interact australia
Building and Supporting Communities

Interact Australia (Victoria) Ltd
Submission to the Productivity Commission
Disability Care and Support April 2011

Introduction

Interact Australia commends the Australian Government for its call to the community to respond to the Draft Report and give direction on the framing of legislation for a new national disability care and support scheme.

We understand that the Government's principal objective is to consider a variety of models and how each would interact with Australia's health, aged care, informal care, income support and injury insurance schemes.

We are grateful for the opportunity to make a formal submission and present at this public hearing, so that the community may benefit input to our observations and findings, particularly in the area of Dual Diagnosis (co-morbidity of intellectual disability and mental health issues), Homelessness and Workforce Development Training and Support.

Further, Interact Australia (Victoria) Ltd welcomes the findings of the Productivity Commission Draft Report in particular:

- That there should be a new national scheme — the National Disability Insurance Scheme (NDIS) — that provides insurance cover for all Australians in the event of significant disability
- Support packages would be portable across state and territory borders, as would assessments of need.
- A creation of a separate no-fault National Injury Insurance Scheme (NIIS) for people requiring lifetime care and support for catastrophic injuries — such as major brain or spinal cord injuries.

We would like to set our comments in context

Interact has been in operation since 1991, providing community and employment services in Victoria and community and lifestyle services in Queensland. It also offers programs and services in Thailand and Kiribati. In 2010 it won the Not-for-Profit Network's Partnership Award as the lead agency in the SUSO project, providing transitions services for men leaving the corrections system.

Interact Australia wishes to make additional comments on some specific recommendations and areas of concern that we have identified.
Interact has extensive experience working with people with multiple and complex disabilities, predominantly intellectual disabilities (ID) and people with dual diagnosis. We also have experience working with prisoners while still in corrections and post-corrections to connect them into community support systems and housing. The organisation emerged from the de-institutionalisation of Kew Cottages in Melbourne, Australia's largest and oldest Institution for people with an ID. Interact therefore have both expertise and a long history in the provision of services to people with high and complex needs.

Chapter 3 – Who is NDIS for?

Tier 2 – ensuring appropriate support from any system

Interact Australia welcomes any attempt to provide consumers and their families with information and support through the disability 'maze'. Particularly by "bringing specialist disability services under

a single umbrella — the NDIS — will go a long way to streamlining the system".[1] As has been outlined in the Draft Report the 'disability service system' is different across jurisdictions and from region to region and within regions. For instance in Victoria, local government (with rate payer subsidies) is involved in the provision of many disability services (respite care, school holiday programs) which is not the case in other jurisdictions. The task facing NDIS in mapping the service system is enormous. Interact Australia urges the NDIS to take a nuanced approach to this mapping that reflects the strengths and weakness of the system. The NDIS will need to develop feedback and quality measures to ensure that referrals and information are current and not biased in favour of particular service providers.

Tier 3 – Creating a specific category of 3(b) for Intellectual disability

Interact supports the proposal outlined in the draft Report to specifically include intellectual disability as a separate group 3(b) in Tier 3 of receiving funding support.

Chapter 4 – What individualised supports will the NDIS Fund?

The Draft Report specifically states, "The provision of health, education, employment, housing, transport and income support will generally remain a mainstream concern. The NDIS would however, have a role in connecting people to, and where needed, supporting the activity of people in mainstream services."[2]

The Productivity Commission in the following discussion argues that there is the potential for the Health and other mainstream service systems to 'cost shift' their responsibilities and obligations to disabled people if the NDIS were to deliver in mainstream service areas. In our previous submission to the productivity Commission we outlined our concerns over co-morbidity of intellectual disability and mental health issues. These concerns are:

- There is increasing evidence to support the high prevalence of mental illness in adults with intellectual disability, with some studies suggesting that the prevalence may be greater than that of the general population (Chan, Hudson & Vulic, 2004; Cooper, Smiley, Morrison, Williamson & Allan, 2007; Hatton, 2002;). For example, a study undertaken by White, Chant, Edwards, Townsend and Waghorn (2005) found that people with intellectual disability are at high risk of developing co-morbid serious mental illness.
- Dual diagnosis is however, often overlooked due to difficulties associated with establishing a diagnosis of a mental disorder in people with an intellectual disability, a problem which is heightened when the individual's capacity to participate in a clinical assessment is limited.
- Research conducted in Western Australia found that overall, 31.7% of people with an intellectual disability had a psychiatric disorder; and 1.8% of people with a psychiatric illness had an intellectual disability. Schizophrenia was greatly over-represented among individuals with a dual diagnosis: depending on birth cohort, 3.7–5.2% of those with intellectual disability had co-occurring schizophrenia.
- Pervasive developmental disorder was more common among people with a dual diagnosis than among individuals with intellectual disability alone. Down syndrome was much less prevalent among individuals with a dual diagnosis despite being the most predominant cause of intellectual disability.
- Individuals with a dual diagnosis had higher mortality rates and were more disabled than those with psychiatric illness alone (Morgan, Leonard and Bourke & Jabkensky, 2008).

[1] Page 3.8 Disability Care and Support draft Report – Productivity Commission 2011
[2] Page 4.1 Disability Care and Support draft Report – Productivity Commission 2011

- The epidemiology of intellectual disability co-occurring with schizophrenia and other psychiatric illness is poorly understood. The separation of mental health from intellectual disability services has led to a serious underestimation of the prevalence of dual diagnosis, with clinicians ill-equipped to treat affected individuals.
- Interact's experience has been that many individuals with a dual diagnosis including ID are referred inappropriately due to the presence of behaviours of concern such as aggression or criminal offending behaviour.
- Many of our clients, particularly in Corrections environments have a dual diagnosis, however due to funding restrictions have to be labelled either as someone with an ID and take one stream of community care or be labelled as someone with a mental health issue and take another care pathway.
- Either way, while the care they receive is excellent, it usually only addresses one of their issues. As posited by Einfeld, Piccinin, Mackinnon, Hofer, Taffe, Gray, Bontempo, Hoffman, Parmenter, and Tonge, (2006), the problem of psychopathology co-morbid with intellectual disability is both substantial and persistent and suggests the need for effective mental health interventions.

Interact believes that given the prevalence of dual diagnosis in people with ID and the accompanying behaviours of concern, there is a real need for:

- Consultation and meaningful dialogue between the disability and mental health sectors to generate recommendations for future action and funding models;
- Opportunities for consideration of the needs of specific populations such as offenders and ex-offenders;
- Research to identify the existing gaps in service delivery;
- Opportunities for integrated clinical training solutions for practitioners dealing with people with complex behaviours as a result of ID and dual diagnosis;
- Opportunities for parents, friends and significant others to be involved in consultation and training opportunities;
- Funding for specialist interventions targeting the population who have an ID and mental issues;
- Recognition of the need to involve a range of other sectors such as the homelessness and alcohol and other drug sectors due to the high numbers of people dually diagnosed that experience significant disadvantage and that have complex coping mechanisms;
- More work on shared care pathways, early intervention and collaborative practice

Specialist accommodation support

Homeless people with Intellectual disabilities (ID) are amongst the most highly disadvantaged groups in the community. They require a unique understanding from service providers and developmentally appropriate approaches to assist them to access and maintain secure and affordable long term housing. Interact Australia approaches homelessness as a rights issue within the framework of the United Nations Conference on Human Settlements, which reaffirmed adequate housing as a fundamental human right.

The Victorian Supported Accommodation & Assistance Program (VSAAP) Data 2008 – 2009 of Clients with Intellectual/Learning Disabilities (Appendix One) shows that 826 clients received 1241 support periods in 2008-09. This is widely recognised as under reporting because clients may not fully divulge their situation at the initial Intake and Assessment nor give permission for this data to be collected.

Furthermore anecdotal evidence has identified a significant percentage of clients in Youth SAAP services are on the Disability Support Register (DSR) but are not being adequately supported by

current support programs. One youth agency (providing both Housing and Juvenile Justice Programs) in South East Melbourne reported to this writer that 30% of their clients were on the DSR.

In the Draft Report the Commission[3] highlights the need for the NDIS to provide homeless outreach services.

Interact Australia believes that the proposed outreach services should have a focus on:

- Supporting homeless individuals with complex needs to access and sustain tenancies in the homeless service system. Very often these individuals have behaviours of concern which are beyond the capacity of many housing service providers;
- Increasing the capacity of Supported Accommodation & Assistance Program (SAAP) services to respond to the complex and unique needs of clients with ID. Through sector wide training, providing secondary consultations for housing support workers.
- In addition to behavioural management supports for housing services the Outreach Support services could provide assistance to translate House Rules and Lease Agreements into 'Scope Easy English Writing' (See Appendix Two).
- The VSAAP data indicates that there are significant numbers of young people in the homelessness service system. We believe that NDIS could usefully intervene in developing specialist lead tenant accommodation that specifically target young people (18-21 year olds) with ID. The aim of such a service would be improving life skills and community participation options so that clients are able to maintain and sustain long-term tenancy options. These would be time limited interventions which build in 'Exit Planning' from the commencement.

Too often the housing and homelessness service sector lacks specific skills and knowledge to identify and support the needs of clients with an ID and the expertise to develop the communication and engagement strategies that may be required to work effectively with this client group. Many people with ID have complex communication issues, learning difficulties, challenging behaviours and/or interpersonal problems that are too often misread by service providers as non compliance or being oppositional.

For instance a Housing Support Worker has complained to this writer that a client was difficult to work with and always missed appointments and the flat was always messy. It was pointed out that ID clients had difficulty retaining information and the use of calendar and other communication tools could help. E.G. Monday - Wash sheets and change bedding, Tuesday – Wash clothes etc. When these tools were utilised the Housing Worker noted a marked improvement in compliance.

Capacity building within the housing and homelessness sector is key to addressing systemic barriers for people with ID to access housing services and appropriate support. The NDIS has a role to raise awareness amongst management and direct care workers of the complex issues faced by people with ID experiencing homelessness or insecure accommodation, highlight their responsibilities to ensure inclusive practice for this client group and provide information, resources and network contacts on strategies that are client directed and effective. In addition to developing training programs and resource materials the NDIS should promote inclusive practice, engagement strategies and self-advocacy approaches for people with ID in the homelessness and housing sectors. The NDIS could through relevant conferences, seminars, forums, workshops and journal articles provide leadership to the supported housing sector and to the wider community.

Employment and Training Services

[3] Page 4.8 Disability Care and Support draft Report – Productivity Commission 2011

Since our inception 20 years ago Interact Australia has been active in encouraging employment for people with a disability. As a provider of Disability Employment Services Interact Australia supports the recommendation that "The Commission considers that employment services should remain a mainstream concern. However, a clear exception would be 'job readiness' programs (targeted support) currently provided by the disability services sector."[4]

Chapter 5 – Assessing care and support needs

Interact Australia agrees with the Draft Report that:

> "A robust process for determining who gets what will be critical for both scheme users and administrators. An assessment tool must provide a reasonably close estimate of a person's support needs and the resource allocation to achieve it. It should avoid being too generous or too tough. The process must be fair, rigorous and safeguard against exaggerated claims of support needs."[5]

We have concerns that the current process of Special Needs Assessments (SNA) has come close to be used primarily as a 'rationing tool'. Clients in our services have experienced:

- Inconsistent assessments from assessors in the same region and between regions;
- Long waiting lists to access new assessments as they age or their health deteriorates;

Section 5.8 of the Draft Report discusses when assessments should occur Interact Australia agrees that "reassessments should occur when it is has been agreed that an individual's circumstances have changed, or are about to change, such that a review of their care and support needs is warranted." [6]

We believe that the process of reassessment needs to be responsive to the sometimes fast changing needs in the lives of people with ID. We have a young client with a relatively recent SNA assessment (made at the transition from secondary school). However, 18 months later he is showing signs if increased cognitive difficulty possibly brought on by early onset dementia. His care and support needs have become more complex and his Individual Support Package is inadequate to meet the changed circumstances. His family have requested a reassessment and our client has been placed on a waiting list which we are advised may take up to 2 years. Interact Australia strongly believes that the NDIS needs to have the infrastructure capacity to respond in a timely fashion to the needs of disabled people and their families whilst 'maintaining professional objectivity' as outlined in the Draft Report[7]

Chapter 13 – Workforce issues

Interact Australia believes that our workforce is our strength. We fully endorse the Draft Recommendation 13.1.

However we have concerns that Draft Recommendation 13.2 may place vulnerable people at risk. Interact Australia has always viewed spent convictions within the context of an employment applicants 'whole of life'. We would view with concern moves to change disclosure on spent

[4] Page 4.13 Disability Care and Support draft Report – Productivity Commission 2011
[5] Page 5.2 Disability Care and Support draft Report – Productivity Commission 2011
[6] Page 5.22 Disability Care and Support draft Report – Productivity Commission 2011
[7] Page 5.21 Disability Care and Support draft Report – Productivity Commission 2011

convictions. Or to limit police checks to "apply only in cases where both the person with a disability is vulnerable AND the risks associated with delivery are sufficiently high"[8]

Maintain low barriers to working in the sector

In regard to page 13.26 we are particularly concerned about the assertion that, "most employees need relatively simple formal qualifications, if any. Their most important skills are informal – a capacity for empathy, an interest in working with people, flexibility and personal experience – skills that are less readily taught or testable in educational institutions".

The majority of our staff holds formal qualifications (certificate, diploma, degree qualifications). Interact Australia's primary need is not in the area of education that leads to qualification, but rather in ongoing learning and development to maintain and enhance skills and knowledge in a changing workplace environment – multi-skilled e.g. ageing population, disability and mental health.

Organisations need access to flexible and affordable learning and development resources that may be implemented by the organisation in the workplace, rather than e.g. attending workshops. Organisations have to pay for the training, the staff hours to attend training, and the staff hours to backfill staff to attend training. This is not financially viable for small – medium size community service organisations.

Flexible and affordable learning and development resources aim to:-

- Providing consistent core skill foundation through induction, refresher training, and professional development
- Providing resources that are convenient , cost efficient and effective
- Minimising loss of productivity and disruption to client service provision
- Improving staff and organisation capabilities and capacity
- Improving quality of service
- Improving supports for people with a disability
- Facilitating a sustainable and skilled workforce
- Facilitating better practice and continuous improvement to meet emerging trends within the sector, and to meet the diverse personal and support needs of people accessing services.

For outcomes to be achieved in self directed approaches, community service staff skill sets are changing. Now, staff skills are to facilitate community development through acquiring and maintaining networks and partnerships to enhance social participation and inclusion of people with a disability as valued citizens in addition to providing personal and health care. That includes assistance with medication administration, peg feeding, colostomy bags; shunts, manual handling, specialised communication tasks.

Disability is a specialised field and staffs needs to be provided with a quality standard of ongoing training – there are many different types of disabilities, including multiple and complex needs (MCN). Dumbing-down the need for trained staff and replacing professional skills with "empathy" and "relatively simple formal qualifications if any", diminishes the level of need experienced by

[8] Page 13.29 Disability Care and Support draft Report – Productivity Commission 2011

our clients. If put into practice, this laissez-faire attitude and policy, would breed disillusionment amongst staff, increase frustration and by default may encourage abuse.

Staff stress and burnout are mentioned in the Productivity Commission's report. The importance of appropriate staff: client ratios are critical and needs adequate funding. Appropriate and regular staff supervision and debriefing is essential and there are costs associated with it. As a society we are ageing and more people are accessing our services. There are more deaths and more emotional stress in the training and support roles. The report also mentions aids and equipment. Sites need mobile hoists, to reduce manual handling risks.

In terms of staff stress I have received regular feedback that it's both the physical side of the work, in addition to the emotional side of the work, that cause staff stress and distress and are significant factors in staff leaving our employment and leaving the field.

Conclusion

We are grateful for the opportunity to present at this public hearing and we applaud the Government's desire to improve disability care and support, consistent with community norms for upholding people's rights and for social justice, which are not fully recognised in current arrangements.

We agree that the costs that fall on people with disabilities, their families and carers should be amongst a wider group of people, through a form of social insurance as the most equitable and efficient manner of sharing the cost burden.

We offer our comments to you, in good faith and in the hope that they will be taken into account during the next compilation of the Commission's report on Disability Care and Support.

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Appendix One

Victorian Supported Accommodation & Assistance Program (VSAAP) Data 2008 – 2009 Clients with Intellectual/Learning Disabilities

The protocols established for the Victorian Homelessness Data Collection (VHDC) require that clients provide consent to collect certain information. If a client's consent is not obtained, only a limited amount of information is provided to the AIHW. As disability is a consented data item, all tables provided here only include records where consent was provided. This may lead to an underestimate of support periods and clients with an intellectual/learning disability.

There are two levels of data provided—support period and client. A support period is a discrete period of time during which a client receives some form of support from an agency. A client can have multiple support periods over the course of a reporting period (financial year). Client estimates are only able to be created for clients who provided consent and a complete statistical linkage key (statistical linkage keys allow data collected on separate occasions from the same person to be combined without identifying the person).

Table 1: Number of VSAAP support periods and number of VSAAP clients with an intellectual/learning disability, Victoria, 2008–09

	Number
Support periods	1,241
Clients	826

Notes

1. Number excluded due to errors and omissions: 0.
2. The disability of the client is a consented data item. Table includes only records where consent was provided.
3. The number of clients in this table refers to records where a valid SLK was obtained. One record per valid SLK is counted.
4. Data are unweighted.

Table 2: VSAAP clients with an intellectual/learning disability, by age, Victoria, 2008–09

Age (years)	Number	Percent
0–14	11	1.33
15–17	104	12.59
18–19	121	14.65
20–24	199	24.09
25–29	84	10.17
30–34	68	8.23
35–39	83	10.05
40–44	57	6.90
45–49	45	5.45
50–54	25	3.03
55–59	16	1.94

60–64	6	0.73
65+	7	0.85
Total	**826**	**100.00**

Notes

1. Number excluded due to errors and omissions: 0.
2. The disability of the client is a consented data item. Table includes only records where consent was provided.
3. The number of clients in this table refers to records where a valid SLK was obtained. One record per valid SLK is counted.
4. Data are unweighted.

Table 3: VSAAP clients with an intellectual/learning disability, by sex, Victoria, 2008–09

Sex	Number	Percent
Male	366	44.31
Female	460	55.69
Total	**826**	**100.00**

Notes

1. Number excluded due to errors and omissions: 0.
2. The number of clients in this table refers to records where a valid SLK was obtained. One record per valid SLK is counted.
3. Data are unweighted.

Table 4: VSAAP clients with an intellectual/learning disability, by Aboriginal and Torres Strait Islander status, Victoria, 2008–09

Aboriginal and Torres Strait Islander status	Number	Percent
Not aboriginal or Torres Strait Islander	729	91.58
Aboriginal and Torres Strait Islander people	67	8.42
Total	**796**	**100.00**

Notes

1. Number excluded due to errors and omissions: 30.
2. The number of clients in this table refers to records where a valid SLK was obtained. One record per valid SLK is counted.
3. Client characteristics are based on the first visit by that client in the reporting year.
4. Data are unweighted.

Table 5: VSAAP support periods for clients with an intellectual/learning disability, by main reason for seeking assistance, Victoria, 2008–09

Main reason for seeking assistance	Number	Per cent
Time out from family/other situation	99	8.20
Relationship/family breakdown	182	15.07
Interpersonal conflict	51	4.22
Sexual abuse	*	*
Domestic/family violence	211	17.47
Physical/emotional abuse	19	1.57
Gambling	*	*
Budgeting problems	31	2.57
Rent too high	11	0.91
Loss of income	33	2.73
Other financial difficulty	23	1.90
Overcrowding issues	49	4.06
Eviction/asked to leave	112	9.27
Emergency accommodation ended	38	3.15
Previous accommodation ended	93	7.70
Mental health issues	41	3.39
Problematic drug/ alcohol/substance use	25	2.07
Diagnosed psychiatric illness	6	0.50
Other health issues	19	1.57
Gay/lesbian/transgender issues	*	*
Recently left institution	26	2.15
Recent arrival to area with no means of support	14	1.16
Itinerant	25	2.07
Other	96	7.95
Total	**1,208**	**100.0**

Notes

1. Number excluded due to errors and omissions: 33.
2. The disability of the client is a consented data item. Table includes only records where consent was provided.
3. Some cells in this table have been confidentialised and replaced with '*'.
4. Data are unweighted.

Table 6: VSAAP support periods for clients with an intellectual/learning disability, by type of support needed/provided/referred, Victoria, 2008–09 (number)

	Needed	Provided	Referred
Assistance to access housing services			
Assistance to access crisis/short-term emergency accommodation	*	*	*
Assistance to access transitional housing	*	*	0
Assistance to access long-term community housing	*	0	*
Assistance to access public housing	11	6	*
Assistance to access long-term private rental	10	10	*
Assistance to access long-term other	*	*	0
Housing support services			
Crisis accommodation support	149	121	44
Transitional housing support	132	89	47
Medium-term housing support	70	47	17
Long-term tenancy support	126	86	36
Other housing support	83	57	17
Support services			
SAAP/CAP accommodation	98	70	28
Assistance to obtain/maintain government allowance	40	33	10
Employment and training assistance	48	32	17
Financial assistance/material aid	161	149	21
Financial counselling and support	59	46	16
Incest/sexual assault	7	4	5
Domestic/family violence	114	109	13
Family/relationship	107	81	19
Parent support	35	25	7
Emotional support	254	245	12
Assistance with problem gambling	*	*	*
Living skills/personal development	170	147	13
Assistance with legal issues/court support	57	46	10
Advice/information	406	396	9
Retrieval/storage/removal of belongings	32	30	3
Advocacy/liaison on behalf of client	260	247	27
Psychological services	45	32	12
Specialist counselling services	27	11	18
Psychiatric services	12	*	9
Pregnancy support	7	6	*
Family planning support	5	*	*
Drug/alcohol support or intervention	31	12	20
Physical disability services	*	0	0
Intellectual disability services	23	5	9
Culturally specific services	11	9	*

Interpreter services	*	*	*
Assistance with immigration issues	*	*	*
Health/medical services	57	35	25
Tenancy/property management	21	13	7
Meals	66	61	*
Laundry/shower facilities	47	44	0
Recreation	44	40	*
Transport	84	79	*
Other	117	108	12

Notes

1. Clients can receive multiple services within a period of support.
2. The disability of the client is a consented data item. Table includes only records where consent was provided.
3. Some cells in this table have been confidentialised and replaced with '*'.
4. Data are unweighted.

Table 7: VSAAP support periods for clients with an intellectual/learning disability, by person receiving assistance, Victoria, 2008–09

Person receiving assistance	Number	Percent
Person with children	162	13.10
Couple with children	60	4.85
Lone person	898	72.59
Couple no children	67	5.42
Group of unrelated persons	22	1.78
Other	28	2.26
Total	**1,237**	**100.00**

Notes

1. Number excluded due to errors and omissions: 4.
2. The disability of the client is a consented data item. Table includes only records where consent was provided.
3. Data are unweighted.

Table 8: VSAAP support periods for clients with an intellectual/learning disability, by DHS region, Victoria, 2008–09

Region	Number	Percent
Eastern Metropolitan	111	8.94
North & West Metropolitan	236	19.02
Southern Metropolitan	377	30.38
Barwon-South Western	71	5.72
Gippsland	103	8.30
Grampians	116	9.35

Hume	86	6.93
Loddon Mallee	132	10.64
Statewide	9	0.73
Total	**1,241**	**100.00**

Notes

1. Number excluded due to errors and omissions: 0.
2. The disability of the client is a consented data item. Table includes only records where consent was provided.
3. Data are unweighted.

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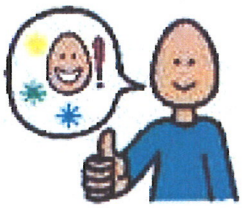
Productivity Commission
Disability Care and Support
Easy English Example

Appendix Two

Do you need support?

- This information is written in an 'easy to read' way.
- We use drawings, pictures and photos to highlight key points.
- You might need support to read this information.
- You might need assistance to understand what it means for you.
- Friends, family member, staff, advocate or support person can assist you.

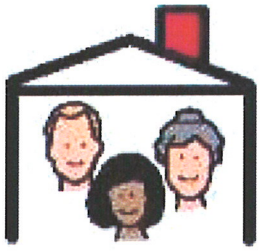


A support person can use:

- Clear, simple language
- Pictures, photos or real objects about this book
- Other information, for example video, DVD, internet websites

Accommodation House

Everyone has a responsibility to take care of the house



Staff

Staff are always at the house.

Staff can help you. You can talk to staff about what you want and get help.

Being involved.

Moving is a time when people think of many things.

Moving to your new home can be confusing.