Action for More Independence & Dignity in Accommodation

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Advocacy, Self Advocacy, Rights, Accessibility, & Community Living for People with a Disability

Feedback on the Specialist Disability Accommodation Pricing and Payments Framework

February 2016

Action for More Independence and Dignity in Accommodation (AMIDA) supports people with disability as valued members of our community. AMIDA recognises that people with disability contribute to and develop our community.

AMIDA acknowledges that people with disability have a right to a choice of who they live with and where they live. Further, people with disability have a right to good quality housing which is accessible, affordable and non-institutional. People with disability have a right to live in the community with access to support to participate and have a good quality of life.

AMIDA is an independent advocacy organisation which advocates for good housing for people with disability. We provide advocacy to individuals, with priority given to people with an intellectual disability, and advocate for change in systems which prevent people from achieving good housing.

AMIDA strongly supports the United Nations Convention on the Rights of Persons with a Disability and works to assert these rights and community inclusion for people with a disability

The following is feedback on the Specialist Disability Accommodation Pricing and Payments Framework.

Framework Part 1. Preliminaries. Vision and Context.

Australia is a signatory to the **United Nations Convention on the Rights of Persons with a Disability** Australia has an obligation to develop the NDIA in line with the UNCRPD. The Vision and Operating Context for Specialist disability accommodation under the NDIS needs to state that this obligation is part of the context in which the Framework is developed in particular;

Article 16 - Freedom from exploitation, violence and abuse
and

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others **and are not obliged to live in a particular living arrangement;**
b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to **prevent isolation or segregation from the community;**
c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their need

Sustainability may well be a key plank of the NDIA but sustainability is more than dollars and cents. Housing people in certain environments more likely to lead to abuse where they have no choice, person centred service or freedom from risk, is also unsustainable. Certain environments have more risk of abuse. The SDA framework must not legitimise and fund these settings or oblige people to live in particular settings such as institutions, cluster living or larger residential settings in order to receive support and with no plan for their redevelopment. The NDIS has to improve outcomes. The Framework provides a tool to leverage this change and for those providers who register, could insist on a time frame to make these changes in order to continue to have dwellings approved.

Research and numerous inquiries have shown us the cost to residents of larger institutional residential settings (Sobsey, (1994). French, P., Dardel, J., Price-Kelly, S. (2009), Civil Society CRPD Parallel Report Group (2012), Felce: (1998), McLean, Appendix 1.) The NDIS cannot allow this model to be legitimised and phase out must be part of the Framework.

Cluster villages attracted interest in the 1990's from governments keen to avoid institutions. However the evidence is in and research into cluster housing and resident group size is now showing that, on a whole range of measures, people with a disability do better in dispersed housing with small resident group sizes. This research also does not support the development of cluster housing. We direct you particularly to the report "Presenting the Evidence: Accommodation and Support for

People with Disability" by The Institute for Family Advocacy and Support. This research was undertaken by Family Advocacy NSW in collaboration with Lesley Chenowith from the University of Queensland and Trudy Van Dam from the Australian Catholic University. They reviewed academic and research literature on this topic and looked at cost effectiveness, staffing, supporting challenging behaviour, supporting people with complex health needs and self-management of funds. The overwhelming conclusion from the research is that larger forms of accommodation offer significantly poorer quality of life for people with disability than smaller forms of accommodation. In fact a number of housing models such as cluster options or villages, inner city town houses, complex behaviour units and 8-10 bed units are not supported by the literature examined in this review. Research has in fact shown that the larger the staff: resident group, the lower the level of resident activity and resident gains were found when the resident group size was reduced (Felce: 1998:110).

And not all people are suited to sharing even in smaller group homes. Group homes are fine for many people but one size does not fit all and choice of co-residents is a right we all must have. However even just looking from the financial perspective there is also the cost blow out in trying to manage tensions between incompatible residents, challenging behaviour and spending vast resources to try and ease the pressure through training programs and workshops, consultancies, meetings, appeals, investigations and assessments – the 'hidden costs' (Mansell 2007) of inappropriate placements.

Adherence to article 16 and 19 of the UNCRPD may on the surface appear to be unaffordable but in fact it is lack of respect for the rights of persons with disability that has led to a broken system which the Productivity Commission rightly found needed redesigning when they recommended the NDIS. The framework needs to place Australia's commitment to The UNCRPD in the Vision and Operating context of the Framework or we risk an unsustainable expenditure of resources establishing an NDIS which simply shifts the funding source but not the actual outcomes for people with disability.

One potential mechanism for ensuring new specialist disability housing complies with our obligations under the UNCRPD is to adopt the federal government guidelines for the Supported Accommodation Innovation Fund as these specified the accommodation must be non institutional and inclusive. Providers seeking to be registered as approved dwellings would have to be compliant with the Supported Accommodation Innovation Guidelines with a sunset clause for existing uncompliant accommodation such as institutions to be closed and innovative alternatives developed. This will be particularly important where private Special Residential Services (SRS) and Rooming Houses, who receive some funding, may seek to become registered under the SDA in order to tap a new funding stream. The SRS's in Victoria average 30 residents but are as high as 80. In the State Ombudsman's 2015 stage 1 findings of her Investigation into Disability Abuse Reporting, she

documented examples of paid government inspectors to the SRS system recording breeches of the regulation over months and years and were still unable to bring about compliance. SRS's have proven they are an intransigent, institutional, redundant model which cause harm and must not be supported or made legitimate by the NDIS. Tightening of the guidelines to rule out large residential settings which congregate and segregate people with a disability is required.

Resident rent contribution

We support the framework clause that maximum rent be 25% of the DSP and that rent excludes board. This should be 25% of received income to account to under 21 year olds whose pension is lower and the fact that some people will work. This way there will be no disincentive to increase work hours.

We note that vacancy management and renter's rights vary state to state at present and that work needs to be done to provide a rental rights framework equal to the rights of other citizen renters and consistent with the UNCRPD. AMIDA is willing to participate in this consultation.

Agency had capacity to pay more in exceptional circumstances

AMIDA support clause 58 of the Framework because it acknowledges the diversity of need that exists amongst people with disability and the fact that one size does not fit all.

Part 3

Participants with high support needs that can only be met cost effectively by specialist disability accommodation

This section talks about SDA being a way of meeting the high support needs of some people by sharing accommodation. It is not always the case. It can be more cost effective for some individuals to have Specialist Disability Accommodation which is individualised. The Framework must acknowledge this. Clause 58 implies this is possible. The following evidence comes from a submission to the Family and Community Development Committee of the Victorian Parliament in 2009.

SUBMISSION TO INQUIRIES INTO SUPPORTED ACCOMMODATION FOR THOSE WITH DISABILITY AND MENTAL ILLNESS
A joint submission by
VALID: Victorian Advocacy League for Individuals with Disability
STAR Victoria Inc. Advocating for people with an intellectual disability and their families.
REINFORCE Inc: Victorian Association of Intellectually Disadvantaged Citizens
AMIDA: Action for More Independence and Dignity in Accommodation

Individualised living arrangements for people with challenging behaviours

People with challenging behaviours are often placed in shared supported accommodation because of their intensive support needs. However, group housing is often the least appropriate model for them. A person with challenging behaviours has serious difficulties to share a home with other people. That person as well as their co-residents will all suffer from such an unsuitable placement, as evident in the account in Box 9 below. Challenging behaviours may be reduced if people are allowed and supported to lead a lifestyle based on their individual needs and desires, in more individualised accommodation settings.

Box 9

VALID reports constant complaints coming from people with intellectual disabilities and families about clashes between residents in group homes, particularly sharing in group homes with one or more people with challenging behaviours or autism. In one case, for example, five people with challenging behaviours were housed together in a CRU. The result was daily incidents, friction between the residents as well as their families and extreme pressure on all concerned, including the staff. Over this time, DHS spent vast resources to try and ease the pressure through training programs and workshops, consultancies, meetings, appeals, investigations and assessments – the 'hidden costs' (Mansell 2007) of inappropriate placements. Eventually, the housed closed down and all residents were transferred to other CRUs. Nevertheless, the problem of incompatibility has not been fixed – just transferred. It should be acknowledged that group living is inappropriate for many people with challenging behaviours, and that a more individualised and specialised approach should be taken to accommodate and support them.

• Evidence shows (see Box 10 below for example) that vacancies in shared supported accommodation in Victoria are often not filled because of the behaviours of some residents. It means that the efficiency of the whole service system is undermined by inappropriate placements of people with challenging behaviours in group settings.

Box 10

Michael, manager in a non-government support agency providing CRUs: "We have 3 residents in one of the houses … who have challenging behaviours, and can be quite aggressive... That's why we have three residents in a six- bedroom house. And we're supposed to have a fourth person in there, but we are not prepared to move another person with a challenging behaviour into the house, because we don't believe it will serve anyone's needs. And we'll be willing to talk about taking two people into the house … who didn't have challenging behaviours. But we're concerned about people being subjected to abuse, and so that has to be the right two people who will be strong enough".

Michael's account raises the impossible dilemmas which are inevitable when people with challenging behaviours are placed in group homes. On the one hand, it is not fair to house two people – even if they are 'strong enough' - in a house with three people who may be abusive; on the other hand, it is also not fair not to fill up vacancies with so many people on the waiting list in urgent need; and, it is not fair nor wise to cluster people with challenging behaviours together. Since each of these solutions is extremely unfair, it appears that the only way forward is to individualise supports for people with challenging behaviours (Vizel, 2009)

• An understanding that group housing is an inappropriate housing model for people with challenging behaviours, and placement in group homes has detrimental outcomes to them as well as for other residents, leads to the conclusion that people with challenging behaviours should be supported to move into more individualised settings with intensive supports.

• Despite the perceived additional costs of providing one-on-one supports for people living on their own, this is unlikely to be so in the long run as savings are made on the costly ad-hoc responses to problems created by incompatible residents in group homes and unfilled vacancies in group homes (see Box 9 for example).

• Once supported in a more compatible model, it is likely that some of the challenging behaviours will disappear and over time support requirements will decrease. Several organizations in Victoria have put in place individualised accommodation and support arrangements for people with challenging behaviours (See Box 11 for example), but such programs continue to operate as isolated 'best practice' cases and have not yet been adapted on a wider basis within the service sector despite the pressing need and placement in a CRU is still the default and only option considered in planning for people with challenging behaviours.

Box 11

Naomi is a 51 years old woman with an intellectual disability. She had first been institutionalised as a child and an attempt to move back to live with her mother failed as their relationship broke-down shortly after. After many years of wandering between different types of inappropriate accommodation in group settings, Naomi has only recently moved to live on her own under a new person-centred program led by the non-government organization that has been supporting her in her previous CRU.

After so many years, she finally lives in a place she can call home and where she would like to stay. Also, there are no other co-residents who suffer from her behaviour. Naomi was able to access individualised housing thanks to the availability of individualised funding and individualised planning mechanisms, as well as her relatively low level of support needs (which was not as low when she lived with other people as it is now when she is living independently). She finally has a real home where her obvious difficulty to live with other people is not constantly tested.

It is important that eligibility for SDA under the Framework looks at level of risk (clause 74) to others in the household due to challenging behaviours if living independently or with families or carers in the community. However if this is an assessed risk for families and carers it should also be an acknowledged risk for people with a disability who must not be forced to share accommodation with the person assessed as a risk.

In his discussion paper Organisational Capacity and people who at times exhibit challenging behaviour, Ian McLean from Golden City Support Services points to, 'The UK governments report into the Winterbourne scandal of 2011 revealed services that were purchased for people who were exhibiting severe challenging behaviour, under the guise of treatment centres, were institutional settings with aversive and restrictive interventions - all

elements linked to the worst outcomes for people with an intellectual disability - and in this case turned into abuse and other criminal acts. This is the potential magnitude of organisational risk when implementing inappropriate practices. The Winterbourne report contains the following reflection *"We should no more tolerate people being placed in inappropriate care settings than we would people receiving the wrong cancer treatment"* (Transforming Care: a National Response to Winterbourne View Hospital). See Appendix 1

AMIDA has welcomed the opportunity to feedback on the Framework and we would also welcome involvement in the further work to come in this area. Please inform us of the outcomes of this Consultation.

Regards,

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AMIDA

Appendix 1

Organisational capacity and people who at times exhibit challenging behaviour

February 2014
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Many disability support organisations report struggling to support people who at times exhibit challenging behaviour. The majority of services continue with practice that is shown to escalate or have almost no impact on challenging behaviour. This is despite a long history of research in this area which has identified effective practice. Many organisations are either unaware or unable to implement and maintain what is known to work. Paradoxically individuals and their families purchasing services are not encouraged to identify organisations implementing effective behaviour support practice. The aim of this paper is to reflect on ways to increase organisational capacity to achieve best practice in behaviour support for people whose lives are too often diminished through ineffective and risky practices.

Emerson (1987) was one of the first to define challenging behaviour in a way that recognised the impact on people's quality of Life:

"Severely challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities."

Why this is important?

All organisations supporting people with an intellectual disability will be supporting people who also have challenging behaviour – this is not a choice. For example, 80 - 90% of organisations providing services to people with an intellectual disability will have times when people exhibit aggressive behaviours, self-injurious behaviours or stereotyped behaviours (Mansell et al 2006); and, it is estimated that between 25% - 40% of people with intellectual disability will exhibit challenging behaviour (Fyffe **,** 1999**)**.

What we know about service design supporting people with challenging behaviour is that institutional care, 'special units' and grouping people with challenging behaviour in staffed housing are all associated with worse outcomes for all involved. Mansell's research suggests that typical support for people with severe intellectual disability is characterised by: reliance on punishment such as time out, 'logical' consequences, restraint; attention focused on problem behaviour and only 'managing the moment'; insistence on the right to exclude and restrict; poor communication; not enough to do; not enough help; inconsistent or no support and the needs of the organisation come first. Spicer and Crates (2013 ASID Conference in Sydney) demonstrated that organisations supporting people with challenging behaviour that adopt aversive or restrictive strategies rather than non-aversive reactive strategies are using the least effective, most unsafe strategies. The findings were that aversive or restrictive practices made the workplace **more unsafe** 46% - 47% of the time by escalating behaviour; showed **no reduction in risk** 42% – 43% of the time and was **only safer** 10% - 12% of the time. In contrast non aversive strategies linked to the function of a person's behaviour resolved the challenging behaviour, making the event safer 100% of the time. These findings provide a stark contrast for organisations that under Occupational Health & Safety legislation are required to reduce risks as much as 'is reasonably practicable'.

The UK governments report into the Winterbourne scandal of 2011 revealed services that were purchased for people who were exhibiting severe challenging behaviour, under the guise of treatment centres, were institutional settings with aversive and restrictive interventions - all elements linked to the worst outcomes for people with an intellectual disability - and in this case turned into abuse and other criminal acts. This is the potential magnitude of organisational risk when implementing inappropriate practices.

The UK Governments Transforming care: A national response to Winterbourne View Hospital recommitted to the directions of the Mansell Report i.e. the best outcomes for people who at times exhibit severe challenging behaviour are associated with small individualised services in a person's local community with skilled staff. (Mansell, Services for people with learning disabilities and challenging behaviour or mental health needs, DH UK, 1993 & Revised 2007). People with severe

challenging behaviour show the greatest improvement in quality of life when moved from institutional accommodation and institutional care to community living and skilled support (Mansell, Journal of Intellectual & Developmental Disability, June 2006; 31(2): 65–76) However, many organisations do not see behaviour support practice as 'core business' and do not develop organisational capacity to implement best practice.

Implications for organisations

Developing organisational capacity requires a comprehensive approach across the organisation to challenging behaviour to build and maintain the staff skill set that has been shown to be effective for the person being supported and safe for staff providing support. Every person/ organisation/ authority that relies on restrictions to make a workplace safe when working with people with an intellectual disability is on a downhill slope. Every new restriction is a new locus for a person's challenging behaviour – the positive behaviour support approaches are not the soft option – they are the safest option.

Organisations need to adjust their approach. First, the person showing these behaviours is not a 'problem' to be fixed, or someone doing something wrong that needs to be stopped; the behaviour is a sign that something – perhaps many things - aren't working for that individual. It shows that there is some need being unfulfilled, or a problem with communication. Unfortunately, even though for most people who have severe learning disability, these behaviours are not premeditated and are not designed purposely to upset, the emotional response they create in us tends to make us think that the person is deliberately trying to 'wind us up' or that they 'are only doing it for attention' (Scope UK)

Second, we need to understand the causes of challenging behaviours in people with an intellectual disability. These include behaviours arising from frustration with communication; feeling out of control, bored, anxious, unwell, overwhelmed or in pain (Ramcharan et al 2009) People with an intellectual disability are vulnerable to these causes of challenging behaviour as a consequence of a history of neglect, sexual or physical abuse, including some 'treatments'; restrictive environment which maximises confrontations; surroundings which an individual dislikes; lack of understanding of the meaning of non-verbal behaviour by staff and family; and low expectations of staff and family (Mansell et al 2006).

Third, research has identified where the capacity of an organisation and the skill sets of their staff need to be focussed. This includes Positive Behaviour Support; Person Centred Active Support; Total Communication; recognising and responding to mental health problems; Person Centred Planning and developmental learning (Mansell, Services for people with learning disabilities and challenging behaviour or mental health needs, DH UK, Oct 2007). Also identified through research are the organisational processes which mean staff respond optimally and sustain staff practice: clear practice-based leadership and vision, Person-centred, induction and refresher, practice competency based training in positive behavioural support, clear proactive intervention and prevention plans, Active Support, well-rehearsed reactive plans, staff supervision, weekly staff meetings, QA system, information driven practice, and proactive stress management for staff (Allen 2010)

Final reflections

In the absence of capacity to implement and sustain proven practice, organisations and their staff are left with the aversive and restrictive practice of punishment, chemical restraint, physical restraint, seclusion and more and more staff: these are high cost, low effectiveness and most unsafe options.

And people who benefit most from the richness of a community life miss out.

The Winterbourne report contains the following reflection *"We should no more tolerate people being placed in inappropriate care settings than we would people receiving the wrong cancer treatment"* (Transforming Care: a National Response to Winterbourne View Hospital).

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