 2000: 6).
 - Adams, Beadle-Brown and Mansell (2006) advocate a need to draw together the principles of person-centred practice and the measurement tools of quality of life indicators to ensure that people are well serviced by any support that is provided in their life.

- › The last principle relates to using quality of life measurements to ensure that a person is safe and in control of their life while receiving the necessary supports to do this.

- The American Association on Mental Retardation has a wide range of relevant publications upon which to develop quality of life measures when providing supports for a quality lifestyle (<https://bookstore.aaid.org>).

Living a supported lifestyle

In adopting the language of enabling people to live a supported, good quality life, you change the course of assistance. There is a change in focus from what the service needs (the dominant theme of the discussion paper) to the individual choices and needs of each individual person. While this has not been how people have been supported in Australia, O'Brien (2004) reveals that since the 1970's many people have been assisted with support to live a good quality life and one that they have been in control of. Based on the success of the experience of people in Canada and the USA, England is now moving to the same support system — an overview of the principles and practice is found at <http://www.in-control.org.uk>.

NCID holds the view that this is the style of supported living that governments around Australia need to be moving towards and to be taking up the available evidence-based practice. For the evidence on 'in control', people are happy to have control over their life – where they live, what they do, how they make decisions and have control over the services they use. They are not restricted to disability industry options and therefore have a wider range of choice.

In Australia, as Westcott (2003) has established, people are sent into the system that already exists, ie. group homes, respite and institutional care. The focus is on the accommodation and support available in the sector, not on who the person is and what they want in their life. This thinking has resulted in an ongoing and increasing demand on services with a large number of people not having their needs met. When the 'person' is the focus, natural lifestyle supports can be drawn upon – family, friends, local community organisations and services – rather than being restricted to the disability industry. In so doing, a wider range of possibilities becomes available to the person. This is the change of direction needed to be taken for people with intellectual disability to enable them to lead good quality lives in supported lifestyle arrangements.

The other benefit of supported lifestyle is that the person who makes the decision lives with the consequences and the outcomes of the decision. This is the experience of

ordinary Australians but has not been available to people with intellectual disability, eg. people who have lived in group homes and been told when to get up, what to wear, where to work and how to spend their recreation time. Many people now express dissatisfaction with these living arrangements and are calling for good quality lives and being in control of their own life (see newsletter Liana Indovina, 2007. <http://www.valid.org.au>).

4. Living a supported life

Examples of lives planned around the needs of the individual:

Maria

Maria is 21 and lives at home with her parents and two brothers. She wants to be a receptionist in her GP's office. On the weekends, she hangs out with some friends from school and one day plans to move out with friends. She plays netball on Saturdays and enjoys cooking for friends and family.

Plan for success to live a supported lifestyle.

In planning what Maria needs to have her choices met, there are two initial planning steps:

1. How does Maria meet the funding criteria?

It is agreed that Maria meets the funding criteria for lifestyle support funding packages via Disability Services and moves on to undertaking a lifestyle assessment.

2. Assess the support that Maria will need to live a supported lifestyle.

Maria needs bond and rent for living in a town house close to her parents and will live with two other friends.

Four days a month, she will need additional support in cleaning the home, maintaining the garden and

assistance in getting to netball.

For the first 3 months, she will need daily assistance traveling between home and work.

Finally, for a three month trial period, she will be provided with workplace support 3 hours per day in the GP's surgery.

In three months, the plan will be reviewed by Maria and her family and friends to see how it is working and what needs have changed or fallen away.

Implementation

Maria receives \$35,000 per year after the assessment process. Maria decides to purchase her supports from Options Coordination and Career System for a three-month trial period with an agreement for an ongoing twelve-month contract if she is happy with the service. Additionally, there are agreements set in place for the times that Maria is unwell. Her brothers are overseeing the funding arrangements.

Jim

Jim has worked with his dad and cousins in the family painting business since he left school: he is now 45 years old. He lives at home with his mum and his extended family live close by. Jim's dad died two months ago leaving him and his mum to start thinking about where he will live when she dies — they call the family support together to consider the future. Jim loves music and plays cards with the men in his community two nights a week. He is an active and welcomed member of his local community known by shopkeepers, the football club and many other locals.

Plan for success to live a supported lifestyle

1. Does Jim qualify for a lifestyle support package?
2. Undertake an assessment of Jim's choices and ways to meet his needs.

It is agreed that Jim should stay in his family home and, if needed, his mum will move into another care arrangement. Jim has expressed that he wants to take care of his mum but they will need help with the housework, gardening, shopping and their community activities. Their extended family agrees to help out on a roster system but this still leaves some days when Jim will need assistance with travel or care.

He will continue to work as a painter.

If he is not happy living alone, he and his extended family will visit local services to see what other choices are available.

Implementation.

Jim is given a support package of \$65,000/year.

Jim decides to buy support from a local home support company that will help twice weekly with cleaning the house and providing four meals a week. Three days a week, his extended family provide dinner.

On Saturday mornings, they will assist Jim with his shopping.

Men from the club will take turns in taking him to and from the football and cards.

Two of his cousins have agreed to become the guardians of last resort and will ensure that Jim is well taken care of by the service that he has purchased. Every 3 months, they will check whether things are going as he wishes and there will be a yearly review of these care arrangements.

Andrew

Andrew is 55 and grew up in a large residential institution. His life was completely controlled by staff and he had no independence or choice., even what to wear, eat or drink. Last year, he was re-contacted by two sisters and he asked to be allowed to move out of the institution and buy a unit close to them. He has enjoyed his work as a skilled gardener in a supported workplace.

Plan for success to live a supported lifestyle

1. Does Andrew qualify for a lifestyle support package?
2. Undertake an assessment.

It is identified that Andrew will initially need to gain some skills in managing a home and self-care. He may also need some community service to provide assistance with meals, transport and house cleaning and with becoming familiar with his new community and joining some groups and making friends,.

Implementation – 12 months on.

Andrew is given a support package of \$90,000/year.

Andrew is proud to be a homeowner, but found that he was quite lonely living without the institution staff and other residents. After long discussions, he decided to rent a room to an international student and they have become good friends. For a while, Andrew contemplated going into a group home and, if the shared housing does not work, he may still buy into that option. What he enjoys the most is having control over his life and what he does – making a coffee, doing his own shopping and buying new clothes.

He has started a new job at the local garden centre and is meeting lots of new people. His sisters are active in his life and, for the first time, he has loving natural relationships. Hiring a housekeeping service alleviated his problem with keeping a clean house. His sisters play an active role in monitoring the funding and assisting him in purchasing additional local community services if required.

5. Planning a supported lifestyle

Supported Living Matrix

Introduction

Below is a matrix setting out the process required to establish a flexible and responsive support process for Australian's with disability. In addition, the matrix provides illustrations of current comparable systems in United Kingdom (www.in-control.org.uk) and Wisconsin, USA (<http://www.wcltc.state.wi.us>).

Activity	Description of Activity	Who makes the decision	What happens in the UK	What happens in Wisconsin
Eligibility Criteria	Eligibility criteria defines who will be eligible to access supported living funding and also who will not be able to obtain funding.	Governments will make decisions about a person's eligibility for support funding. These decisions must be based on: <ul style="list-style-type: none"> equity, criteria must apply to every one who meets the criteria set out in Disability Services Act a persons disability, not on other criteria such as age, living arrangements or region 	Valuing People Initiative	<ul style="list-style-type: none"> People ask to be part of the Community Relocation Initiative and Family Care Program. Funding moves from a nursing/supported facility to the community in which they want to live. The county resource centre explains all possible care models to each person over the phone or in a home visit and outlines the associated rights and risks in each choice.
Assessment	Assessment of a person's need for support is determined. Disability is defined a limitation or restriction in participating in community activities and will provide information on what support a person needs to participate in their community.	The best form of assessment is self assessment; it is quick, easy and makes the person themselves the decision maker – <u>the basis of the process being self-direction</u> <ul style="list-style-type: none"> The self assessment is completed and there are points allocated according to what the person states. 	Self Assessment; people answer 4 – 5 questions in the following areas: <ol style="list-style-type: none"> looking after myself relationships being part of the community work learning and leisure making decisions staying safe from harm complex needs and risks 	<ul style="list-style-type: none"> Self assessment to be introduced with appropriate support for all people with disability. Focuses on each person's strengths and relationships. An assessment that is simple and straightforward that will not consume an abundance of resources.

Submission to discussion paper – Disability Support Accommodation

Activity	Description of Activity	Who makes the decision	What happens in the UK	What happens in Wisconsin
		<ul style="list-style-type: none"> A mapping process occurs and the no. of points gathered equates to levels of financial allocation. This allocation can be a range of \$ e.g. level one (the lowest) Range may be \$3,000-\$8,000. The plan will then refine exactly how much within that range is required. An issue to be considered is that people will under-assess their needs. <p>Where people do not want to make a self-assessment or they are unable to do so, there will be a range of people available to assist and their availability should be on the form. Or a Centrelink Transition Officer will provide information on local people.</p>	<p>8. family and social support</p> <p>People may get assistance to complete. Mapping process equates to levels of funding.</p>	<ul style="list-style-type: none"> The assessment focuses on the strengths of the person and their connectedness to the local community and support networks.
Assessment Verification	<p>The assessment is subjected to review by a government officer Centrelink Transition Officer</p> <p>(Within 10 working days of receiving the assessment)</p>	<p>The Centrelink Transition Officer will verify the assessment to ensure that it is a reflection of the persons needs and wishes, and also that it is not influenced by factors other than a persons disability.</p> <p><u>Centrelink Transition Officer</u> together with a panel:</p> <ul style="list-style-type: none"> Parent/self advocate Professional <p>This panel should have access to a team of professionals available to consult to ensure</p>	<p>Verified by Local Authority Social Worker or Care Manager.</p> <p>Amount of funding the person might expect to receive, the individual budget level, will be indicated.</p>	<p>Resource centre case manager assesses a person using a functional screen assessment tool</p> <ul style="list-style-type: none"> ○ Social worker ○ Case manager

Submission to discussion paper – Disability Support Accommodation

Activity	Description of Activity	Who makes the decision	What happens in the UK	What happens in Wisconsin
		when necessary e.g. <ul style="list-style-type: none"> • Speech Pathologist • O.T's • Medical • Psychologists who have experience with how people communicate (behavior) As a safeguard, confirm that the assessment is not underestimated. In order not to set the process up to fail.		
Allocation of Funding	Based on a person's assessment there will be an allocation of funding made. This funding will either be equated to a formula or will directly equate to a person's assessed needs.	Transparency & equity are important at this point and can be ensured by attaching a formula to the assessment. A banded system is the best as it allows for an amount of flexibility. <ul style="list-style-type: none"> • The Australian Government already operates such a system for its disability employment program. 	Verification as above	In this model the funding that is used to support a person in an accommodation services follows the person into the community sector when they choose to move back to the community.
Support Plan	The support plan provides an indication of how a person's needs and wishes will be addressed. Plans outline outcomes desired by the person.	How a plan is constructed will depend on the individual. <ul style="list-style-type: none"> • For someone who wants to take control then very little planning may be necessary as they will be making daily decisions. They may have an individual budget plan that outlines what they will spend their money on, as well as what expenses the plan does not cover. • Others may want a detailed plan according to the 	Assistance with Planning is offered. Person may develop own support plan (based on the principals of Person Centred Planning).	<ul style="list-style-type: none"> • Resource centers that employ Support Planners who are already a planning facilitator – e.g. social workers and case managers.

Submission to discussion paper – Disability Support Accommodation

Activity	Description of Activity	Who makes the decision	What happens in the UK	What happens in Wisconsin
		<p>supports they need. This may be with personal care, being part of the community or assistance with recruiting staff. Some people may choose to purchase some of their supports from different agencies.</p> <ul style="list-style-type: none"> • There will be different options for planning provided by independent organisations and individuals. <p>Centrelink Transition Officer may ask family, advocates or a specialist provider to draw up the plan with the person and family/friends.</p>		
Plan Verification	Plan is subject to review by a panel of 3 including Centrelink Transition Officer. Turnaround to be within 10 working days.	<p>Small panel</p> <ul style="list-style-type: none"> • Centrelink • Parent/Self Advocate • Other invited professional <p>Professional stream people need to be available to be consulted by panel if necessary e.g.</p> <ul style="list-style-type: none"> • Speech Pathologist • O.T's • Medical • Psychologists who have experience with how people communicate (behavior) <p>As a safeguard, confirm that the assessment amount is adequate.</p>	<p>At a subsequent meeting the care manager will review the process to date and the suggested support plan; if satisfied with the plan the care manager will agree the budget.</p> <p>There are published examples of existing assessment practice, and caps on pricing of standardized service responses.</p>	<ul style="list-style-type: none"> • Risk enablement panel • Person/people/organization having responsibility to be instrumental in this decision.
Budget	As part of support plan, a budget is drawn up so that appropriate	<ul style="list-style-type: none"> • Various types of budgets 		Individualised funding with the option of self-managed funding

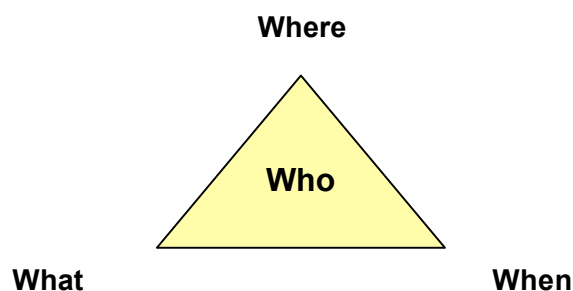
Submission to discussion paper – Disability Support Accommodation

Activity	Description of Activity	Who makes the decision	What happens in the UK	What happens in Wisconsin
	periodic payments can be made.			
Budget Holding	The person and mechanism for holding onto the funds	The important issue here is for the person to get the funds as and when they need them without any bureaucratic or administrative holdups. A dedicated personal bank account is the preferred option.	There are a number of opportunities: <ul style="list-style-type: none"> • Direct funding • Agent • Trust • Care Manager Policies and procedures for self directed support are available.	<ul style="list-style-type: none"> • Payments quarterly • Receipts/invoices related to plan
Support Guarantor, and Support Trustee	A support guarantor is a person who provides support as a last resort – if planned arrangements fail. A support trustee is a person who has regular contact with the person to ensure all is well.	To ensure that people with disability receive the support they need, two roles are necessary. Who these people are is decided by agreement between the person with disability and the Centrelink Transition Officer.	The Support Guarantor and Support Trustee process is used.	<ul style="list-style-type: none"> • Purchase any needs that are legal (not against criminal law) • Including vehicle • Equipment from other funding streams have priority, e.g, home assist. • If in plan you have priority
Regular Review of support	A review of support is necessary to ensure that as a person's needs change so does their funding and support. Also, a person's wishes and desires will change and these need to be accounted for. (10 working day turnaround)	There should be a regular review, every 12 months, with the provision that a review can be called for by the person or the support trustee at any time. 14 day turnaround	Reviews are conducted on a regular basis by care manager. People may need more or less support.	<ul style="list-style-type: none"> • Built into the model are 12 monthly progress reports.
Requested review of support	A review of support may be requested at any time. There are funds available for any increases that are verified. (10 working day turnaround)	Centrelink Transition officer and panel.	Review can be made upon request, to verify if there are any less or more requirements, either ongoing or one off.	

6. Response to Supported Accommodation consultation forums

Response to Supported Accommodation consultation forum questions.

1) At the consultation forums, the Government asked for comments on which of the following has priority?



In asking this question, it is evident that the Government is confused and/or in conflict over who to 'privilege' in developing this package. NCID wants to make it clear that people with disability should be the priority in any support package. Without people with disability, there would be no need to develop a support package. Throughout the discussion paper, there is a strong 'privileging' of the needs of providers. If providers and/or parents become the dominant focus of who the packages are set up for, it will inevitably fail to meet the needs of people with disability who want a supportive lifestyle — the Government will continue the dominant model of care that meets the needs of support staff and service providers and does nothing other than put a roof over the head of a person with disability (Westcott, 2003). This would be a great travesty of justice when there is new funding available to set up a package that, for the first time, can be developed on the grounds of scientific research and rationale. When you start from who the person is and what they need to live a good quality lifestyle, the person and the service is set up to succeed. The proof of this is that, around the world, people with disability and parents are living good lives that they have total control over. (<http://www.in-control.org.uk>). Additionally, there is a large body of literature which will be outlined in this paper that provides strong evidence-based practice on the key ingredients for supporting people with disability to live good quality lives.

2) A word on language: There is increasingly a strong body of literature that establishes the primary role that language plays in setting up that which it names (Hall,

1996, Redman, 2000, Butler, 2005). Throughout the consultation, the presenters used a number of terms that indicated there is a gap between what the Government is saying and what it is planning.

Firstly, parents provide lifelong loving care and support for all their children including any child who has a disability. Caring for their son or daughter with disability is only one of their roles. Through the entire document there is no mention of parents, only of carers. The Government needs to reinstate the primacy of parents and families in the lives of people with disability and recognize that families will always be involved in the life of their child with disability. Parents need to have some authority in the provision of family support type services in planning for the future of their children with disability and in teaching them the necessary skills for an adult lifestyle. The Government's package must meet the needs of the person with disability first and foremost which in turn will also meet the needs of parents because of the close relationship.

3) People with disability and the aged are two groups of Australians who currently pay the majority of their income in putting a roof over their head (Clear and Gleeson, 2000). There is a confusion here that has somehow evolved over the life of the DSP which needs analysing — the introduction of equity with other Australians is needed. If a government provides a roof over the head of other Australians via defence housing, public service accommodation, first home buyer's loans, rental assistance or public housing, a person is charged up to a third of their income in rent. The rest of their income is spent on food, clothing, healthcare and entertainment if it goes that far. People with disability need to be accorded the same treatment. If you earn a wage, be that DSP or salary, it needs to be substantial enough to live a good quality life. That means your income pays the rent, keeps you fed and healthy and lets you do some things you like now and then. To ask the poorest Australians who live in group homes and larger residential facilities to pay 85% of their paltry pension is a gross act of injustice. When lifestyle packages are provided, people with disability have the freedom to pay only some of their package on a housing option – the same way other Australians do in accessing a home.

4) Quality Assurance measures are ineffective in measuring how a service is meeting the needs and aspirations of a person living in the service. If the Government is seeking to measure how a service is being accountable for its funding, then the adoption of Quality of Life measures is needed which will give an explicit measure on what is happening to people in a service (Adams, Beadle-Brown and Mansell, 2006).

Community Benefits from supported community living

The benefits to people with disability of supported community living are becoming self-evident. What is not so obvious are the benefits to the general community.

An environment that not only maintains a person's skills but further develops their skills will mean:

- › better health outcomes for individuals, with a decrease in medical expenses
- › less reliance on formal supports by individuals, with a decrease in support funding
- › individuals equipped to get and hold a job, with a decrease in income support and an increase in taxation collected.

For the community there is a greater 'pool' of people who are able to participate in community activities (incl. employment, voluntary work, etc), this will lead to an expansion of community capacity. The local community will also benefit as people living in a community will be consumers of that communities goods and services.

Using market place principles in a supported lifestyle

The discussion paper asks many questions about the introduction of private providers and how to encourage them into the sector. It has been the experience of the "in control and community living styles" of support that the private sector will respond to the need developed in the market place. Indeed, these are the principles upon which the Commonwealth Government has lead the country over the last 11 years in allowing the market forces to act in all sectors. When the individual is left to live the life that they choose, the market forces will meet the requirements of individuals. Given this position, the questions relating to this sector relate to what is the role of the Government in funding support packages. Therefore, the role of government becomes one of:

1) ensuring equity between people with disability and that this is done via clear and transparent funding criteria, combined with

2) good assessment tools that ask people what they want and what they need (see possible tools at In Control website: www.in-control.org.au)

Finally some questions for the Commonwealth Government

Following the support accommodation consultations our members have some questions for the Minister and his Department:

- › Is it the role of the Commonwealth Government to establish a new disability service or to ensure equity of funding for all people with disability? — leaving the type of support that a person receives to be determined by the person and their families and or supporters!
- › Will the Government create a support system that is designed for the person with disability and that responds to his/her unique dreams and aspirations? — not a support network that is determined by the needs of service providers or government officials!
- › Will the Government play the role of funder? — leaving the person with disability to purchase any service (not restricted to the disability industry) that they wish!
- › Will the Government use evidence-based practice and person-centred practice as the foundation elements for all policy that evolves from this incentive?

Supported community living is not only for people with low support needs ...

Warren

Warren is 7 years old. He lives at home with his loving family and goes to school by bus every day. Whether Warren is happy with his life is hard to judge, but he seems so and his family regard him as a delightful young boy who has so much to give.

Warren had a traumatic birth and, as a consequence, needs 24hour support. He is unable to control his temper, is deaf and blind, is fed through a 'gastric button', has profound spasticity, requires frequent suctioning so that he can breath and profound intellectual disability.

Warren is supported at home by his family, with \$100,000 of funding to buy necessary aids and support hours from carers. The carers are employed by an agency with the recruitment, training and rostering being undertaken by the family, principally Warren's mother.

For the family, supporting Warren at home with his sister is the only option. Just as they would not send his sister away, so they would not send Warren away to a home or to a nursing home (options that have been suggested to them by the local community services department).

Warren's future is unknown. He was not expected to live until he is five and many expect him to be dead before he is 10 years old, but what he can be assured of is his family's determination to have him as one of the family.

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