

29 April 2011

Ms Patricia Scott – Commissioner  
Inquiry into Disability Care and Support  
Productivity Commission  
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Dear Ms Scott,

The Board and management of Scope, thank you for the opportunity to provide comment on the Productivity Commission's Draft Report into Disability Care and Support.

Scope is a major provider of disability support services to nearly eight thousand people with a disability across metropolitan and regional Victoria. As a service provider Scope sees the need for major reform to the way services are currently funded and delivered to people with a disability.

Scope welcomes and supports the overall findings of the Productivity Commission's Draft Report. The changes proposed in the Report, in particular the proposed introduction of a National Disability Insurance Scheme (NDIS), is a significant and necessary step towards addressing the issues faced by people with disabilities in their daily lives.

This submission aims to provide evidence for further consideration and recommendations specifically addressing the following key areas:

- **Supported Decision Making**
- **Community Building and Inclusion**
- **Minimum Training Qualifications**
- **The Quality Framework**

Scope has considerable expertise in these areas and would welcome the opportunity to discuss the contents of this submission and any other issues you may wish at a time of your convenience.

Kindest regards,

Diana Heggie  
Chief Executive Officer



FOR PEOPLE WITH A DISABILITY

Submission to  
**Productivity Commission Draft Report**  
**Disability Care & Support**

29 April 2011



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see the person



do it together



do it right



do it better

## EXECUTIVE SUMMARY

Scope supports the Productivity Commission's Draft Report into Disability Care and Support and considers it one of the most comprehensive reform documents that present a framework to largely address the existing underfunded, unfair, fragmented, and inefficient current disability support system.

Scope understands and supports the shift of decision making power to people with a disability, and we want to be fully engaged with this process. From our experience, we would like to draw your attention to the following issues for your consideration.

### 1. Supported Decision Making

The success of the 'consumer choice' model proposed is dependent upon people with a disability and their carers making informed decisions about the types of services they will purchase.

Scope proposes that for many people with Severe to Profound Intellectual Disability (SPID) a supported decision framework will increase the validity of proxy decision making.

#### Recommendation(s):

- a. *Scope recommends that the Productivity Commission's final report articulate the Commission's view on supported and proxy decision making to ensure that decision making in the context of an National Disability Insurance Scheme (NDIS) upholds the rights of people who are not fully able to participate in those decisions.*

### 2. Community Building and Inclusion

Community building and inclusion work leverage community resources to support people with a disability participate in community. This work ultimately leads to a decreased reliance on segregated / specialist service offerings.

Scope proposes that the delivery of positive outcomes for people with a disability through their full participation in community and full access to community services requires an investment in community building activities.

#### Recommendation(s):

- a. *That the Productivity Commission acknowledges in its final report the importance of community building and inclusion work as an important element in achieving successful outcomes in the lives of people who receive funding through an NDIS.*

*This to include:*

- i) *Recognising that service delivery that incorporates community building and inclusion work is an important part of the service mix funded by an NDIS.*
- ii) *Recognising that the pricing of services delivered to individuals needs to factor in the cost of undertaking community building and inclusion work.*
- iii) *Reframing Tier 1 of the scheme to include community building and inclusion work at both a local and at a systems level to facilitate the development of more welcoming and inclusive communities.*

- b. *That the Productivity Commission acknowledges in its final report the need for an NDIS to support the creation of an evidence base for, and implementation of, effective community building and inclusion strategies.*

### **3. Minimum Training Qualifications**

The skills required of disability support workers continue to expand as people with a disability choose more individually tailored supports. The autonomy of support workers is increasing as work becomes less supervised in community settings.

Scope suggests that the Productivity Commission considers minimum training requirements for support workers be determined at the time of assessment of services.

#### Recommendation(s):

- a. *That the Productivity Commission applies a modified test of 'Reasonable and Necessary' (PC draft report 4.27) criteria in the determination of minimum training qualifications for the supports identified in the assessment process.*
- *The benefit to the participant – there is evidence to show the training will benefit the participants (the support worker and the person receiving supports)*
  - *Appropriateness of the training – the training is in keeping with current clinical practice, evidence-based practice and/or clinical guidelines*
  - *Appropriateness of the provider – the provider is appropriately experienced to provide the training*
  - *Cost effectiveness considerations – consideration is given to the long-term compared to the short-term benefits of training, based on evidence-based practice, clinical expertise or consensus.*

*This process will enable competency based training modules to be identified that are linked to individual needs.*

### **4. The Quality Framework**

People with a disability are entitled to services provided within a quality framework, just like other Australians accessing other types of services.

Scope argues that the disability services quality framework needs to encompass all service providers, not just specialist providers.

#### Recommendation(s):

- a. *That the Government aligns government driven quality frameworks related to the delivery of community services with the National Disability Standards to ensure a basic level of consistency in the approach to quality assurance across both generic and specialist providers of services to people with a disability.*

Thank you again for the opportunity to present this information. We are available to discuss this information and any other issues you may have at a time of your convenience.

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## 1 INTRODUCTION

This submission is made by Scope, a large not for profit organisation that provides disability services throughout Victoria to nearly eight thousand children and adults with physical and multiple disabilities. Over 4000 of our clients have severe and profound disabilities. Our services include early childhood intervention, open employment, accommodation, day services, in-home attendant care and community participation support.

Scope has an operating expenditure of approximately \$67 Million and employs over 1600 staff across over 90 sites across Victoria. Scope is a membership based organisation that currently has over 6000 individual and organisational members. Scope also acts at a systemic level providing advocacy, community education and research. The Scope Board includes members with a disability.

The paper will take as its central principal the Government's statement on p.3 of the Productivity Commission Issues Paper:

'This inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible, and live a happy and meaningful life.' (Sherry, 2009)

Scope supports the Productivity Commission's Draft report into Disability Care and Support and considers it one of the most comprehensive reform documents that largely addresses the underfunded, unfair, fragmented, and inefficient current disability support system.

Scope understands and supports the shift of decision making power to people with a disability, and we want to be fully engaged with this process. From our experience, we would like to draw your attention to the following issues for your further consideration.

- **Supported Decision Making**

The success of the 'consumer choice' model proposed will be enhanced with the scheme investing in supported decision making to strengthen the validity of 'proxy' decision makers.

- **Community Building and Inclusion**

Community building and inclusion work leverage community resources to support people with a disability participate in community. Investing in this work will ultimately lead to less reliance on segregated / specialist service offerings.

- **Minimum Training Qualifications**

The skills required of disability support workers continues to expand as people with a disability choose more individually tailored supports. Duty of care risks can be minimised if the NDIS determines the skills and associated training requirements at the time of assessment of required supports and services.

- **The Quality Framework**

Scope argues that the disability services quality framework needs to encompass all service providers, not just specialist providers.

*Recommendations regarding each of these key issues are included within each section.*

## 2 SUPPORTED DECISION MAKING

The market oriented system proposed by the Productivity Commission has at its heart the empowerment of people with disability to make decisions about the services they receive. Scope welcomes the shift in policy from a government and service provider controlled service system to one that shifts the control to people with a disability and those who care for them.

Scope is cautious, however, about the dilemma of ‘proxy’ decision makers.

Watson, J. (2011). **Supported decision making for people with severe to profound intellectual disability: A brief review of the literature (unpublished)**. provides an important insight into the challenges associated with the use of proxies. It states:

*As people with severe and profound intellectual disabilities cannot express their views using traditional communication systems it is common practice to ask a proxy (substitute decision maker) to respond on their behalf when decisions are to be made. Proxy reporting for this population is highly inferential, posing obvious dilemmas, and therefore should be used cautiously. It is clear that reliance on one person to ‘speak for’ someone is fraught with serious questions around whose voice is truly being broadcasted. Obtaining and interpreting the preferences, interests and wants of people with SPID is difficult and challenging to say the least. Researchers and practitioners interested in decision making and choice for people with SPID are faced with a quandary. As Petry and colleagues point out the choice they have is to:*

*Either ignore these individuals because they cannot self report, or obtain data from proxies that maybe biases or invalid’ (Petry, Maes et al. 2009).*

*The ongoing debate about the utility of proxy response in the literature cannot be ignored. However, proponents of supported decision making are sympathetic to Petry and the view of her colleagues as stated in their quote above. Supported decision making starts with the premise that in order to truly hear the voices of those who cannot by the very nature of their disability advocate for themselves there is a need to rely on the collaborative efforts of their circle of support. It proposes that a key to increasing the validity of proxy reporting as truly representative of a person’s preferences may be by approaching the decision making in a collaborative way. Such an approach is at the heart of supported decision making.*

See Appendix 1 for a copy of the full report.

Scope believes it is critical to the overall success of a National Disability Insurance Scheme (NDIS) that investments are made, not just in building the capacity of people with disability to make informed decisions, but in delineating and supporting options for supported and proxy decision making.

While this is partially addressed by the Productivity Commission in the draft report (Section 8.14 and 8.23) where the role of DSOs and NDIS case managers include providing their clients with the information needed to make informed decisions, Scope argues that the Commission needs to go further in articulating its view on the use of supported and proxy decision making.

Scope agrees with Watson and proposes that a key to increasing the validity of proxy reporting as truly representative of a person’s preferences maybe by approaching the decision making in a collaborative way, such as Supported Decision Making.



The Commission is also encouraged to consider the Victorian Law Reform's Guardianship – Consultation Paper March 2011 for insights into the most recent thinking about decision making for people with cognitive impairment. This paper can be downloaded from:

<http://www.lawreform.vic.gov.au/wps/wcm/connect/justlib/Law+Reform/Home/Current+Projects/Guardianship/LAWREFORM+-+Guardianship+-+Consultation+Paper>

### **RECOMMENDATION:**

- a. Scope recommends that the Productivity Commission's final report articulate the Commission's view on supported and proxy decision making to ensure that decision making in the context of an NDIS upholds the rights of people who are not fully able to participate in those decisions.

## **3 COMMUNITY BUILDING AND INCLUSION**

In the Productivity Commission's Issues Paper, the Australian Government announced:

*This inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible, and live a happy and meaningful life (Sherry, Rudd, Macklin and Shorten 2009).*

Scope interprets this to mean that the supports provided through an NDIS need to be provided in a way that maximises the capacity of people with disability to be in and of their community.

Scope argues that there are two types of work critical to achieving this:

1. The provision of person centred direct supports that empower people with a disability to make decisions;
2. Community building activities that works to build communities in order to facilitate the inclusion of people with disability.

It is Scope's position that these two types of work are often inseparable.

In reviewing the Commission's draft report, Scope believes that the first of these is well consolidated in the report, while the second is not well articulated, even though it is fundamental to the success of the first.

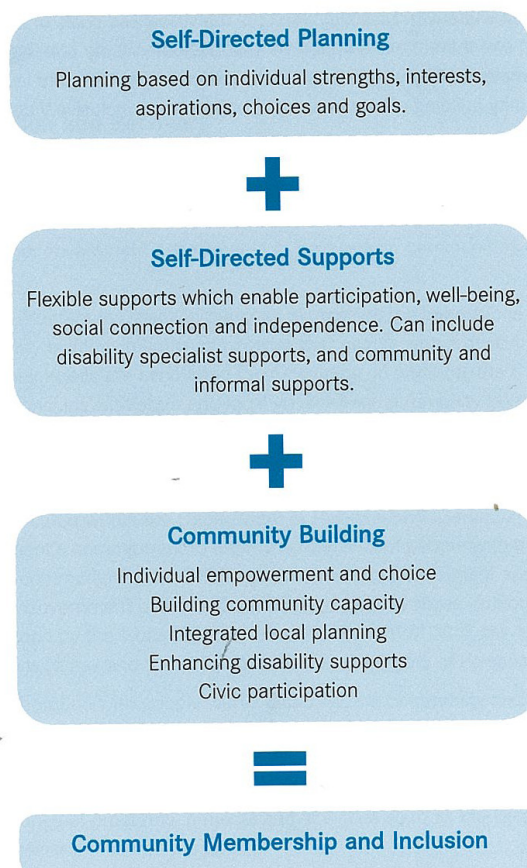
If an aim of NDIS is to facilitate the delivery of positive outcomes for people with disability through their full participation in community and full access to community services, then there must be meaningful investment in community building and inclusion work.



The Victorian Department of Human Services, in its publication *The Community Building Program in Disability Services: Supporting self-directed lifestyles for Victorians with a disability* (2009), puts forward the following model to highlight the role of community building in the context of self-directed funding and individualised service delivery. (See Figure 1).

Scope refers the Productivity Commission to Scope's report – *Inclusion: making it happen* (2009), which was commissioned by the Victorian Department of Human Services, for an overview of the key concepts and a range of examples of services and service models that exemplify best practice in community building and inclusion work.

A copy of the report is attached for the Commission's information (See Appendix 2 – *Inclusion: Making It Happen*).



**Figure 1** Community membership equation (Victorian Department of Human Services, 2009)

The report and also can be downloaded from:

<http://www.scopevic.org.au/index.php/cms/frontend/resource/id/342>

In particular, Scope highlights that community building and inclusion work can operate from three orientations:

***Orientation 1: Individual person-centred work leads to inclusion.***

Inclusion work and community building happen in direct response to the expressed interests, needs, and aspirations of specific people with a disability.

***Orientation 2: Opportunities are created in community.***

Inclusion work and community building require workers to be proactive in identifying, creating and offering opportunities to people with a disability.

***Orientation 3: Broad level community change.***

Inclusion and community building focus on broader structural and attitudinal work.

The first two orientations are of particular relevance to the design and delivery of services within an NDIS.

Scope estimates (there are no publicly available figures) that the Victorian Government provides funding for these and other similar disability-specific community building programs exceeds, but is close to, \$10 million per year. This does not include services run by local governments, community organisations or disability service providers such as Scope with a long-standing commitment to community building and inclusion work.

Community building and inclusion work are critical elements of service models that enable people with disability to be in and of their community. Benefits of investing in community building and inclusion work include:

- decreased reliance on segregated / specialist service offerings
- better leveraging of community resources that have untapped capacity to support people with disability that can be achieved through service redesign and capacity building of services and systems
- minimising the cost of failure when people with disability try to access mainstream services and 'bounce back' because the system, staff or fellow program participants fail to respond appropriately – communities and community services need support to accommodate people with disability, particularly during any transition from a system where there is a strong reliance on specialist support to one that includes a stronger role for community support

### **Community Building and Inclusion Work in the context of a NDIS**

Scope recognises that some elements of community building and inclusion work fall outside the remit of an NDIS. However, it believes that some of this work does fall within the remit of an NDIS.

Scope argues that the Commission needs to go further in articulating the need for community building and inclusion work in its recommendations to the Australian Government.

### **Need for a strong evidence base**

Scope recognises that there is not a strong evidence base for the efficacy and effectiveness of community building work, particularly from an economic perspective. It is for this reason Scope undertook the research that underpins the Inclusion – Making It Happen report. There is more research that needs to be done in this area. Having said that, as is the case with much of the early intervention work referenced in the Commission's draft report, there is strong anecdotal evidence of success which has led to Governments in Australia and overseas funding this work.

**RECOMMENDATIONS:**

- a. *That the Productivity Commission acknowledges in its final report the importance of community building and inclusion work as an important element in achieving successful outcomes in the lives of people who receive funding through an NDIS. This to include:*
- *Recognising that service delivery that incorporates community building and inclusion work is an important part of the service mix funded by an NDIS.*
  - *Recognising that the pricing of services delivered to individuals needs to factor in the cost of undertaking community building and inclusion work.*
  - *Reframing Tier 1 of the scheme to include community building and inclusion work at both a local and at a systems level to facilitate the development of more welcoming and inclusive communities.*
- b. *That the Productivity Commission acknowledges in its final report the need for an NDIS to support the creation of an evidence base for, and implementation of, effective community building and inclusion strategies.*

## 4 MINIMUM TRAINING QUALIFICATIONS

Scope supports the Productivity Commission's intention for the assessment of support needs to be 'reasonable and necessary' and considerate of people's aspirations. In line with this, Scope suggests that during the assessment process and determination of supports that the skill level of people delivering the supports is also identified.

Ultimately, the minimum qualification level of disability support workers will be determined by the market. It is only in some circumstances that government determine minimum qualifications for a professional group. Rather, it is more often professional associations who set minimum qualifications in determining eligibility for membership. For example, Occupational Therapy Australia sets the following eligibility:

- Occupational therapists who are qualified to practice in all States/Territories of Australia;
- A graduate of an accredited Australian occupational tertiary course or;
- An overseas qualifications which satisfy the requirements specified by Occupational Therapy Australia and COTRB (<http://www.ausot.com.au>)

It is usually then service providers who recruit staff based on whether or not they are eligible for membership to the related professional association. For example, if you want to work as an occupational therapist in a government-funded agency in Tasmania, New South Wales, Victoria or the Australian Capital Territory, you are usually expected to have qualifications acceptable to OT AUSTRALIA. (<http://www.cotrb.com.au>)

Scope therefore considers the determination of minimum qualifications for non-professional workers in the disability sector as the domain for associations such as Disability Professionals Victoria, and not government. Scope agrees with the Commission's statement 'The Commission does not recommend that certificate 111 (or any other qualification) be a pre-requisite for non-professional workers in the disability sector (Section 13.45).

However, Scope does propose that there are minimum training requirements for many of the activities that a disability support worker undertakes.

Often when an incident is investigated by the Coroner, one of the first questions asked is 'What training did the staff undertake?'. This implies that there is a level of training expected by society in order to provide an adequate level of care, and that it is a part of the organisation's duty of care to provide that training.

Equally, when an incident is reported by media, the level of training a worker undertakes is also questioned. Again, this implies that there is a minimum level of training expected in order to meet duty of care obligations.

Under the proposed market oriented system, service providers will decide how to manage this risk, and the level of training provided to support workers will largely be determined by service providers.

Service users can then choose whether or not they want to pay for that training. The level of 'quality' will largely be determined by the person with a disability. This assumes that the person with a disability (and/or their family) are in circumstances that enable them to choose to carry the risks associated with untrained staff.

Scope sees this as shifting the duty of care risks from service providers to the person with a disability. For many people, it can be argued that this is appropriate (Section 8.26). However, for people with profound and significant disability and their families, the training benefits of a skilled workforce are often hidden in the day-to-day struggle of managing life, where quality is often defined by service attributes such as ‘a capacity for empathy, flexibility and personal experience’ (Section 13.26) and other practical skills learned through training (such as manual handling skills) are less understood, and not as highly valued.

## **RECOMMENDATION**

- a. *That the Productivity Commission applies a modified test of ‘Reasonable and necessary’ (PC draft report 4.27) criteria in the determination of minimum training qualifications for the supports identified in the assessment process.*
  - *The benefit to the participant – there is evidence to show the training will benefit the participants (the support worker and the person receiving supports)*
  - *Appropriateness of the training – the training is in keeping with current clinical practice, evidence-based practice and/or clinical guidelines*
  - *Appropriateness of the provider – the provider is appropriately experienced to provide the training*
  - *Cost effectiveness considerations – consideration is given to the long-term compared to the short-term benefits of training, based on evidence-based practice, clinical expertise or consensus.*

*This process will enable competency based training modules to be identified that are linked to individual needs.*

## 5 THE QUALITY FRAMEWORK

Scope recognizes that developing a quality framework for the NDIS will be a complex process. When services are to be provided by a diverse range of organisations and individuals, with some relationships managed through contracts and other arrangements self-managed by people with disability or their families, it is difficult to imagine how one approach can be applied. Scope notes in particular the challenges of organisations that provide services to a diverse range of people who are funded from multiple Government sources inheriting multiple and sometimes conflicting quality regimes each with their often onerous assessment and reporting requirements.

While these issues need careful consideration, Scope wishes to highlight that the current disability service quality frameworks include both generic elements and disability-specific elements.

Scope therefore emphasises the need to ensure that the disability-specific elements in existing quality frameworks are not put aside in the effort to minimize complexity and reduce excessive administrative requirements of the quality framework under an NDIS.

### **RECOMMENDATION**

- a. *That the Government aligns government driven quality frameworks related to the delivery of community services with the National Disability Standards to ensure a basic level of consistency in the approach to quality assurance across both generic and specialist providers of services to people with a disability.*



## APPENDIX 1: SUPPORTED DECISION MAKING FRAMEWORK

*This document has been prepared for the purpose of research which is yet to be published and therefore any use of the material should be acknowledged and referenced appropriately using the following citation:*

### **Watson, J. (2011). Supported decision making for people with severe to profound intellectual disability: A brief review of the literature (unpublished).**

*Today, supported decision making is found at the centre of discussions around guardianship reform both here in Australia and Internationally. The Victorian guardianship legislation (Victorian Government. 1986) is currently under review. Documentation around this review, drafted by the Victorian Law reform commission places supported decision making firmly at the center of their proposed reform. Although on the surface it appears to be a relatively new paradigm, as an approach elements of it have been used with people with profound intellectual disabilities who communicate informally for decades. It has played a pivotal role in the development of good practice specifically in the area of augmentative communication for people who communicate informally (Parsons and Reid 1990; Newton, Ard et al. 1993; Windsor, Piché et al. 1994; Parsons, Harper et al. 1997; Hughes, Pitkin et al. 1998; Grove, Bunning et al. 1999; Logan, Jacobs et al. 2001; Porter, Ouvry et al. 2001; Cannella, O'Reilly et al. 2004; Porter, Aspinall et al. 2005; Maes and Bea 2006; Horrocks and Morgan 2009; Kodak, Fisher et al. 2009). This body of literature has played an important role in the development of a supported decision making agenda within Victoria particularly for people with PID (Pepin, Watson et al. 2009; Watson J. 2010; Watson and Joseph In Press).*

Today, the principles of supported decision making have moved beyond literature focused on people who communicate informally and are gradually appearing in adult guardianship legislation across the globe, with Canada largely taking the lead (Gordon 2000) and Western Europe following close behind (Blackman 1997). Focus on Supported Decision-Making in more recent times has largely been driven by the United Nations Convention on the Rights of Persons with Disabilities (2006), which is strongly supportive of this approach as a viable alternative to court-ordered guardianship. Barbara Carter in her recent paper 'Supported Decision-making: Background and discussion paper' states:

*'Guardianship in Australia has, under the Guardianship and Administration Act 1986, been conceptualized as a last resort with a guardian appointed only when less restrictive options have failed or are not available. For guardianship to properly be a last resort there must be an adequate first resort. The United Nations Convention establishes supported decision-making as the first resort: the preferred alternative and, where necessary, precursor to guardianship'*  
(Carter 2009).

Victorian based disability service providers are increasingly adopting supported decision making approaches. Scope, a Victorian based disability support provider, have developed and are currently piloting a framework for people supporting those who communicate informally to live lives they prefer through supported decision making (Pepin, Watson et al. 2009; Watson 2010; Watson J. 2010; Watson and Joseph In Press).

*'This framework is designed to gather a consensus view on what a person who communicates informally may be saying or what is in their best interests and from there make a decision'.*

(Watson 2010)



It guides circles of support through a process of supported decision making focusing on a particular decision the person they support is facing. The framework does not claim that supported decision making is an easy process. It recognizes that the role of a supporter is a highly responsible one, requiring an understanding of collaborative decision making, and a desire to respect the dignity of the represented person, who might be particularly vulnerable.

The United Nations Handbook on the Convention of the Rights of people with Disabilities (United Nations. 2009) states:

‘Supported decision-making can take many forms. Those assisting a person may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity’.

(United Nations. 2009)

While some examples of support decision making exist in practice both within Australia and internationally (Ontario Association Community Living. 1993; Gordon 2000; Bach 2006; Department of Health United Kingdom. 2007; Paradigm 2008; Brayley 2009; Watson and Joseph In Press), currently there are no clear policy frameworks around supported decision making.

#### People with severe to profound intellectual disabilities

For people with severe or profound intellectual disability there is a clear lack of consensus regarding the conceptualization, classification and terminology of their disability. Within the literature a variety of terms exist including “profound and multiple intellectual disability,” “profound mental handicap,” “profound and multiple learning disability” and “severe and profound intellectual disability”. Internationally there is inconsistency not only in terminology but in diagnostic procedures and classification systems (Luckasson and Reeve 2001; Schalock, Luckasson et al. 2007; Thompson, Bradley et al. 2009).

Despite a clear lack of agreement around terminology, some fragmented definitions exist for people with intellectual disability generally, as well as for those with severe and profound intellectual disabilities (SPID).

Section 3 of the Victorian Disability Act (Victorian Government Department of Human Services. 2006) defines a person with an intellectual disability (ID) as someone who has ‘significant sub-average general intellectual functioning’ and ‘significant deficits in adaptive behavior’ (Victorian Government Department of Human Services. 2006) evidenced before the age of 18. The Act (Victorian Government Department of Human Services. 2006) makes no mention of those with severe or profound intellectual disability. Intellectual disability is described as “learning disability” in the United Kingdom and predominately “mental retardation” in the United States. The most recent edition of DSM-IV equates an Intelligence Quotient (IQ) score of less than 70 as indicative of an intellectual disability. According to DSM-IV (American Psychiatric Association 1994) someone who has a severe or profound intellectual disability has an IQ less than 35.

A report commissioned by the Victorian Department of Human Services about disability supports, points out that there is a clear move toward disability being classified in terms of levels of support needed, rather than IQ scores (Parmenter and Arnold 2008). In this report, Parmenter and Arnold make reference to the publication by the World Health Organisation (WHO) of the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation (WHO). 2001) They emphasize WHO’s focus on concepts of limitations to activities and barriers to participation rather than a focus on a person’s Intellectual Quotient (IQ) score.

In step with current trends in classification, Scope define people with severe to profound intellectual disability, not in terms of their IQ score, but in terms of the amount of support they need with a particular emphasis on communication. There is no argument within the literature that people with severe or profound intellectual disability have considerable difficulty with communication. Judith Goldbart, a prominent researcher and practitioner in the field reiterates this position. In a recent conference presentation she stated:

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**‘SIGNIFICANT IMPAIRMENTS IN LANGUAGE AND COMMUNICATION ARE A CORE FEATURE OF PROFOUND INTELLECTUAL DISABILITY (PID). MANY PEOPLE WITH PID WILL HAVE ADDITIONAL SENSORY OR PHYSICAL DISABILITIES, COMPLEX HEALTH NEEDS OR MENTAL HEALTH DIFFICULTIES. CHILDREN AND ADULTS WITH PROFOUND INTELLECTUAL DISABILITY CAN THUS BE SEEN AS ONE OF THE MOST VULNERABLE GROUPS IN SOCIETY’**  
(GOLDBART 2010)

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For the purposes of this document people with severe and profound intellectual disabilities (SPID) are considered to be those people who are unable to use or understand formal communication such as speech, sign, written word, pictures or photos. They are unable to advocate for themselves without support from those who know them well. They are unintentional or early intentional/informal communicators. Communication at this level is characterised by behaviours produced unintentionally in response to internal and external stimuli. These behaviours can be assigned meaning by a communication partner. Communication considered intentional informal are behaviours which act on the environment to create a purposeful specific effect through informal rather than symbolic means (Iacono, West et al. 2009).

#### PREVALENCE OF THOSE WITH SPID: WHERE IS THE DATA?

Existing prevalence data in relation to SPID is scarce, fragmented and inconsistent, not only in Australia but globally. Although some data is emerging, it pertains primarily to developed countries (Wen 1997; Arvio and Sillanpaa 2003; Emerson 2009). Within the literature the name assigned to this group of conditions varies tremendously therefore it is very difficult to be clear as to who is being counted within research studies, leading to questions around the reliability of prevalence data for this population.

#### **PEOPLE WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITIES**

- Use and understand little or no speech;
- Are thought to use behaviours of concern;
- Use informal communication systems such as gesture, facial expression and behaviour;

An Australian epidemiological study carried out by Leonard and Wen claimed that in 2002 the prevalence in the state of Western Australia of people with SPID (an IQ under 35) was estimated as 0.14% of the general population. In Finland, the estimated prevalence of SPID in 1966 varied from 0.09% (Tarvainen 1966) to 0.2% (Ruoppila 1966). A more recent Finish study revealed an estimated 0.13% of the population had a severe or profound intellectual disability (Arvio and Sillanpaa 2003).

In relation to people with severe to profound intellectual disability, a 'snapshot' of Scope clients in 2009 revealed that approximately 32-35% of Scope service users communicated in an informal way (Watson and Garde 2009). Informal communicators are sometimes referred to as having a severe to profound intellectual disability. This figure however should be approached with caution as the methodology used within the study was limited.

## CIRCLES OF SUPPORT

A Circle of Support is a group of people who ideally know someone well and support someone to make decisions. For the purpose of this document supporters may include family, friends or paid support workers. These people are likely to have different roles in the person's life. They may provide care and protection for them, or simply be there for guidance and support.

## LISTENING TO THOSE RARELY HEARD: A FRAMEWORK DEVELOPED BY SCOPE

Scope have developed a resource/training package designed to assist those who care for/about people with Severe to Profound Intellectual Disabilities support them to make decisions that reflect their preferences. Embedded within this package is a framework used to guide 'circles of support' through a process of supported decision making with people with SPID (Watson 2010), see Appendix A. The training package includes a video developed for the purposes of training titled 'Listening to those rarely heard' (Watson and Joseph 2011). The video can be viewed at <http://vimeo.com/21176882>. The video is accompanied by a manual and PPT presentation.

The supported decision making process outlined in the package is carried out over a period of 3-6 months. During this time the circles and support and those they care for/about are involved in a customized workshop and a period of guidance and mentorship. Specifically the focus person's circle of support is guided through a process of supported decision making with the person they care for or about.

## TOWARD A COLLABORATIVE VIEW OF DECISION MAKING

A common view of decision making is characterised by the need for decisions to be carried out independently using one's own internal resources. A consultation paper issued by the UK Government (Lord Chancellor's Department. 1997) clearly describes this view of decision making.

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*'THE FIRST QUESTION IS WHETHER THE PERSON CONCERNED IS ABLE TO UNDERSTAND AND RETAIN THE RELEVANT INFORMATION, INCLUDING THE CONSEQUENCES, NOT ONLY OF DECIDING ONE WAY OR ANOTHER BUT ALSO OF MAKING NO DECISION AT ALL. THE SECOND QUESTION IS WHETHER THE DISABILITY MEANS THAT THE PERSON CONCERNED IS ABLE TO USE THAT INFORMATION IN ORDER TO ARRIVE AT A DECISION: SOME PEOPLE MAY BE UNABLE TO EXERT THEIR WILL, WHETHER BECAUSE OF DELUSIONS OR COMPULSIONS, OR BECAUSE OF SUSCEPTIBILITY TO INFLUENCE, OR ANY OTHER REASON CONNECTED WITH THEIR DISABILITY'*

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(Lord Chancellor's Department. 1997)

Although this view clearly outlines the cognitive aspects of decision making, unfortunately it ignores the importance of support within the process of decision making and therefore does not entirely resemble the way in which ordinary decisions appear to be made. This view emphasizes individual intellectual 'capacity' and explicitly excludes the role which social and environmental factors make to a person's decision making (Bach and Rock 1996). It is particularly unhelpful as a way of thinking about choice and decision making for people who by the very nature of their disability are reliant on those who know and love them for support (Watson and Joseph In Press). Wehmeyer states:

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*'WHEN SELF-DETERMINATION IS INTERPRETED STRICTLY TO MEAN "DOING IT YOURSELF", THERE IS AN OBVIOUS PROBLEM FOR PEOPLE WITH SIGNIFICANT DISABILITIES, MANY OF WHOM MAY HAVE LIMITS TO THE NUMBER AND TYPES OF ACTIVITIES THEY CAN PERFORM INDEPENDENTLY'*

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(Wehmeyer 1998).

In referring to supported decision making, Gordon argues that,

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*'THE CONCEPT SIMPLY RECOGNIZES THE WAY IN WHICH MOST ADULTS FUNCTION IN THEIR EVERYDAY LIVES. IT IS ARGUED THAT INDEPENDENT DECISION-MAKING IS A MYTH; THAT EVERY ADULT USES INTERDEPENDENT DECISION-MAKING IN THE COURSE OF GETTING THROUGH THE DAY'*

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(Gordon 2000)

In complex post-industrial and post-modern societies, so called 'competent' decision makers depend greatly on the skills, ability and knowledge of others to make a variety of decisions. Many people don't hesitate to use the knowledge of accountants and investment brokers, some purchase the services of lawyers, and others seek the counsel of members of the clergy. Most use the services of health care professionals, who will often assist with complex health care decision making. 'Competent' decision makers routinely seek the support of others to make decisions about interior design, horticulture, cranky computers,

and malfunctioning automobiles, to name but a few. Most people would not deny the extent to which they engage in interdependent decision-making. Importantly, as Gordon points out 'this interdependence is not seen as indicative of mental incapability' (Gordon 2000). The amount of support and assistance people seek and receive to make decisions varies, depending on the person's ability, personality and life circumstances and on the particular decision at hand. Some people, such as those with severe to profound intellectual disabilities simply need a great deal more assistance and support than most.

SOME PEOPLE REQUIRE MORE IN THE WAY OF SUPPORT AND ASSISTANCE THAN OTHERS, AND WITH RESPECT TO MORE AREAS OF DECISION-MAKING THAN OTHERS; IT IS A MATTER OF DEGREE, RATHER THAN A CASE OF ABSOLUTES.

(Gordon 2000)

## SO... IS THERE TRULY POWER IN A UNION?

A growing body of literature both within disability and non disability related fields promote the value of collaboration within decision making. This body of work downplays the concept of individualization within decision making processes and promotes the value of supported decision making.

This literature promotes a collective view of autonomy, whereby optimal decision making is seen as a collaborative rather than an individualised process (Grove, Bunning et al. 1999; Iyengar and Lepper 1999; Bach 2006; Hesselbein 2008). Many of these cross-cultural researchers strongly criticize the notion of individualised autonomy highlighting the value of collaborative/supported decision making particularly in non Western, less individualistic cultures (Markus and Kitayama 1991; Iyengar and Lepper 1999; Snibbe and Markus 2005; Vansteenkiste, Zhou et al. 2005; Vansteenkiste, Lens et al. 2006; Kim and Sherman 2007). Iyengar and Lepper in particular describe a collective view of autonomy in Asian cultures, whereby optimal decision making is seen as more of a collaborative rather than an individualized process (Iyengar and Lepper 1999).

Through their research they claim that individualized autonomy is generally a western desire and is not typically coveted in more socially interdependent cultures. Through their studies they challenge the notion that all cultures value independent choice. Iyengar and Lepper claim that the provision of individual independent choice seems to be more crucial to American children 'for whom the act of making a personal choice offers not only an opportunity to express and receive one's personal preference, but also a chance to establish one's unique self-identity' (Iyengar and Lepper 1999). For Asian American children however, independent personal choice does not seem to be as critical, and suggest that some may actually prefer to have choices made with the help of those who know and love them.

This perspective on decision making and choice is in line with the principles of supported decision making.

## WHY IS IT SO DIFFICULT FOR PEOPLE WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITY TO MAKE DECISIONS WITHOUT SUPPORT?

### 1.1 THE CHALLENGE OF BEING HEARD: COMMUNICATION

Stancliffe and his colleagues claim that the factors having the most consistent and robust association with a person's self determination are their ability (Heller, Miller et al. 1999; Stancliffe, Abery et al. 2000), particularly in terms of their communication. The greater level of support someone needs to communicate the less likely they are to lead self determined lives (Stancliffe, Abery et al. 2000).

It is difficult to dispute that the majority of people, including those with severe and profound intellectual disabilities have preferences. The challenge for people with severe and profound intellectual disability however, is having these preferences heard. An enormous body of research predominately within the field of augmentative and alternative communication has lead to the development of some valuable resources designed to support people with severe and profound intellectual disability to 'be heard' (Parsons and Reid 1990; Newton, Ard et al. 1993; Windsor, Piché et al. 1994; Puddicombe 1995; Lovett 1996; Parsons, Harper et al. 1997; Hughes, Pitkin et al. 1998; Sanderson 1998; Grove, Bunning et al. 1999; Logan, Jacobs et al. 2001; Porter, Aspinall et al. 2005; Maes and Bea 2006; Bloomberg and West 2009; Hostyn and Maes 2009). It is clear that overcoming the very real hurdle of 'listening' to people who communicate informally is a fundamental factor in supporting them to lead lives that reflect their preferences.

For people with severe to profound intellectual disabilities current practice emphasizes that the onus for change should be focused not on the individual but on those who support them. In recent decades there has been a fundamental shift of focus from the individual to the communicative partners as well as to the environment of which they are a part. The importance of communication partners is widely recognized in the literature (Granlund, Björck-Åkesson et al. 1995; Golden and Reese 1996; DeSimone and Cascella 2005; Wong and Wong 2008). Golden and Reese concluded that the quality of staff-resident interactions in residential institutions was an essential indicator of QoL, but that 'lower functioning' residents received less stimulating interactions than those who were more competent. This research has fuelled a greater appreciation that the onus for ensuring people with severe to profound intellectual disability are 'heard' is not on the individual themselves but on their supporters. Individualized functional training with a person's circle of support within their everyday environments is increasingly being accepted as an effective avenue for promoting change, particularly within the area of communication (Carr and Durand 1985; Clarke 2001; Durand and Merges 2001; Bloomberg, West et al. 2003; Watson and Joseph 2011; Watson and Joseph In Press).

### 1.2 THE CONCEPTUALIZATION OF SELF-DETERMINATION FOR PEOPLE WITH SPID: HAVE WE GOT IT RIGHT?

Another theory worth noting is related to how self-determination is defined. A review of the literature reveals that many, including people supporting those with Severe and Profound Intellectual Disabilities believe that self-determination is not a relevant concept for this group of people (Singer 1993; Brown and Gothelf 1996; Stancliffe and Abery 1997; Wehmeyer 1998). Bioethicists such as Peter Singer argue that people with profound intellectual disability lack the attributes that define personhood, such as reason, self awareness and self determination and therefore cannot be considered human (Singer 1993). Supported decision making is in direct opposition to this view and holds the assumption that self-determination is not only relevant for this group of people but fundamental to their happiness and well-being. Supported decision making holds the view that people with Severe and Profound Intellectual Disabilities can, with support, lead self-determined lives that reflect their personal preferences. The common belief that people with Severe and Profound

Intellectual Disabilities cannot be self-determined stems from a general misinterpretation of the concept of self-determination.

An alternative view of self determination that is inclusive of people with Severe and Profound Intellectual Disabilities and those who support them is offered through a supported decision making process. Challenging the notion of decision making competence, a Supported Decision Making approach assumes that everyone can lead lives they prefer by being supported to build their preferences into choices and from there into decisions. This approach recognizes the value of collaborative decision making for all especially for those who are unable to advocate for themselves, people with Severe and Profound Intellectual Disabilities.

## THE DILEMMA OF RELYING ON PROXY DECISION MAKERS

As people with severe and profound intellectual disabilities cannot express their views using traditional communication systems it is common practice to ask a proxy (substitute decision maker) to respond on their behalf when decisions are to be made. Proxy reporting for this population is highly inferential, posing obvious dilemmas, and therefore should be used cautiously.

It is clear that reliance on one person to 'speak for' someone is fraught with serious questions around whose voice is truly being broadcasted. Obtaining and interpreting the preferences, interests and wants of people with SPID is difficult and challenging to say the least. Researchers and practitioners interested in decision making and choice for people with SPID are faced with a quandary. As Petry and colleagues point out the choice they have is to

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**'EITHER IGNORE THESE INDIVIDUALS BECAUSE THEY CANNOT SELF REPORT, OR OBTAIN DATA FROM PROXIES THAT MAYBE BIASED OR INVALID'**

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(Petry, Maes et al. 2009)

The ongoing debate about the utility of proxy response in the literature cannot be ignored. However, proponents of supported decision making are sympathetic to Petry and the view of her colleagues as stated in their quote above. Supported decision making starts with the premise that in order to truly hear the voices of those who cannot by the very nature of their disability advocate for themselves there is a need to rely on the collaborative efforts of their circle of support. It proposes that a key to increasing the validity of proxy reporting as truly representative of a person's preferences maybe by approaching the decision making in a collaborative way. Such an approach is at the heart of supported decision making.



## CONCLUSION

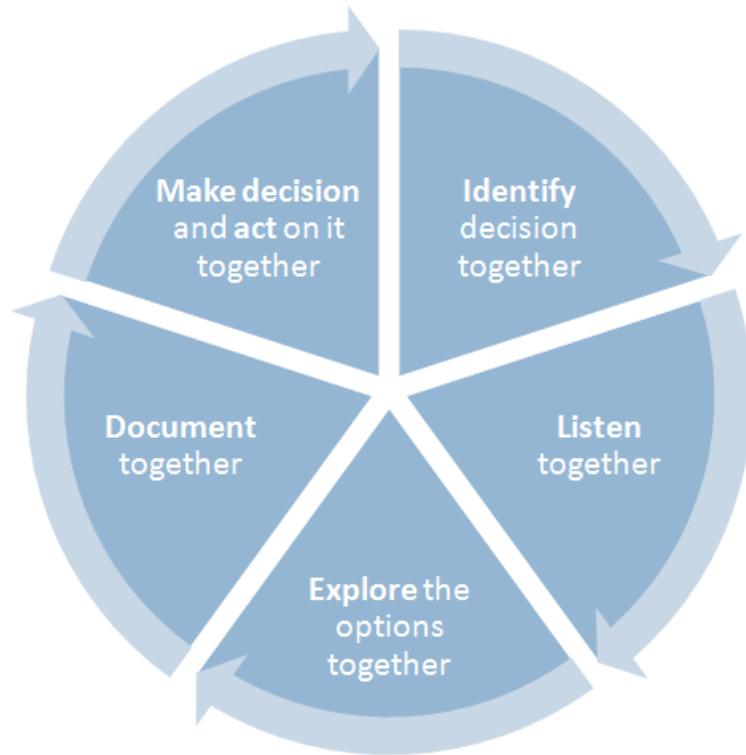
This brief literature review has attempted to highlight existing evidence and support of a supported decision making approach for people who are rarely heard, those with severe to profound intellectual disability. A Supported Decision-Making approach is emerging as a viable method of supporting people who by the very nature of their disability need the support of others to have their preferences heard and acted upon. Although a supported decision making approach is not yet backed by a large body of empirical studies, the concepts underpinning it are sound and are well supported within the literature.

These concepts form the heart of Scope's supported decision making approach and they include:

1. All human beings can communicate with the support of people who know them well (Donnellan, Miranda et al. 1986; Miranda, Iacono et al. 1990, p.3; Durand and Merges 2001)
2. This communication can become clear expressions of preference when someone is supporting by people who know them well (Belfiore, Browder et al. 1994; Green, Middleton et al. 2000; Cannella, O'Reilly et al. 2004).
3. There is value in human beings working collaboratively to make personal decisions (Grove, Bunning et al. 1999; Iyengar and Lepper 1999; Bach 2006; Hesselbein 2008).

APPENDIX 1A

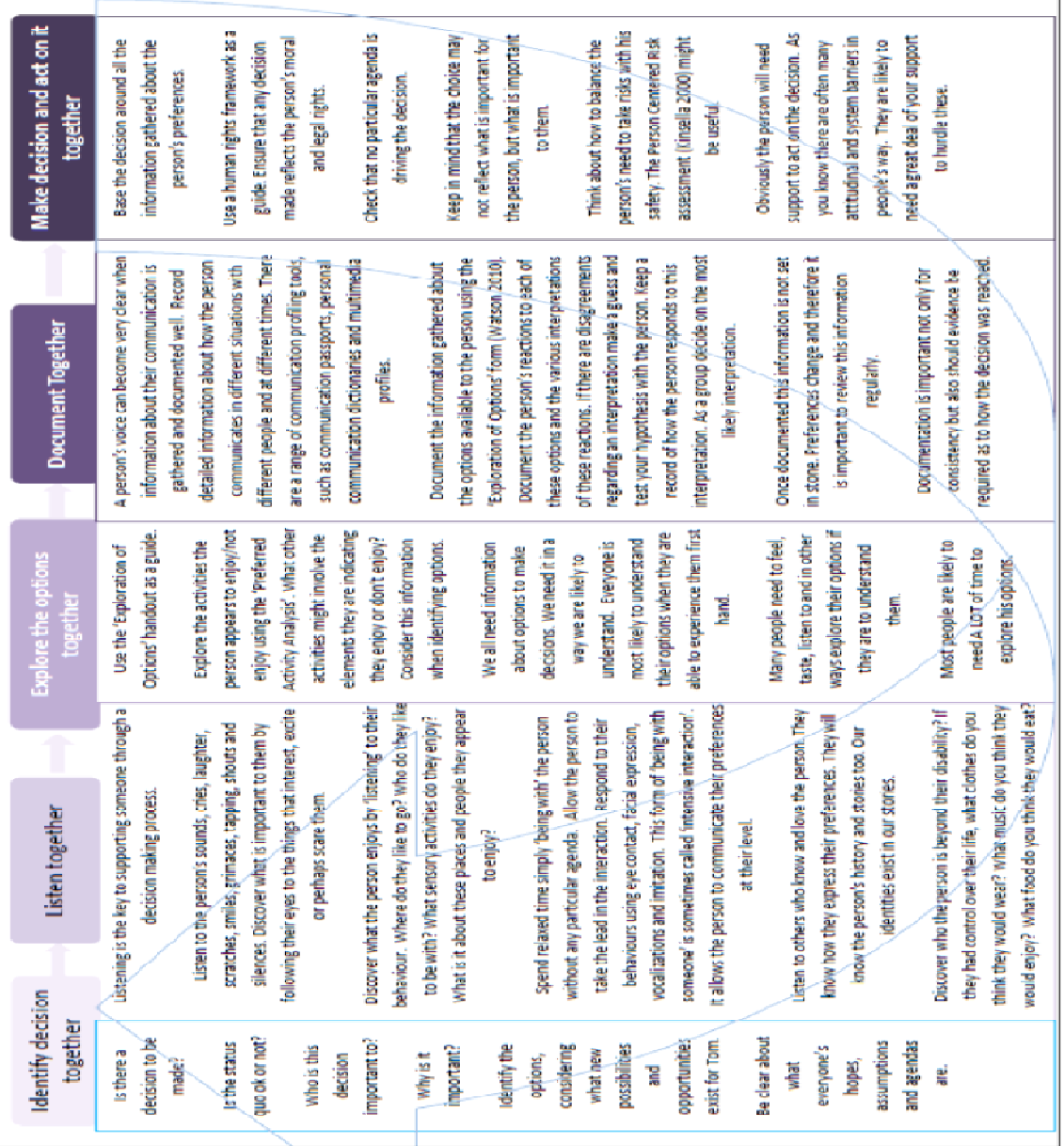
**SUPPORTED DECISION MAKING FRAMEWORK**  
**A TOOL FOR PEOPLE SUPPORTING THOSE WHO COMMUNICATE INFORMALLY TO LIVE LIVES THEY PREFER**  
**JO WATSON (2010)**



## Supported Decision Making Framework

A tool for people supporting those who communicate informally to live lives of their preference

Jo Watson 2010



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