

**Comments on the Queensland Government Submission on the Productivity Commission's
*Disability Care and Support: Draft Report 2011.***

This submission is endorsed by the following organisations:

FSG Australia

PWD - People with Disability Australia Incorporated

MAMRE Association Incorporated (Family Support)

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Key Recommendations

1. We recommend that the Commonwealth looks to models other than *Growing Stronger* for an NDIS.
2. In particular, we do not commend the *Inventory for Client and Agency Planning* (ICAP) disability assessment tool for a national scheme. The assessment tool should be based on the ICF (International Classification of Functioning, Disability and Health) framework officially endorsed by all 191 WHO Member States. The ICAP questionnaire reduces a person with various physical, emotional and social needs and desires to a set of adaptive behaviours. Its model is inappropriate, out-dated and contrary to the intent of Article 26 of the *Convention on the Rights of Persons with Disability* which calls for effective measures to enable people with disabilities to participate in all aspects of life through the 'multidisciplinary assessment of individual needs and strengths'.¹
3. We strongly advise against the adoption of the carer assessment tool used for *Growing Stronger*. (Appendix A) It is universally condemned by carers, people with disabilities and advocates alike for its callous reduction of the carer role to degrees of burden, and for the damage it is doing to carer/cared-for relationships.

1. About QAI

QAI is an independent, community-based, systems and individual legal advocacy organisation. Our mission is to promote and protect the fundamental rights of people with disabilities, extending beyond the defence of civil and political rights to the defence of rights without a legal foundation, rights to self-respect and respectful treatment embodied in the simple quality of human dignity.

We hold ourselves to account by including people with disability as paid staff, in our membership, and in key board positions. Our board members have experience in advocacy, institutional living, community legal services, private legal practice, legal aid, accountancy and community work. QAI is a member of the National Disability Advocacy Network of Australia (DANA) and Combined Advocacy Groups Qld (CAGQ).

As well as its traditional systems advocacy QAI provides individual legal advocacy to people with a disability at risk of human rights abuses, particularly around guardianship and restrictive practice matters, and assists people required to appear before the Mental Health Review Tribunal. We also provide non-legal advocacy to

¹ At <http://www2.ohchr.org/english/law/disabilities-convention.htm>

people with disability at risk from the criminal justice system by working with legal and community services that help the person with a disability remain in the community.

We acknowledge that our comments in this submission were developed collaboratively with a number of advocacy organisations and people with disability organisations around Australia.

2. Introduction

The following are QAI's comments on the Queensland Government's response to the Productivity Commission's Draft Report on an NDIS. We have already made a submission on the draft report, but we particularly want to respond to the Queensland Government's assertions about the new *Growing Stronger* reforms. We believe this is important because:

- a) in its submission to the Productivity Commission and in the media the Queensland Government has presented *Growing Stronger* as **an exemplary needs assessment and support linking approach**, one whose 'tools and processes align well with those proposed for an NDIS' and **one that may provide a foundation for a national scheme** (Department of Communities, 2011 *The Courier Mail*, 9 June 2011). We argue that while on paper *Growing Stronger* includes some sensible initiatives that guarantee more equitable service delivery (such as the strict separation of assessment and support allocation) the recent assessment and referral experiences of many people with disabilities and carers **have not been positive**.
- b) *Growing Stronger* has been years (2007-11) in the making, but officially has only just been launched (July 2011) after a phased implementation beginning in 2010. Advocacy groups like QAI have therefore only recently been approached by consumers who have been subject to these reforms.

Growing Stronger introduces new processes for screening, intake, assessment, prioritisation, referral, service matching, complaint handling and data collection. Here we limit our comments to disability assessment and support linking only. These are the stages in the *Growing Stronger* process about which we have relevant anecdotal evidence. That evidence suggests that *Growing Stronger* ought not to be promoted as a model for a national scheme.

3. Intake and Assessment

3.0 The Assessment Tool

The Draft Report proposes that a range of disability assessment tools be considered, with regard to a number of criteria including:²

- Consistency with the International Classification of Functioning (ICF) framework;³

² See *Draft Report* Chapter 5

- Accessibility (preferably open source).
- Ability to assess support needs (objectively and subjectively identified);

Growing Stronger has adopted the Inventory for Client and Agency Planning (ICAP)⁴ tool developed in the US in the mid-1980s and briefly discussed in Appendix B of the *Draft Report*. The ICAP is consistent with none of the above criteria suggested in the Draft Report. It is not compatible with the ICF framework, it is not open source, and it does not record people's need for support, or their health and well-being, focussing only on adaptive/maladaptive behaviour.

The ICAP is not appropriate for an NDIS and should not be considered.

We elaborate this point below.

- 2.1.1 Assessment tools were introduced to make decision-making rigorous and fair. The subjective opinions and value-judgements of assessors should have no influence. We do not dispute that ICAP is a well-tested tool with proven reliability and validity. It is internally consistent, provides reliable indications across a range of disabilities, and for untrained assessors is relatively easy to administer. However, ICAP is grounded in an 'adaptive/maladaptive' disease model rather than a support needs model. Other tools, such as *ICAN*,⁵ use a support needs model without loss of all important validity and reliability. A support needs approach is preferred by many people with disabilities because disability is not synonymous with 'disease'. We all have abilities to varying degrees. The issue is whether we have the means to live a flourishing life - and specifically whether certain physical and social supports are needed to guarantee it.
- 2.1.2 The *Growing Stronger* process puts the cart before the horse: it fails because it starts by assessing and allocating resources and *then* conducts a personalised planning process with the individual. The process should start by looking at what resources are already available to the person, i.e. natural supports etc. and then build capacity around existing supports. This clearly cannot happen, when the ICAP functional assessment of paid support allocation by the department is determined first without looking at existing natural, family and community supports available. The Community Living Initiative Pilot Project assessment (here in Queensland) starts from this point and builds outwards.
- 2.1.3 ICAP appears to have been adopted for administrative reasons. Its design is easily adaptable to ICT software and facilitates more accurate costings. The NDIS assessment tool must of course meet administrative needs for accountability and provide a 'line of sight' on expenditures, but planners have lost their way when they choose an assessment tool for its administrative virtues over its ability to accurately represent support needs of people with disabilities and carers.
- 2.1.4 The assessment tool should be mapped to the conceptual domains of the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001). Tools based on the ICF domains facilitate greater awareness and understanding of the need for support to enhance the participation of people with disability in our communities.
- 2.1.5 One of the problems highlighted by advocates and confirmed in the literature is that the ICAP's General Maladaptive Index (GMI) may underestimate the need for support where challenging

³ The ICF domains of activity and participation (at <http://www.who.int/classifications/icf/en/>) are holistic and ability focussed. They include: communication; mobility; self-care; domestic life; interpersonal interactions and relationships; learning and applied knowledge; community, social and civil life; general tasks and demands; and major life areas (home, work, school, economic transactions).

⁴ Bruininks, Robert A, Bradley K. Hill, Richard F. Weatherman and Richard W. Woodcock. 1986. Inventory For Client And Agency Planning (ICAP). Riverside: DLM Teaching Resources.

⁵ Instrument for the Classification and Assessment of Support Needs <http://www.i-can.org.au/info.php>

behaviour is 'circumscribed or infrequent'. A person's GMI may be low because they rarely exhibit problem behaviours; they may nevertheless have high support needs. These anecdotal observations are supported by research by Palucka and Homatidis (2010) that the GMI may, in some cases, 'underestimate the need for support if the very serious behaviour is very circumscribed or infrequent'.

- 2.1.6 Conversely, we are aware of an instance where a person with a recently amputated arm was very low scoring in a number of areas and therefore assessed as having high support needs. But the assessment was inaccurate because many of the questions were irrelevant to the type and level of support required.⁶
- 2.1.7 Respondent bias: Palucka and Homatidis (2010: 62) have observed that the administration of the ICAP with people with dual diagnosis (intellectual disability and mental health issues) is subject to respondent bias 'that may result in significant under- or over-rating' and warn that 'caution is recommended'.
- 2.1.8 The assessment tool must also account for the influence of a person's current environment on their perception of support needs. A person's current circumstances may undermine their perception of their capacity, goals and desire for participation.
- 2.1.9 The ICAP assessment is limited, failing to give an accurate account of the support required. After completion of the ICAP assessment Disability Services or the family have subsequently requested and paid for an independent assessment.
- 2.1.10 We agree that the assessment of demand (needs assessment) and supply ('support linking' in Qld terminology) should be - indeed must be - separated to ensure objective and therefore equitable allocation of resources. But this separation is also a source of weakness. The quality of support linking will necessarily depend on the quality and accuracy of needs assessment: there is no other client-specific information on which to make judgements about support.

3.1 Carer Assessment

The Draft Report proposes an assessment framework to establish what 'natural supports' can 'reasonably and willingly be provided' by unpaid family carers, consistent with circumstances and lifecycle stage (5.8). It recommends a separate assessment for carers who provide a 'substantial share of the care'. This assessment would focus on the sustainability of caring and the carer's own support needs, as well as on respite.

⁶ E.g. A person with a physical disability (her left arm recently amputated) was asked if she could print his first name, copying from an example. This person was rated never or rarely. There was no place in the assessment for her to inform the assessor that she could not write her name as her arm had been amputated. The questions continued, under social and communication skills, (offers help to others, holds a door open for someone whose arms are full or picks up an object dropped by another person). Again she rated the lowest score, never or rarely. Again there was no place for an explanation that the person used a wheel chair for mobility and that his amputation made it physically impossible for him to perform these tasks. Under community living skills questions include; 'finds way to a specified room when told', 'buys items from a vending machine', 'crosses streets and roads alone'. The person again scored the lowest score for these questions and again there was no way to inform the assessor that the reason she could not perform these tasks was because she lived in an institution and did not have an opportunity to access the community and cross roads. She did not have access to an electric wheel chair so could not move from one room to another because she was seated in a manual wheel chair, her left leg in a splint and her right arm amputated. She therefore could not move independently from room to room. Many of these questions are irrelevant in terms of the type and level of support required by the person. There seems to be no correlation between the level and type of support needed and her responses to these questions. The assessment results in a service level score. For the person referred to, the description of his care was that she required extensive personal care and constant supervision. This is not accurate as she does not require constant supervision (pers comm).

The *Growing Stronger* carer assessment tool has deeply upset a number of carers *and* people with disabilities to whom we have spoken, feeling that the tool has no bearing on the support their family member may require. It is not possible to exaggerate the distress that the tool has caused. Advocates, people with disabilities and carers attest that the carer assessment process is disturbing and demoralising. (Please see the tool itself in Appendix A)

3.2.1 Carers are asked to respond to loaded statements such as these:

Since caring for (my daughter, son, partner etc.) I feel that my family has abandoned me.
Caring for has made me miserable.
I feel trapped in my caring role.
Since caring for ... I hate the way my life has turned out.
Care giving has worn me out.

The scores from the carer's responses are totalled and used to determine priority for alternative care and respite. The tool's designers have not taken into account the (negative) effect of the tool itself on the self-perceptions of carer and cared-for.

3.2.2 While it is clear that the purpose of the carer tool is to solicit measureable responses, it is also clear that the administration of this tool undermines the carer – cared-for relationship, and that more importantly, the assessors would get a more accurate picture of the relationship with less emotive prompts.

3.2.3 Once assessed, a person's (and their carer's) requirements should be matched to available resources (subject to financial and administrative constraints) and translated into an individualised support package. To ensure objectivity, accountability and equity *Growing Stronger* policy requires that these two processes be strictly separate. This is critical, but the downside of this separation is that the assessment process must be particularly accurate and holistic in order to ensure that judgements about priority, resource allocation and referral are made with as complete a picture of each person's circumstances, needs and aspirations.

4. Conclusion

Growing Stronger's assessment process is not a good model for an NDIS. The ICAP fails because it reduces a person with various physical, emotional and social needs and desires to a set of adaptive behaviours. The carer assessment is universally reviled for its callous reduction of the carer role to degrees of burden.

5. Bibliography

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Appendix A - *Growing Stronger* Carer Assessment Tool

(respondent is asked to give a Strongly Agree – Strongly Disagree graded response)

Q.1 The constant interruptions make it difficult to find time for relaxation.

Q2 My financial resources are adequate to pay for things that are required for care giving.

Q3 Caring for ... has made me miserable.

Q.4 I am healthy enough to care for

Q.5 I have to stop in the middle of my work activities to provide care.

Q.6 My health has gotten worse since I have been caring for

Q.7 If I could afford it, I would find some other way to care for

Q.8 I feel trapped by my caring role.

Q.9 It is very difficult to get help from my family in taking care of

Q. 10 Since caring for Sometimes I hate the way my life has turned out.

Q.11 My family has done all they can to help with caring for

Q. 12 My family works together at caring for

Q. 13 I resent having to take care of

Q. 14 I have eliminated things from my schedule since caring for

Q15 sometimes disrupts meals and makes them unpleasant.

Q16 Since caring for I feel that my family has abandoned me.

Q17 Since caring for It seems like I'm tired all of the time.

Q18 Care giving has worn me out.

Q19 Others have dumped caring for ... on to me.

Q 20 I get very discouraged with caring for

Q21 It is difficult to pay for's health needs and services.

Q22 It takes all of my physical strength to care for

Q23 At this time in my life I don't think I should be caring for

Q24 I wish the family depended less on me to care for

Q 25 I feel like I was forced into caring for

Q26 Caring for ... has put financial strain on the family.

Q27. My activities are centred around caring for

Q28 I visit my family and friends less since caring for

Q29 I feel overwhelmed by the problems I have caring for

Q 30 I have enough physical strength to care for