FOR PEOPLE WITH A DISABILITY

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In March 2011, a group of people with disabilities, who are members of Scope's Community Educators Group, came together to read and discuss the Productivity Commission's Draft Report into a proposed National Disability Insurance Scheme.

The Community Educators Group is a team of people who all have a disability, and who provide training to members of the community to help them understand the complexities of a life with disability. The Community Educators Group joins with several other teams within Scope to provide this training: primarily with the Disability Educators Group, Scope Young Ambassadors, and the Community Inclusion and Development department – and their influence is growing throughout the organisation.

The following members of the Community Educators Group were able to attend this discussion regarding their impressions of the Productivity Commission's Draft Report: Viviana Ortolan, Shane Kelly, Tim O'Keefe and his father Danny O'Keefe, Cameron West, Ron Morey and Irene Kwong. They were supported on the day by professionals who work in the field of Disability: Libby Price (speech pathologist), Julie Edginton (trainer and direct support worker), and myself, Annie Millar (speech pathologist and team leader of the Disability Educators Group). As their Team Leader, I chaired the meeting and took notes about people's individual and group ideas.

One of the team members, Irene Kwong, made a separate individual submission to the Draft Report Enquiry. Shane Kelly wrote down his thoughts later in the piece which features in the Advocacy section of this summary.

The rest of the team members asked me to represent their thoughts in a group submission here.

There were a number of reasons for that, but Viviana Ortolan has given me permission to explain her reasons as a case in point. Viv's story, provided at the end of this submission, underlines yet again, the need for the types of changes that the Productivity Commission is proposing, and endorses a great many of the solutions offered in its Draft Report.

Summary of Response.

The Community Educators team, supporting the Disability Educators Group, and Scope Young Ambassadors, congratulate the Productivity Commission on their exhaustive research into the dilemmas faced by people with disabilities throughout Australia.

As a group of people with disabilities who have spent many years educating the community on these issues, they welcome the Productivity Commission's outline of a scheme which would go a long way towards solving many of those life-draining problems.

The Group was encouraged that emphasis was placed on a resource-allocation process that would be "*person-centred and forward looking*" and which would "*consider the supports that would allow a person to fulfill a range of functions, rather than only respond to what an individual cannot do*". This gives the Group hope that this would be an 'enabling' system, rather than one aimed at a maintaining a recipient's vital signs, without regard to their vitality.

Section 3.3 Tier 1 — minimising the impacts of disability
Societal attitudes, awareness and inclusion

The Community Educators Group enthusiastically applauds the Commission's recognition that "*societal attitudes and practices are potentially just as disabling as the conditions themselves. In this sense, influencing attitudes and practices in society may be one of the most significant roles of the NDIS, outside of its role of directly providing much needed supports*."(3.5)

However, the group is concerned that there are inadequate recommendations in the Draft Report that people with disabilities be involved directly and consistently in changing the attitudes of other community members about people with disabilities.

In their work, members of the Group experience the powerful impact of talking directly to people and teaching them how to understand and interact with people whose abilities are different to theirs. Their audiences report, after every session, that they understood the experience of disability so much more vividly having had the chance to meet someone with a disability personally and hear their story first hand.

The Community Educators Group believes strongly that as “trained ambassadors for disability”, working to promote inclusion at personal, community and systemic levels, many people with disabilities could find personally and financially rewarding employment, and thereby fulfil a number of the goals of the NDIS in Tiers 1, 2 and 3. Such ‘ground-tilling’ training to enhance their inclusion into different communities, should also be promoted and made available to people to select as an element of their personal entitlement packages, in Tier 3.

Importantly, in Tier 1, the NDIS could have power to preferentially endorse and support disability and inclusion awareness training that is both developed and delivered by people with disabilities, and should insist this preferential ability as another means of fully enabling people with disabilities to reach their potential.

3.8 Implementation issues

The group also wishes to express their fervent hopes that the current bank of knowledge of people’s needs, as well as their current entitlements, (so hard won), would not be lost in the implementation of a new system. The Group understands that the Commission is fully aware of this concern, expressed in section 3.8 *“This raises the question of whether a so-called ‘no-disadvantage’ test should apply. The Commission understands the intrinsic appeal to current service users in disadvantage tests and that people would seek some undertaking that they be no worse off under new arrangements. However, beyond the much greater funding of the NDIS, a further protection against the risk of losing supports is that the nature, frequency and intensity of a person’s support needs would comprehensively and objectively assessed. The assessment process would be person-centred and forward looking. It would consider the supports that would allow a person to fulfil a range of functions, rather than only respond to what an individual cannot do. In that context, the Commission does not consider that ‘no disadvantage’ tests would be appropriate. This reflects the practical complexity of such arrangements, the fact that needs change from year to year anyway and their unfairness — given assessment of needs under the NDIS will be objectively based rather than inferred from past service use”*

However, the Community Educators Group wants to underline that, in the implementation phase of any new system, anxiety levels of potential recipients are going to be high. Regardless of the levels of reassurance given by the administrators, nothing will allay people’s fears or remove obstacles to implementation like a ‘no-disadvantage’ test, and nothing will obstruct the implementation of a new system like fears of disadvantage. If the conversations around this topic within the Community Educators Group are any indication, great efforts to quell concerns of disadvantage will need to be made by the administrators, if a ‘no-disadvantage’ test is dismissed as an option.

Advocacy

The Community Educators were particularly pleased to note in the Draft Report's Table 1, (outlining how the new Scheme plans to overcome the problems of the current system), that one measure for improving people's "*confidence about the future: what services will and will not be available*" , will be to institute "*Strong complaints, appeals and advocacy arrangements*".

This and several other references to advocacy throughout the Draft Report document, have, for the most part, allayed the Group's fears about at potentially diminished role for advocacy under a new system.

However, the Community Educators Group has one important recommendation regarding the role of advocacy services at Tier 3, which is made below.

As the Report notes, in a sector which has grown organically as needs arose, like a shanty town, fragmentation is inherent and *"Advocacy groups, support groups and other networks have been an important response to this. Among other things, they provide information and advice to people with disabilities, and highlight gaps or other problems to service providers and government agencies*" (8.12)

There was some concern within the Community Educators Group that in an effort to create a streamlined, architecturally designed "Canberra-esque" system, agitators and educators such as those employed by advocacy groups may find themselves 'ironed out' of a slick new scheme.

The Report states the Commissions preference to the contrary however, "Work *would be needed with interested support and advocacy groups to plan how to build confidence so that people with disabilities will exercise choice in the new arrangements. People with disabilities and their carers will be looking for information and guidance about the assessment procedures, case management, self-directed funding and complaints mechanisms. Existing disability organisations and advocacy groups should play a key role in disseminating this information*" (17.6) .

In our initial discussions, there were also queries within our Group regarding the potential independence of advocacy services from the influence of the National Disability Insurance Agency administrators.

In the Overview of the proposed NDIS, advocacy is specifically mentioned in the list of services which would sit outside the NDIA (Overview 31). In another reference to the independence of advocacy as a service, the Draft report states in relation to cost-saving, that "*One way to… (reduce)* *other transaction costs by making information flow more effectively throughout the market for disability support services and equipment) is through the systematic compilation of information about service providers, into a single searchable database…..Ideally, a service provider database should:*

- *be easy to find and use, particularly in terms of searches for type and location of service. It should **also** include both **advocacy** and relevant mainstream services*" (8.13) (emphasis mine)

The Draft report pleasingly refers to the potential role of advocacy groups in developing National Standards, and even goes on to mention an example of advocacy in relation to the potential for service-specific disability standards that recognise the diversity of different disability services (8.29).

Recommendation regarding Availability of Advocacy at Tier 3

Disappointingly, it is not made explicitly clear in the report, however, that an individual can elect to purchase personal advocacy services as part of their entitlement package, and this element requires greater emphasis and elaboration within the report. Shane Kelly's personal response below highlights the importance of the issue of access to advocacy for people with disabilities.

Shane Kelly's Personal Response to the issue of Advocacy.

The idea of creating an insurance scheme that covers all funded disability services through out Australia is long overdue. I myself love the idea, but I am concerned about people who have multiple disabilities like people who can't talk at all, people who can't communicate freely, and or people who don't understand what is going around them and need an advocate for all aspects of life.

A National Disability Insurance Scheme needs to develop a system where all people are treated as equal, regardless of the level of their disability. This system should not discriminate against anyone with a disability.

The role of advocacy should be clearly defined, and should sit away from service organisations, so no conflict of interest can interfere with the day-to-day working of the scheme for people with disabilities.

Advocacy gives people with disabilities a way to deal with issues and problems that they have with the workings of the scheme, such as the level of funding they receive, the type of equipment they are given, and the attitudes of the person dealing directly with people with disabilities. It should be a basic service that everyone can have access to.

I would like to stress that advocacy should be completely separate from the National Disability Insurance Scheme.

In summary, the Community Educators Group would like to present "Viv's Story" – the true and current situation facing one of our most long-standing and loved members. We hope that it will give still more emphasis to our endorsement of the Productivity Commission's Draft Report into a proposed Disability Care and Support Scheme.

Viv is a published writer and poet, who was one of the founding members of the Disability Educators Group, in the late 1990s. Viv has been a driving force and guide behind much of the community education that the Disability Educators have provided to thousands of people since then. She is deeply thoughtful, and expresses herself elegantly and with dark wit. Her written work stuns audiences with its biting but humble directness about her life as woman who has a significant physical disability. Her presentations are funny and moving, and they command respect.

Ordinarily, Viv would have gladly written a powerful response to the Draft Report into a National Disability Care and Support Scheme. She has been a careful and wise advocate for people with disabilities throughout her adult life, and she has dreamed of the chance to join in serious, potentially life-changing, society-wide debate about improving funding, supports and choice for people who have a disability.

But at the moment she cannot. Her vision, on which she has relied for her dearly-held independence of expression, has substantially deteriorated over the last 18 months. She can still see to a degree, and she can still write, but the process is so much slower. Slower than the 2-3 words per minute that she could type before, using a probe in her right hand which she presses into a specially modified keyboard.

But that is not why she cannot write this response now. She cannot write because she cannot concentrate on the analysis of theoretical concepts of support and choice at the moment – she is too busy just trying to survive with very little of either.

Viv's mother has become very unwell, and has been hospitalised, and her frail and aging father is unable to care for her as her mother did. Viv is spending week after week in Respite care, where her access to a computer is minimal.

Now her efforts go into managing her day-time work in a supported employment service, and into communicating her everyday needs to casual and unfamiliar staff in an ever-changing respite setting.

On weekends she must return to her family home, to the grief of her mother's absence - the absence of her mother who intuitively provided for her needs, emotional and physical, so that she could concentrate on thinking and writing.

Now at home, Viv spends her energy training and retraining a string of agency support personnel to make sure they know what she can do, and what they need to do, to assist with her toileting, meals, dressing, etcetera.

And at this stage, there is nowhere else that is reasonable for her to live.

As the Draft Report states in its recommendation 5.2, the processes informing an ideal support scheme *"should be person-centred and forward looking and consider the supports that would allow a person to achieve their potential in social and economic participation, rather than only respond to what an individual cannot do*".

Viv's story tells us that an Enabling Support Scheme must ensure for people with disabilities one of Maslow's fundamentals for survival – shelter. It is reassuring to see that the Draft report acknowledges that "*Given the capital-intensive nature of specialised accommodation services and the current deficit of places, this particular issue warrants further discussion*" (4.4).and that "*Given the* *shortfall in specialist housing, and the consequent impact on families, the Commission has explored some more inventive housing options*." (4.6).

It is to be commended for the fact that the Commission's 'inventive options' recognise that we all make trade-offs in our choice of accommodation, based on how our priorities intersect with our budgets.

But the Commission most importantly acknowledges that for people with disabilities, often there just aren't enough options to allow people to even discuss their priorities, let alone exercise them - as the Commission puts it, "*for many people with disability — particularly those that require specialist disability housing — their choices are constrained*." (4.6).

A good support scheme must at a minimum allow people, so far as is possible, to live with housemates who have chosen each other, or have chosen the level to which they need to interactive with each other, as most adults in our community expect and strive for.

Everyone of us deserves a safe 'home-base" where we are nourished and protected, from which we can go out and contribute to the common good, and then return to renew ourselves.

When your own body or sensory system takes a great portion of your energy and time, just to control it or to modify its interactions with the outside world, your shelter has to be a refuge from the days efforts.

One of Viv's longest standing colleagues and dearest friends, has had a similar struggle to "achieve his potential in social and economic participation", because he has never had a home where he felt that he had a reasonable level of control over his environment, or over the way the people in it behaved – neither those who lived there nor those who worked there.

His story is about the balance of power, and the fact that it is always in the hands of the 'able bodied, typically communicating' people. As another of his colleagues, who uses speech, has said "even though I can talk, all I can do is ask people to do things for me. I can't make them do anything. I can't do the basics for myself. I'm still completely dependent on other people deciding whether or not they'll do what I have asked of them."

A National "Enabling" Insurance Scheme, such as that proposed by the Productivity Commission, which focuses on the supports that someone would require to reach their greatest potential, could have enabled Viv to set up an independent lifestyle for herself decades ago, before her parents became unwell.

Such a scheme as the Draft Report outlines would have helped Viv, as a young adult, to chose, train and remunerate staff she could trust in her home and at work, as is suggested in Draft Recommendation 6.1. That is, of course, as long as the 'cashing out' it refers to, gave Viv enough money to keep pace with the necessary improvements in pay for direct support workers.

If workers aren't recognised for their skills and intelligence as support people, they won't stay long in the profession. Without good staff, Viv could not spend her energy on achieving "her potential in social and economic participation".

Viv has achieved all that she has because she has had the unceasing efforts of her family to help her meet her basic needs, so that she could spend her spare energy aiming for higher goals.

Her disability means that just the effort of sitting upright takes its toll, and every other task adds to the physical strain, so reaching the middle of Maslow's triangle is hard enough, let alone the self-actualisation at the top.

Viv's story reinforces the Draft Report's observations that a new scheme needs to ensure that there is adequate funding for the expertly trained personnel, who could assist people who have complex communication needs, to express themselves: Referring to people's mental health, the Commission does state that "*The NDIS would have a significant role in meeting the support needs of individuals with a dual diagnosis*" (3.26) .

However, whilst the scheme clearly recognises the need for adequate counselling for carers to be funded through the NDIS, less emphasis is placed on the counselling needs of those who experience a disability personally – especially those who do not use typical speech to express themselves.

A truly Enabling Scheme would give Viv the chance to use her 2-3 words a minute communication device, to work through her grief over her mother's illness. No one in Viv's life currently has the extraordinary amount of time and expertise to properly help her make life-changing choices about where and with whom she might live.

She needs help to work through the overwhelming anxiety she feels about facing a life of unpredictable, poorly paid support, after forty-nine years of loving family care. An "Enabling-Scheme" would recognise that the sadness and confusion, joy and understanding, that we all feel at different points in our lives, are all felt every bit as much by people who have significant physical and communicative impairments as by anyone else on the planet. Their opportunities to release those emotions are often very different, though.

People who do not live with a disability can talk through with friends and counsellors, or express themselves legitimately in art or sport or fights or sexuality or any number of other ways.

An Enabling Scheme would recognise and fund for the fact that, for people who are physically dependent, their chances to sort through and helpfully express their humanity-bound feelings, depend very much on time-intensive opportunities provided by other people. An Enabling Scheme would give Viv the choice to set up her life so that she could give the time and energy she needed to self-understanding and expression - pursuits that everyone in our society assumes as a necessity and a right.

This would bolster her mental, emotional and physical health throughout her life, and of course, in times of crisis, such as the one she is facing now.

For the first time in Viv's life, the Productivity Commission's Draft Report offers real hope that the radical changes, so desperately needed in the disability sector, will be made. It is hoped that these changes will allow people with disabilities "to boldly go where everyone else has gone before".

If properly implemented, the proposed Scheme will allow people with disabilities to reasonably expect that they will have a level of input which is similar that afforded to every other adult in the community, into where they live, who they spend time with, and what they do with that time.

If Viv were the recipient of an Enabling Support Scheme, she might now have somewhere to live that was acceptable to her. She might have reasonable say in who supports her intimately, and how. She might be able to structure her life so that she can choose who she talks to, when, and about what.

And then Viv might have the space in her heart, mind and life to absorb, digest, and provide incisive analysis of, a Draft Report on a National Disability Insurance Scheme.

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