

# Office of the Senior Practitioner

Experiences of restrictive practices:  
A view from people with disabilities and  
family carers

A final research report to the  
Office of the Senior Practitioner

*Supporting people  
to achieve dignity  
without restraints*

A Victorian  
Government  
initiative



## **Abbreviations**

APO	Authorised Program Officer
BSP	Behaviour Support Plan
CRU	Community Residential Unit
DARU	Disability Advocacy Resource Unit
DHS	Department of Human Services
DSC	Disability Services Commissioner
IDRP	Intellectual Disability Review Panel (now disbanded)
OPA	Office of the Public Advocate
OSP	Office of the Senior Practitioner
PCP	Person Centred Plan
RIDS	Restrictive Intervention Data System
RMIT	Royal Melbourne Institute of Technology
SARU	Self Advocacy Resource Unit
UN	United Nations
VCAT	Victorian Civil and Administrative Tribunal

Paul Ramcharan, Co-ordinator Research and Public Policy, Australian Centre for Human Rights Education, RMIT University

Karen Nankervis, Associate Professor, Division of Disability Studies, RMIT University

Maria Strong, Self Advocate and co-researcher, Division of Disability Studies, RMIT University

Alan Robertson, Self Advocate and co-researcher, Division of Disability Studies, RMIT University

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please phone 9096 8427 using the National Relay Service 13 36 77  
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## Contents

Executive summary	2
Acknowledgements	7
<b>1 Background</b>	<b>8</b>
1.1 Report status and summary of methods	8
1.2 The policy context	8
1.2.1 The Disability Act, 2006 and the role of the Office of the Senior Practitioner	9
1.2.2 The Disability Act, 2006 – some assumptions and premises	9
1.3 Some related literature	11
<b>2 The views of people with intellectual disability</b>	<b>15</b>
2.1 Introduction	15
2.2 Skit 1	15
2.3 Skit 2	16
2.4 Skit 3	18
2.5 Skit 4	20
2.6 The voice of people with disabilities – discussion	22
2.6.1 Discussion	22
2.6.2 Some interim conclusions	24
<b>3 The views of family carers</b>	<b>27</b>
3.1 Introduction	27
3.2 Understanding restrictive practices – contextual factors	27
3.2.1. Staff input (or lack of it)	27
3.2.2 Plans not implemented	27
3.2.3 Staff attitudes, perspective and approaches	29
3.2.4 Service and organisational issues	30
3.2.5 Environment	34
3.2.6 Communication and choice	36
3.2.7 Collateral damage	37
3.2.8 Some further issues in constructing the case for a restrictive intervention	38
3.3 Things that work	40
3.4 Final points for discussion	42
<b>4 Discussion and recommendations</b>	<b>46</b>
4.1 A structure for the discussion	46
4.2 The service system and service delivery – some options	48
4.3 Individualised planning and choice – a rallying call	50
4.4 Characteristics of the environment – the grounds for further research	53
<b>5 Conclusions</b>	<b>55</b>
References	57

## Executive summary

- Under the Disability Act 2006, the Senior Practitioner seeks to manage one interface between individual freedom and public good, that is, to manage behaviour that is of danger to the person with disability or to others, or to their property.
- Authorised Program Officers (APOs) are required to identify ‘behaviours of concern’ and to say, within a Behaviour Support Plan (BSP), what restrictive interventions will be used to change the person’s behaviour.
- In this research, focus groups and interactive theatre work with twenty-three people with disabilities and interviews with eleven family carers were undertaken to find out their views on restrictive practices and behaviours of concern.

### This report of the views and analysis of these views shows that:

- Feeling safe is a priority for people with disabilities and their family carers; yet many people feel unsafe.
- Many behaviours seen as being ‘of concern’ can be understood better as adaptive behaviours to maladaptive environments. These behaviours can be seen as forms of ‘resistance’ or ‘protest’.
- Behaviours of ‘resistance’ and ‘protest’ should be seen as legitimate responses to difficult environments and situations, and not a reason for restrictions designed to change the person and their behaviour.
- Restrictive practices challenge human rights and give rise to concerns over social justice. Changing the person and their behaviour should not be the starting point. Rather, it is necessary initially to examine how to change services, systems and environments as a means of changing behaviour.

In this view the formula below will apply (Figure 1).

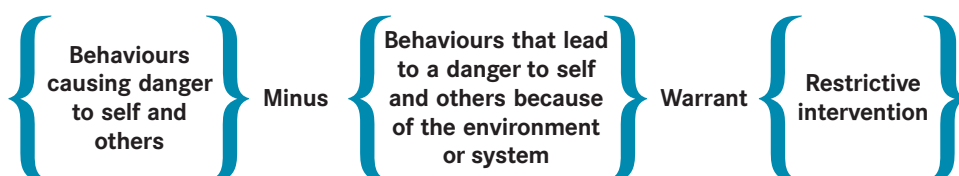
However, in this research people with disabilities and family carers identified a number of seemingly repetitive and recalcitrant problems making the accomplishment of the formula difficult. These are set out in the summary findings below.

### The following are key findings of this work:

- There is very little literature and research about the views and experiences of people with disabilities and family carers in relation to restrictive practices, which can inform policy and practice.
- Some people with disabilities:
  - do not know their rights
  - do not complain out of fear or resignation
  - have no access to advocacy
  - are simply unseen and unheard by all but those in direct support roles
  - find that advocates and families often have to fight to the very top for their views to be heard
  - find that communal settings multiply behaviours which make them feel unsafe
  - undergo many ‘informal restrictions’ that are never recorded but are implemented by staff to maintain overall control of a setting
  - find that managing private space and safety is more difficult where staff numbers are low, there is no active engagement, there are locked areas, and where there are too many people
  - have to trust staff to manage behaviour and interactions in places they use and inhabit, and find this hard where they perceive that trust is broken
  - communicate their views about different environments by their varying behaviours in those environments
  - have their rights infringed where planned services are not delivered, services are withdrawn, changed or reduced, where staff attitudes are negative, where restrictive acts

Feeling safe is a priority for people with disabilities and their family carers; yet, many people feel unsafe

Figure 1: Current formula of practice



are re-badged, and where scrutiny and access by others is denied.

- When people with disabilities have rights taken away, then over a lifetime:
  - they sometimes come to accept this because they do not know better
  - if they do know better, they feel they are under ‘forced compliance’ in which they often see staff as perpetrators
  - they are often willing to sacrifice their own rights if the result is greater safety
  - but, for many, their behaviour becomes *acquiescent* or *institutionalised*,

or, alternatively,

- they find ways of beating the system to get what they want where a restriction applies
- their level of protest increases, and they find less and less ways of expressing their anger legitimately
- cycles of violence, control and counter-control ensue.

In this view,

- the actions of staff should be perceived as ‘behaviours of concern’ where they infringe a person’s rights. Restrictive practices, *ipso facto*, infringe rights.
- Good ways to accomplish acceptable behaviours are:
  - to start with the person’s choices, wishes and aspirations
  - to successfully and transparently support the person to accomplish their goals
  - to ensure that Incident Reports are not solely based upon one incident reported negatively, but are placed within a life history and considered in relation to a person’s individualised plan
  - to work with positive behaviour management strategies
  - to work on the principle of positive support– to ensure people are fully aware of situations in which they should complain and that there are advocates to help them do so
  - to have an independent means of accessing advocacy

- to have an ‘equality of arms’ in situations where there is disagreement.

**A number of *values* characterise services that support people to achieve dignity without restraint:**

### In relation to power

#### Achieving rights:

- The need for advocacy
- Equality of arms
- Not sacrificing ‘fundamental rights’ for the greater good
- Recognising infringements on human rights and freedoms and, also, neglect
- Recognition of the under-reporting of restrictive practices

#### Safety:

- Of personal possessions
- Recognition of where people have had to sacrifice rights and choices for the behaviour of the few
- Allowing choice that promotes safety
- Recognising that seclusion must be about safety and active engagement and support

#### Visibility:

- Being more visible
- Services and interactions being open to scrutiny
- Open door policy for families and advocates

#### Being informed:

- All people being aware, informed and educated about rights
- Staff awareness of effects of their decision-making

#### Positive approaches:

- Choices, hopes and aspirations reflected in support to accomplish these
- Choice of support and services

#### At the level of interaction:

- Inverting power relations between staff and people who they support
- Recognising staff interaction as a potential ‘behaviour of concern’

A good way to accomplish acceptable behaviours is to start with the person’s choices, wishes and aspirations

- Recognising power in communal groups
- Trust and respect

### Services and service system issues

#### Social justice:

- Equal access to services for all
- No withdrawal/reduction/change of service without consultation
- Services that cater for diversity

#### Individualised planning and interaction:

- Individualised plans as part of BSP decision-making mechanism
- Positive views of the person and their goals
- Positive support always

#### Fundamental values required:

- Honesty, especially about hard to serve clients
- Working on principles of human rights
- Recognition that there is no right to do something that is wrong
- Hearing the voice of people with disabilities and family carers
- Working with families and people with disabilities collaboratively and co-operatively
- Recognising the rights of access and scrutiny of family carers and advocates
- Recording systemic issues leading to organisationally restrictive practice
- Avoiding re-badging of restrictive interventions
- Policy compliance auditing
- Review of Incident Report mechanisms at DHS level

### Recognising legitimate causes of behaviour

- Change the setting; not the person
- Recognising environments of concern and characteristics of such environments
- Solutions that produce honest behaviour
- Changing behaviour is not sufficient grounds on its own for a restrictive intervention

- Recognising when informal restrictions are a product of environment or the culture
- Recognition of the effects congregate and communal groups have in producing behaviour
- Understanding the relative comfort produced in different environments.

### More broad-ranging recommendations, made on the basis of the report findings and values identified above, are as follows:

- A small minority of people do not understand their behaviour as wrong. There is no intent to cause damage or harm. Those people are also likely to be unable to understand the link between their behaviour and aggressive interventions. In this way, restrictions are likely to be perceived as a form of torture, and human rights and social justice dictate they not be used except to prevent self harm.
- A potentially good way to empower people with disabilities and their circles of support is to place them in control to choose, purchase and monitor their own services. Individualised funding represents one good way of achieving this and it is, therefore, recommended that further pilot schemes are set up for people who might not be able to administer their own payment.
- Consumers should have a voice in all aspects of decision-making about their own services. This applies to people with disabilities too. Evidence suggests that this will be dependent upon building, over time, a strong and independent self advocacy movement and the right support to advocates and participatory approaches, that maximise participation of diverse groups and interests.
- People with disabilities should be empowered to, themselves, monitor quality frameworks and service standards. Their work should be fully paid, independent and targeted around those services in which people are least visible.
- A system of social justice requires a balance between claims and counter-claims and equality of arms. In the present system, not as many complaints are being made as could be made.

A small minority of people do not understand their behaviour as wrong. There is no intent on their part to cause damage or harm.

The Senior Practitioner should work with the Office of the Public Advocate, legal-, systems-, citizen- and self advocacy organisations, as well as the Disability Advocacy Resource Unit (DARU) and Self-Advocacy Resource Unit (SARU) to extend the visibility of those who are most vulnerable. Ways of making staff free to advocate should also be examined tying their interest to those of the people they support.

- The system of values guiding scrutiny of services should be based on the quality framework and standards but, additionally, the Victorian Charter of Human Rights and Responsibilities Act, 2006. The Office of the Senior Practitioner might make links with the Office for Disability to further operationalise these values.
- Rights can be individualised by creating, over time, an individualised list of those things that the person prefers, likes and wants, as well as those they find difficult, stressful or distasteful. These should become a charter of personal rights and should be widely known to those who provide support. Infringements of these would represent a case for complaint. Each BSP should append this individualised charter of rights and state whether the rights are being in any way infringed.
- Reduction and withdrawal of services by providers, and independent of plans and agreement by the person with disability and their family, should be recorded on any application to introduce a restrictive intervention. They should have been taken into account in explaining the behaviour of concern that is the target of the intervention.
- Any application for a restrictive intervention should be accompanied by a form in which the person, and their advocates and allies comment upon the level of success in accomplishing stated objectives of the person centred plan. Their views should also be recorded in relation to whether they accept that the outcome of the proposed intervention accords with the outcomes stated in the individual plan, and whether they perceive the intervention as justified.
- A review should be undertaken of Incident Forms and how these forms are used by APOs in constructing a case for intervention.
- By ensuring that risk and benefit are considered together, the restrictive practice can itself be seen as a behaviour of concern which has to be counter-balanced by the stated benefit and against the behaviour of concern it is designed to address. This not only ensures a system in which both rights and risks are put to the test, it also establishes a system of proportionality and justice. More research on the reconfiguration of risk is required.
- The principles of positive support are hugely significant in defining the experience of people with disabilities and should be adopted as an important principle for the operation of services, and as being important to any restrictive interventions that are planned.
- It is recommended that, if people with disabilities and their advocates and allies have the right in the submission to the Senior Practitioner to challenge the service application for a restrictive intervention, it be referred to an independent panel constituted out of the range of stakeholders which can arbitrate a decision based on balancing risk with benefit of intervention. The same channel of complaint should also be available where services are perceived to be restricting the person because of withdrawal of service or other factors.
- To ensure visibility, services should work on the principle of being open to family, recognised advocates and friends, except where the services apply for a legal order preventing such access.
- The OSP should work collaboratively with the Department of Education and Early Childhood Development and the Office for Disability to develop core values based around a human rights approach that can be commonly applied in schools, communities and disability services around rights and restrictions.
- Additional research is required to identify, quantify and codify behaviours of protest and resistance, so that they may be more easily used by those who need to understand the cause of much behaviour and reconstruct the evidence about what constitutes a least restrictive alternative by taking such factors into account.

- Reconfiguring the equation between individual restriction and public good, requires more research to: codify behaviours of resistance and protest; to interpolate the Victorian Charter of Human Rights and Responsibilities, 2006, the UN Convention on the Rights of People with Disabilities 2006, with the Quality Framework and disability service standards; and, to find a new balance between risk and benefit to challenge risk averse services. Coupled with a positive support approach, APOs will gain through this an armoury which assesses restriction in the light of rights and social justice.
- If some of the central findings of this report are accepted by the Senior Practitioner it is suggested that the range of potential solutions would benefit from further consultation with people with disabilities, their advocates and allies, families, and members of the service sector. To get people to work in unison necessitates that change is a product of consultation, participation and agreement. It is therefore suggested that this report be used as a basis for a consultation exercise to elaborate further on some of the potential solutions that exist.



## Acknowledgements

This report would not have been written without the contributions of the many people with disabilities and family carers who gave freely of their time. They are truly experts by experience and we are indebted to them for providing a window on their lives.

Barbara Rogalla was involved as a research assistant in the early days of this project. She also contributed to a literature review of restrictive practices, some which appears in the present report.

We are grateful to the Office of the Senior Practitioner for providing the funding for this research. However, we are even more thankful for the patience they have shown whilst difficult data was being analysed and synthesised. That patience has meant the chance of delivering a report that the authors feel does justice to the data. The authors have benefited from the opportunity to 'dwell' on the data and to consider the fundamental meanings attributed to behaviours of concern by family carers and people with disabilities.

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# 1

## Background

### 1.1 Report status and summary of methods

This is one of two final reports being submitted to the Office of the Senior Practitioner (OSP). The companion report contains the views of people with intellectual disabilities about restrictive practices and is written in easy words and pictures. The current report combines the views of people with intellectual disabilities and those of family carers.

The OSP has a role to support research around restrictive practices and, in line with policies for inclusion, felt that policy and practice could not be improved if the views of people with disabilities and family carers were not taken into account. Additionally, in introducing the Inaugural Annual Report, the Senior Practitioner noted that,

*Behaviours of concern do not take place in a vacuum. The behaviours occur in a context of the person's experience, environment and community. Any intervention that primarily focuses on the person alone will not effect positive sustainable change. The intervention needs to include the systems that are required to support the person. (Office of the Senior Practitioner 2008b, p. 6).*

The Disability Act 2006 represents the contemporary policy approach to the management of these issues and the Office of the Senior Practitioner has the responsibility for implementation and monitoring

Funding for the present study was therefore provided by the Office of the Senior Practitioner to bring the voices of people with disabilities and family carers onto the agenda and to establish the contextual, environmental and systems factors that produce or affect people's behaviour.

For those readers who are interested, the detailed methods used for the study is set out in a separate Appendix (available from lead author on request). In summary, the research approach was to talk with people using interviews with eleven family carers and to use focus groups, interactive theatre and life history interviews with a total of 23 people with intellectual disabilities. Permission was granted for this research by the RMIT Human Research Ethics Committee and, as part of this agreement, we have used means to ensure the anonymity of participants in this report.

The samples sizes for this research are modest and are therefore limited for the purposes of generalisation but, correspondingly, descriptively

rich. The emphasis on such 'thick description' helps us to understand the values and views that prompt people to act in certain ways, rather than provide an unexplained collective count of recurrent features of their behaviour. The data was tape-recorded, listened to several times and then what each person said was placed into categories that summarised their view or views. The data was collected with two co-researchers with disabilities who were paid university rates for their research. The co-researchers were also involved in the analysis of all data collected from people with disabilities.

The remainder of this introduction sets out the present Victorian policy framework and summarises the very limited evidence-base around restrictive interventions from the point of view of people with disabilities and family carers.

If you would prefer to do so, you can jump to Section 2 now to find out the views of people with disabilities and family carers.

### 1.2 The policy context

None of us are completely free to do what we choose. In making our own choices we consider the effect of the choices we make on those close to us; at other times the services or goods that we would wish to have or to use are not available; economic or geographical accessibility may put some things out of our reach; and we choose not to harm others, except, perhaps, in defending ourselves.

This liberal model of freedom proposes that our freedom should not be at the expense of others. In this view, restrictions are legitimate if they produce the greatest good for the greatest number and if they prevent harm to self or others.

*There is a limit to the legitimate interference of collective opinion with individual independence; and to find that limit is as indispensable to a good condition of human affairs, as protection against political dogmatism. But though this proposition is not likely to be contested in general terms...how to make a fitting adjustment between individual independence and social control, is a subject on which nearly everything remains to be done. All that makes existence valuable to any one depends on the enforcement of*

*restraints upon the actions of other people.  
(J.S. Mill – On Liberty).*

The problem with these ideals is that a judgement must be made about *when* it is legitimate to restrict people and what *type of restriction* is acceptable. In setting out policy and legislation to operationalise these questions, the State is empowering its functionaries, in this case disability services and its workers, to implement restrictions on people's freedoms in certain circumstances. Essentially, the formula being used is based on the assumption that the 'greater good' is being served to the person and/or others by the type of restriction and means of implementation.

The Disability Act 2006 represents the contemporary policy approach to the management of these issues and the Office of the Senior Practitioner has the responsibility for implementation and monitoring of restrictive practices.

### **1.2.1 The Disability Act 2006 and the role of the Office of the Senior Practitioner**

This research was undertaken against the context of the Disability Act, 2006 which states in its purpose that,

*The purpose of this Act is to enact a new legislative scheme for persons with a disability which reaffirms and strengthens their rights and responsibilities and which is based on the recognition that this requires support across the government sector and within the community.*

More specifically Section 224 of the Disability Act 2006 repealed the Intellectual Disability Review Panel (IDRP) and appointed a Senior Practitioner. In contrast with the powers of the IDRP, Section 148 authorises the Senior Practitioner not only to monitor restraint and seclusion, but also to oversee the reporting requirements and time frames of these reports. It also mandates the Authorised Program Officer to submit these reports to the Senior Practitioner. The Act imposes 'penalty units' for various breaches of the legislation by persons who are authorised to perform restrictive practices.

The rights-based approach of the Disability Act is also reflected in the rights and responsibilities of the Senior Practitioner and are more formally

recognised in the Victorian Charter of Human Rights and Responsibilities and the UN Convention on the Rights of Persons with Disabilities. Accordingly, the Senior Practitioner, who 'is generally responsible for ensuring that the rights of persons who are subject to restrictive interventions and compulsory treatment are protected and that appropriate standards in relation to restrictive interventions and compulsory treatment are complied with'. For this purpose, the legislation confers on the Senior Practitioner special 'powers, duties, functions and immunities'.

Section 3 (1) of the Disability Act 2006 defines a 'restrictive *intervention*' as 'any intervention that is used to restrict the rights or freedom of movement of a person with a disability', and this includes chemical or mechanical restraint, and also seclusion. *Vitality*, the intention of such interventions is directed at achieving '*behavioural control of a person with a disability*' and must occur within a behaviour support plan. Authorising an intervention requires three conditions to be met: 'to prevent the person from causing physical harm to themselves or any other person; or to prevent the person from destroying property where to do so could involve the risk of harm to themselves or any other person'; second, the restrictive intervention is the least restrictive option 'as is possible in the circumstances'; and third, 'the use and form of restraint or seclusion' are part of a previously defined 'behaviour management plan' for the person, and the intervention is authorised by the Authorised Program Officer.

### **1.2.2 The Disability Act 2006 – some assumptions and premises**

If the Act provides the structure for implementation, the Behaviour Support Plan (BSP) guide provided by the OSP and the Restrictive Intervention Data System (RIDS) represents the reporting framework services are required to use and the basis upon which the Senior Practitioner reports. In compliance with the Act, this document establishes the circumstances of use for behaviour support (a focus on behaviour), how it will benefit person (a focus on outcomes) and that it is the least restrictive option (conferring maximum rights) and that it has involved all parties, including the client, guardian, representative or others as required.

In making their judgement about the proposed intervention the person’s disability goals, behaviours of concern (which includes the behaviour, impact on self and others, predictors and frequency, intensity and duration) have to be documented along with why the behaviour occurs, what changes to environment will stop such behaviour and, only then, the intervention to be used, when and how the intervention is monitored and reviewed, its success and what changes to the plan are suggested as a result.

Things that are important to note in terms of the findings of this study are the following:

- a) Although there is room in the Behaviour Support Plan form for asking the level of changes possible to the environment, it is not clear that ‘other environmental options’ have been, should be, or can be tried *as an alternative* to the intervention. This means the default position is that the restriction is taking place to *suit the present environment* and is considered by Authorised Program Officers to be a least restrictive intervention there, and there only.
- b) There is a focus on behaviour change. In this model since the unit of interest is an ‘act of behaviour’ it immediately predisposes one to see what is necessary to change as being the agent of that behaviour, that is, the person with a disability. In doing so, it offers a pathological model in which it is more likely that the fault is seen to lie with and within the person with the disability.
- c) Policy, and indeed academic discourse privilege calculations of restriction of freedom against contribution to public good in terms of behavioural acts or categories of restriction. In other words, both behaviour and the categories of restriction are assumed to go together and are seen as essential in the equation of balancing the person’s individual independence and rights against the need for social control in the interests of public good or personal safety as shown in Figure 2 below.

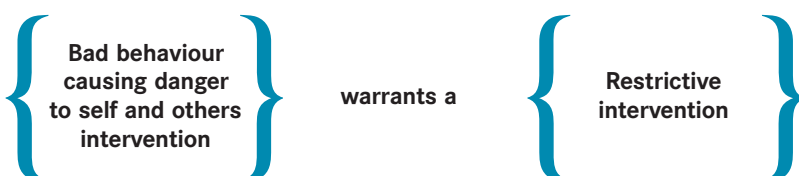
These assumptions are by no means insignificant and, indeed, are hugely consequential. They represent a particular range of powerful voices: an academic history of ideas drawing on studies of engagement; a concomitant history of disability related interventions based on behavioural interventions, a service-based response to the behavioural model with Behaviour Intervention Support Teams specialising in changing behaviour; and a policy-related service framework which, in accepting this dominant paradigm, informs the policy and legislative mandate around controlling the lives of our fellow citizens with disabilities.

Chemical restraints, mechanical restraints and seclusion are defined in the legislation. The unit act of a restrictive intervention may be considered to be such acts as administering a chemical, preventing the person from moving or using time-out. The seemingly ironic coterminous *rights perspective* with *restrictive intervention* is managed via the liberal ideal of balancing the person’s rights against those of others (see below) or against self harm. Moreover by considering what unit acts are ‘acceptable’ new ways of thinking about controlling ‘acts of concern’ can, and have, emerged. In this light, aversive therapies were repealed under the IDRP as unacceptable whilst, as McVilly (2008) points out ‘prone position’ restraints such as hog-tying and mechanical restraints using clothing, are seen as infringements to rights and, indeed, as potentially dangerous having led to a series of deaths by asphyxiation. In the words of one US policy,

*The use of restraints as a behavioural intervention continues to be a concern... due to the risk of serious injury or death, emotional harm and trauma, and the disruption of relationships with family members, peers and staff... Except in the case of emergency, [this State] is dedicated to the need for ongoing reduction and the eventual elimination of all restraints and restrictive practices. (Department of Public Welfare 2006, p. 2).*

The concentration on the ‘unit act of behaviour’ now stretches to approaches that seek to support the person to reconstruct stress-provoking situations in order to re-direct behavioural response. For example, the ‘stress thermometer’ suggested in the OSP good practice guide ‘*From Seclusion to Solution*’

Figure 2: The basic restrictive intervention equation



suggests working with people to: stop, calm down, relax, think about what you really want, think about something good, make yourself happy. Similarly, the good practice guide on ‘mindfulness’ proposes a method in which, instead of externalising behaviours of concern, the client is taught to use self reflection and meditation techniques to internalise and reorganise reactions to stressors. These approaches are important, though, it should be noted that where the resentment, stress and anger is justified, these approaches could be in danger of hiding abusive relationships too. Indeed, such arguments may relate to staff also, given their attitudes and emotional reactions to behaviours of concern (Lambrechts *et al.* 2008). More broadly though, what is being suggested is that the assumptions of present policy and practice favour a focus on *behavioural acts* which privilege one form of input, that the input is predisposed to *changing the individual* and that this necessarily works on pathologising frameworks.

As will be seen in this report, people with disabilities and family carers tell us clearly that many behaviours should not be seen as being inside the individual, or that the individual is ‘bad’ and must be changed. Rather, the behaviours should be seen as adaptations to very difficult environments. We must not get ahead of ourselves, but it is worth noting that in making the case for a restriction on the personal freedom of a person with disabilities in order to benefit public good, no system of weighting or proportionality is given to the extent to which the environment produces their behaviours. Again, to reiterate the present policy and practice assumption, ‘the fault is in the person’.

### 1.3 Some related literature

It is not the intention of this report to systematically review literature on restrictive practices. Indeed McVilly (2008) has undertaken a significant review funded by the Office of the Senior Practitioner in this regard. That document reviews a substantial amount of current knowledge in relation to definitions of different forms of restriction alongside the varying policy and practice responses worldwide and in different jurisdictions in Australia.

As the McVilly review highlights, the knowledge base around restrictive practices is largely academic,

professional and policy-driven and produced. Maybe this professional dominance is not surprising as there is a whole industry based upon its central ideas. However, the literature review for this study also clearly indicates moves to ban certain practices, to reduce to a minimum those practices that are left in the repertoire of acceptable interventions, and to extend mechanisms to achieve personal control to avoid stress and anger being displayed aggressively.

A number of reasons can be cited for this change in emphasis, *inter alia*: deaths attributed to restraint (Patterson *et al.* 2003; Nunno, Hoden & Tollar 2006); a recognition that inflicting ‘pain’ cannot be a moral stance for those charged with care and support (O’Brien 1991); difficulties in reconciling restraint with emergent human rights frameworks and resultant successful litigation; the psychological and emotional effects on clients (Sigafos, Arthur & O’Reilly 2003) and staff (Duperouzel & Fish 2007); questions about the extent to which interventions have any effect on behaviour (Harris 1996); and evidence from pilot projects such as the Everyday Lives and Positive Approaches project, run by Pennsylvania Public Welfare Office of Mental Retardation, showing over more than a decade that substantial decreases in the use of such restrictive interventions are possible, (Smith *et al.* 2005).

The complexion of current policy and practice is therefore coloured by the intention to reduce both the need and incidence of restrictive practices, though most national and state jurisdictions, including Victoria, maintain in policy statements the necessity for such practices as a least restrictive alternative. The Office of the Senior Practitioner aim, as stated strategy: ‘*Supporting people to achieve dignity without restraints*’ (Office of the Senior Practitioner 2008) is therefore bold and is, over time, seeking to establish how far new knowledge, experience and evidence can be used to accomplish these ends.

In moving to this end it may be important to visit and learn from jurisdictions which seem to be successfully moving towards the OSP aspiration, drawing on new techniques and developing pilot projects in Victoria to test new approaches. However, doing so without recognition of the experiences and evidence of people with disabilities and family carers would potentially only empower further, and

The Office of the Senior Practitioner, in their stated strategy: ‘*Supporting people to achieve dignity without restraints*’ (Office of the Senior Practitioner 2008) are therefore bold and are, over time, seeking to establish how far new knowledge, experience and evidence can be used to accomplish these ends



give precedence to, another professional discourse, the tenets of which would, without meaningful participation by people with disabilities and family carers, simply be imposed.

The views of people with disability and family carers are not inconsequential given estimates that 10-15 percent of people with intellectual disability display behaviours of concern (Emerson et al. 2001) and that between 50–60 percent of these are subjected to regular physical restraint (Emerson 2002). In its Annual report for 2007/8 (OSP 2008, p. 12) the Senior Practitioner reports on 2349 Behaviour Support Plans submitted in the Year 2006-7. This represents a significant number of people upon whom some form of restriction is being placed. As the report goes on to say:

*The majority of plans (78 percent) indicated chemical restraint would be used, 7 percent identified using mechanical restraint and 9 percent reported that seclusion would be used. Of the plans reviewed in detail, 12 percent described using more than one restrictive intervention... (OSP 2008, p. 12).*

Like the IDRP before them (IDRP 2006), the OSP indicates that even these data may indicate a substantial amount of under-reporting in relation to restraint and seclusion (OSP 2008, p. 24). Indeed, as the present report will show, the reporting is really only of one very small subset of a much larger group of practices which in some way limit the person's life and experience.

In short, the lives of a substantial number of people with disabilities who receive services and support in Victoria are in some way affected by both informal and unreported, as well as formal and reported, restrictions. Despite this, precious little information is available on the views of people with intellectual disabilities or family carers in relation to restrictive practices. Perhaps the most well-known voice of protest incorporating the views of some family carers in alliance with advocacy, legal and rights groups has been the Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS). *In the Name of treatment: A parent's guide to protecting your child from the use of restraint, aversive interventions and seclusion*, (APRAIS, 2005) reports that,

*Every day in this country [the U.S.] children with disabilities are needlessly being subjected to harmful practices in the name of treating "challenging behaviours". They are brought down to the ground and straddled, strapped or tied in chairs and beds, blindfolded, slapped and pinched, startled by cold water sprays in the face, deprived of food, secluded in locked rooms, and more, despite the fact that research and practice show that these techniques exacerbate challenging behaviour and do nothing to teach the child appropriate behaviours, (p. 3).*

The view of APPRAIS takes a particular position and more will be said of this later. However, there are still very few empirical studies of the views of people with disabilities and family carers which contribute to our understanding of restrictive practices.

So what do people with disabilities and family carers think? Reflecting the key interest of this report, a search of literature on the views of people with disabilities and family carers was undertaken (see methodological Appendix, available from lead author on request) and is summarily reported here. The search yielded very few specifically relevant studies that were published mostly within the last decade, and none that report the views of family carers. The approach to knowledge production adopted in this report does not therefore set out to 'fill a gap in the literature', but uses new evidence, that is, the views and experiences of family carers and people with disabilities, to test the evidence-base presently available and, from this, to develop new ideas which take into account their experiences and interests.

Cunningham et al. (2003) used two videos, two of restraints by holding on the floor and one of a mechanical restraint in a chair, and asked 18 people with disabilities to rate each of the approaches to restriction on a scale of 1-5 and then to respond to two open-ended questions: how would you feel if you saw this happening, and how would you feel if this happened to you? Failing miserably to analyse and report the data from the open-ended questions, the authors report there were negative views of all methods with views of the restraint on a chair being least negative. The authors assert that their study indicates consumers can be involved in rating the relative merits of different approaches

little information is available on the views of people with intellectual disabilities or family carers in relation to restrictive practices

to restriction and that, 'The current concerns over restraint relate to consumer safety rather than treatment acceptability' (ibid., p. 315). This current report will contend that each of these conclusions is false. Furthermore, asking people to rate how they would prefer to be restricted assumes they should be restricted in the first place and the research approach is demeaning and perhaps unethical. Whilst the present study adopted videos and both the questions from the Cunningham *et al's.*, (1999) study, the findings produced were substantially different, as will be seen shortly.

In an early case study Peter (1999) proposed that, '... it was not Barry's disability that was the primary source of his deviant behaviour, but rather the human service support system' (p. 807). Peter described how Barry would hit himself during times approaching a celebration such as Christmas or a birthday, leading, at times, to hospitalisation. He would continue to 'up the ante' until such time as he was invited to spend the day with someone rather than being on his own. From Peter's perspective Barry's behaviour was not 'manipulative' or 'maladaptive'. Rather, he was seeking to mould the service, to influence those around him to listen to his needs and to create the accomplishment of his preference and choice.

Another study that used open-ended interviews with 16 direct care staff and nine people with disabilities, the views of people with disabilities were summarised as follows:

*Clients cited other clients and ward atmosphere as the main reason for aggressive behaviour. Some clients said that the use of physical intervention made them more frustrated and brought back memories of frightening experiences. Staff reported that incidents of aggression and use of physical intervention were upsetting and traumatic, causing feelings of guilt and self reproach... Time-out and post-incident discussions were valued by both groups as were strong staff/client relationships, (Fish & Culshaw 2005, 93).*

These findings resonate with some aspects of those in this present study and indicate an important move away from seeing 'behaviours of concern' as being innate, biological or individually owned. Behaviours

are produced in and by both environments and interactions.

The experience of pain, discomfort and feelings that they were being targeted for punishment was also reported by Sequeira and Halstead (2001), whose sample included women with intellectual disabilities amongst those receiving mental health services. Some women reported that staff enjoyed physically restraining them and this led to resentment and more aggression towards the staff. A second study in a psychiatric setting by the same authors (Sequeira & Halstead, 2002) also pointed out that those at the receiving end of such practices had very little information before, during or after the incidents which led to panic and then anger. Other studies of clients' views in psychiatric settings have found that people felt hospitals to be inherently unsafe (Robins et al. 2005) and some patients looked at their experience with shame and felt ignored and distressed during the incident and isolated afterwards (Bonner et al. 2002). Recollections of time spent in psychiatric hospitals has also been studied, with 73 percent of participants claiming that years later, they had not been a danger to themselves and others at the time of the restrictive intervention and, compared to those who had not been restrained whilst in hospital, had a more negative view of the overall hospital treatment, (Ray, Myers & Rappoport 1996). In their review of the literature relating to clients views of restrictive practices in mental health settings, the authors went on to assert that,

*Each of these studies suggests that the patients' perspectives are likely to differ from those of clinicians and reinforce that these experiences are viewed negatively by patients (Ray, Myers & Rappoport 1996, p. 12).*

Finally, in their semi-structured interviews with ten people with intellectual disabilities living in a secure environment, Jones and Kroese (2006) found complex and varied responses from the participants. Whilst all participants could see the ways in which restriction could protect them or others, only half felt it was the correct way to 'calm them down', four felt that staff took pleasure in implementing such interventions and that better communication was important:

where there is a relation of power, and where choice and self-determination are appropriated by one over another, the result is likely to produce the very behaviours it sets out to address

*One participant said that when they did not feel listened to it made them become more aggressive... Talk to you. Calm you down. Restraint makes me more violent. I get more violent and lash out, (p. 57).*

The participants indicated that a good proportion of incidents started with staff refusal to react to requests and that no efforts were made to explain nor to de-escalate. In such circumstances all the residents seemed left with was that staff had power to dictate their choices. Moreover, as the authors suggest, 'environments of high stress and aggression restrict opportunities for positive communication between staff and service users...', (Jones & Kroese, 2006, p. 53).

A few observations can be made about the limited data from people with disabilities described above.

Firstly, a good number of the studies and those in psychiatric facilities have been undertaken with people in hospitals or secure settings. There is good reason to suggest that, in the more widely distributed community residential units and those places providing day care or respite, restrictive practices are less visible and, therefore, less easy to monitor. Moreover the intention of everyday living arrangements is necessarily based upon mimicking, if not accomplishing, everyday lives as opposed to 'treatment'. RIDS represents one administrative tool meant to address this issue but it is not clear whether, in community environments, the restrictions RIDS was designed to record are the sum of restrictions that are experienced. This may raise issues about the cost and efficiency of the system as a bureaucratic device.

Secondly, the data indicate that restrictions involve at least two parties and that the interactions have largely negative emotional effects on those subject to restriction. Indeed the smouldering resentment we have all felt at times at being controlled and being forced into compliance is likely to lead to

further stress and aggression. In short, where there is a relation of power and where choice and self-determination are appropriated by one over another, the result is likely to produce the very behaviours it sets out to address.

Thirdly, the data indicates that, since much behaviour is initiated as a response to interaction with others or to the environment, behaviours are not innate and owned biological characteristics. We need to look outside the individual for causes to their behaviours, and not at their label of 'disability' and its assumed link with 'aggression'. Rather, it may be necessary to look at how maladaptive the environment itself might be.

Fourthly, the data indicate that people communicate, *ipso facto*, whether verbally, by their aspect, demeanour, their mood or their attitude. Generally speaking we are socially aware when such communications are being made. Why then are expressions ignored or missed to such a degree that the only way left to get across their point is through behaviours which may then be defined as 'challenging' or 'of concern'?

Fifthly, like all of us, restrictions to our choices and actions are distasteful. We may understand and then comply. But it is only by understanding that we *choose* to comply, even if we do not agree or do not like it. This implies the need for information and communication at all times, another fact that featured in the above studies.

In Sections 2 and 3 of this report we rehearse what this study has found out from people with disabilities and family carers about their views and experiences of restrictive practices. As will be seen, many of the themes outlined from what is already known from empirical data repeats itself in the present study. However there are many additional points thrown up that we hope gain some wider currency and attention in policy and practice spheres.



# 2

## The views of people with intellectual disability

### 2.1 Introduction

The majority of data for this section was collected from 19 people with intellectual disability (see methodological Appendix) who watched four skits of different restrictive interactions and then responded to what they saw and whether they had personally witnessed or experienced such interventions before. Four of these people returned on invitation to further discuss their views further on a one-to-one basis and these are also included in the data analysis. The findings reported in this section are reported with the Senior Practitioner in mind and with those people working in services who, in their everyday work, are faced with difficult decisions about how to achieve the best for the people with and for whom they work. However, to make sure that people with disabilities can use the research information, a separate report has also been written in easy words and pictures that can be used by people with disabilities. Please ask the Office of the Senior Practitioner for this report. It is called: *Restrictive Practices in the Lives of People with Disabilities*.

In this section the responses by people with intellectual disability to the four skits are reported in consecutive sub-sections and supplemented, where possible, with data taken from the four further interviews, (see the methodological Appendix for some of the issues and difficulties faced in collecting this data). At key points tables are used to summarise key points of which the Senior Practitioner should be aware. These are supplemented by a discussion of the implications of these findings. It should be remembered that in recruiting people as participants we tried to ensure that they could participate meaningfully in the research. It is likely then that those who participated were amongst those most able to communicate their views and experiences. Whilst they are not the group most likely to have experienced formal and recorded restrictive practices they nevertheless collectively brought a wealth of evidence from their experiences and as witnesses.

### 2.2 Skit 1

Skit 2 shows a man with a disability who wants to leave his home and is able to do so independently without support. However, the door is locked and the

member of staff will not unlock the door until there are more staff available.

Most of the participants were able to recognise that the member of staff was not opening the door. The resident was stuck indoors with no choice. As participants said,

*'The guy know what he's doing' [ie. he can do things for himself]*

*[Unhappy?] 'Yes. The boy because he was locked inside'*

Most participants also expressed the view that this led to the person getting 'angry', 'making a fuss', 'getting 'frustrated' whilst a smaller group said the person was 'frightened'.

*'You get emotional. Take it out on somebody else. You get frustrated. It builds up in your mind''.*

*'What happens if there is a fire and we need to get out?'*

*'They want us to have a normal home but they lock the doors. That's not normal when you live at home'.*

When asked why the person should be frightened some of the participants indicated that they would not complain to the staff. Some said it would not make a difference and that it was pointless to complain as staff would not open the door, implying that there was simply no point to a complaint. Here are some of the examples participants gave when asked whether they had similar experiences to those in the skit,

*'Yes. Complained. Was scared'*

*'Yes. The doors were locked all day long'.  
[person did not complain and did not know why they did not complain].*

*'Feel upset. Angry at someone'.*

*'Makes me angry at staff. Staff should give you the choice'.*

*'I did complain to myself, to the house staff. Staff did nothing'.*

*'We can't complain, not allowed to complain, everyone says you can't.*

In explaining how the people with disabilities often

behave, one person suggested:

*'If staff keep treating you that way and telling you over and over and you aren't told anything else, you don't know any better'*

Moreover, despite most participants recognising that the person had a right and capability to make the choice to go out and that to prevent him was restricting his 'freedom of movement' there was, surprisingly, a strong thread in the responses around understanding and even agreeing with the position the staff member had taken. In some cases this indicated acquiescence,

*'No. He has to wait for people to come back'.  
'He [the resident] wants things his own way.'*

In other cases there was a recognition of the difficulties staff have in judging what to do:

*'He might run away'.  
'The people that you can trust to leave and come back should have a key',  
'It's OK for some but not for others'  
'If they can be controlled and trusted then they can go outside'.*

In other cases there was a genuine concern expressed for the staff themselves,

*'If he's allowed to go out the staff will get into trouble'  
'The person asking to go out is being difficult'.  
'Yes. Staff had a difficult job. He ran out across the road'.*

There was a real recognition that staff were working under a lot of pressure and that staff shortage led to grounds for implementing restrictions.

We asked how the member of staff should have dealt with the situation in the skit. Because we were using interactive theatre in the groups as well as discussion, one person acted out how they would have handled the situation and, using a loud voice and speaking very close to the person's face, the following was enacted:

*'STOP! NO! Have to wait for staff. Calm down and take a break'.*

The point was being made even more forcefully to the person with the disability than in the video skit.

In contrast, others did make suggestions which respected the person's right to move freely: simply open the door and then lock it again once he has left, order a taxi, give the person their own key, provide a beeper so they can be located, help people to know their limitations and get people in the community to go out with the person. The latter is important and ties to a point made in the family carer interviews. If family and community are more involved in people's lives it widens and distributes their network of support and produces further freedoms.

However, like all the data in this research the question is not one about whether the arguments people make are right. Rather, their responses are used to understand their thinking and why they act or choose to act the way they do. It should also be noted that, like all other skits, not one single participant was aware of anything called a behaviour support plan, whether they might be on one, or whether any restriction they had experienced was recorded. In light of the data from the first skit the Senior Practitioner should be cognisant of a number of important points which are set out in Table 1. The right hand column indicates the characteristics that should feature in the recommendations later made in this report.

In light of the above, mechanisms need to be found: to extend knowledge of rights amongst all people with disabilities; to extend self advocacy; to have a system of independent advocacy sufficiently good to ensure that there is both scrutiny and action to protect rights, or take action where rights are infringed; to avoid situations in which there are informal and non-recorded restrictions because of environmental issues or staffing; and, to have systems through which, when necessary, people have ways of dealing with their emotions. As will be seen later, these are the source of a number of wider recommendations emerging from this report.

### 2.3 Skit 2

In this skit a person with a disability wants to get a drink from the fridge which is locked. The member of staff tells the person to stop trying to open the fridge and, when the person persists, the staff member

**Table 1: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware	Characteristics that should feature in recommendations
1	Some people are not aware of their rights – If this is the case they will not understand when such rights are being infringed.	The need for advocacy
2	Some people who are aware of their rights do not complain because they are scared. Others, having complained or spoken up for themselves in the past to no effect, do not choose to do so again.	Equality of arms (that each person has equal power in situations of disagreement of Finnegan & Clarke, 2005)
3	There is no system of scrutiny and advocacy sufficiently comprehensive to ensure people's rights are protected as a matter of course.	That all people and services are visible.
4	When people have their rights taken away it makes them feel angry and emotional and those emotions might spill over and affect others. It should be noted here that where negative emotions such as anger or frustration have no legitimate avenue for complaint then they are let out in other ways.	Recognising legitimate causes of behaviour
5	People have experienced a huge number of informal restrictions and this indicates that such restrictions are likely to be taking place which never appear in BSPs or the Senior Practitioner dataset.	Addressing the under-reporting of restrictions.
6	In any single setting it is hypothesised that there is an inverse relation between staff: resident ratio and level of control. The less staff the more they exert restrictions to maintain overall control over the environment. Since they hold power to do so, it is often safer to organise the environment informally to establish restrictions and keep check of what is happening than to provide freedoms that may lead to accusations of neglect.	
7	There is clearly an imbalance in power between the staff and clients. Clients do not control their choices and destinies.	Inverting power relations
8	Not one person was aware of (the need to) record any restrictive practice.	People being informed about rights.

threatens to stop the person watching the footie later. When the person tries to open the fridge once again, the staff member bans them from watching the footie.

There was unanimity that it was unfair to stop the resident from watching the football! However, there was heated discussion amongst participants around whether it was right to stop the person going into the fridge! One person expressed the view that

*'People have the right to do what they want in their house. If they pay the rent it's their house. If it's coming out of their pension it's their right to do what they want.'*

However, there were other contending views. Here are some of the responses:

*'People were drinking the milk,'*

*'Not getting into cupboards. Don't pinch food. It's wrong,'*

*'If we complain [about others pinching food] we get into trouble. The boys in the house call me a dobber'*

*'There's one fridge at home [and that] upsets me,'*

*'There's a staff fridge and a client fridge.'*

People also indicated that when their things went missing from fridges they did not know how to speak up and complain. These views seemed substantiated by their experiences in the past:

*'No-one was allowed to drink'. [How did you feel?]' 'Sad',*

*‘One resident comes into my room and steals stuff’,*

*‘In most institutions they had the kitchens locked off’,*

*‘There’s one [a lock] on my fridge at home. I get hungry when I get home. That makes me upset. At work I go into the kitchen and get milk out of the cupboard. Not locked’,*

*‘There’s a staff fridge and a client fridge ‘cause they have staff meetings’.*

*‘Some staff have fridges in a room. Can go to it. Only staff. They stay in the room. They sit down. Calm and talk with each other’.*

There were lots of discussions about how to ensure that food was available when people wanted it. In one group a long discussion ensued around what times a ‘communal’ fridge should be open and what times not. It was hard for communal fridges to be made into ‘personal spaces’. It worked best where

staff responded positively to all requests for access. However, to own their own fridge and keep it in their own space, such as their own bedroom, was seen as preferable to all other solutions.

The findings from this skit are central to this study and key issues are presented in Table 2 below.

The recommendations from this, and the following skits, highlight the central importance of autonomy and choice around: who to live with, who they associate or congregate with, what people do with their own time and with whom, and, where people are thrown together, the need for clear and agreed rules for groups with which all persons agree.

### 2.4 Skit 3

In this skit a bottle of poisonous detergent is left on a table. A person with a disability grabs it to take a drink and the member of staff shouts at her to put it down, quickly follows this with twisting the resident’s

**Table 2: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware	Characteristics that should feature in recommendations
9	People with disabilities want to feel safe and want their personal goods to be safe too. Like everyone else in society, this is their number 1 priority.	Safety of personal possessions
10	Communal situations set up a context in which safety is compromised. Congregate settings give rise to the very behaviours they seek to prevent. In settings which are not of a person’s choice their personal safety (as will be seen) and the safety of their personal items are therefore more likely to be compromised. The sense of threat to safety increases as the congregation of people increases.	Minimising congregation or communal access to common goods
11	As indicated by one person in this data, peer pressure is often exerted to keep people’s complaints quiet from within the congregate group. Like any other congregate situation, interactions are characterised by internal power relations, alliances and peer pressure. To live by ‘the convict code’ or a code of silence and informal rules about ‘dobbing’ is to point to such power relations. In such situations relationships of trust are very hard to establish.	Recognising power relations in communal groups
12	The form of restriction leads to behaviours in which ‘choice’ is exerted independent of the intended restriction. If a person is hungry and the fridge is locked they will find other ways to find food. The restriction therefore leads to ‘behaviours of resistance’.	Solutions that lead to honest behaviours and ones that are not driven underground.
13	Most importantly, people are willing to sacrifice choice and to undergo restriction in order to secure the higher order goal of safety.	Minimise sacrifice of choices to secure safety
14	Behaviours that lead to restriction are often not owned by or inside the individual. They are a product of congregate or difficult environments in which personal choice and autonomy are compromised. Such compromise changes behaviour and emotional reactions to those around. There is no comfort in relations with others where people are motivated by fear for their own safety and that of their personal goods.	Recognising the part played by environment in producing behaviour.

arm up her back when she does not comply and, when the resident continues to struggle and protest, insists on her taking a tablet to “calm her down” which another member of staff administers. The person is not released from having her arm twisted around her back until she has taken this medication.

Once again, the researchers were surprised that there was significant debate in the groups about whether the staff had done the right thing:

*‘Staff was right to help her. If she had drunk it she’d have to go to hospital’;*

*‘The girl was dangerous’;*

*‘I think to calm her down it was necessary only as required’;*

*‘If a person gets aggressive you have to calm them down somehow’.*

These views were set against the following contrasting views.

*‘It made me angry. What medicine do?’;*

*‘It’s wrong. Arm behind her back and make her yell’;*

*‘Staff are making the person take the tablet. Go and see the doctor to stop that. Staff are making the person take medicine. Tell the staff off!’;*

*‘Staff are silly to leave detergent on the table’;*

*‘Arm behind the back. Pain. Make them yell’.*

Again, the issue of compliance was also mentioned by one person

*‘You’ve got to take it’ [drugs when told by staff].*

The issue about physical restraint and staff holding clients will be covered in the next paragraph. For the moment it is worth noting the ways in which the participants felt the situation might have been handled better by staff:

**Table 3: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware	Characteristics that should feature in recommendations
15	Once again, people with disabilities are not always cognisant of their rights. This was found to be true for many participants and even for some of those who were involved as self-advocates.	Education and information about rights
16	People with disabilities have to trust staff to do the right thing to keep them safe.	Maintaining mutual trust
17	People with disabilities recognise the central role the staff have in setting the conditions in which they experience their lives.	Mutual respect
18	Many people with disabilities, whether they like it or not, rely on staff on an everyday basis to arbitrate decision-making around their safety and choices.	Staff awareness of good decision-making and responsibility for that decision-making, that they do not abuse their power, they feel free to express concerns over restrictions and understand that behaviour can reflect stress in the environment
	This implies that power is handed over to staff in settings and they have a profoundly important responsibility to do what is best for the people for whom they provide support.	
	However, the power and latitude over decision-making creates a situation which can be restrictive because of: inertia, laziness, balancing competing interests, misconstrued values or, exceptionally ‘abuse’. In this view staff have power, not only to make residents do what they want them to do; they also hold the agenda so that residents can only do things within set parameters. It should come as no surprise that the reaction to this curtailment of choice and autonomous action is frustration and its external expression.	
19	Staff can get things wrong either by accident or by design. If the level of scrutiny and monitoring of settings is not sufficient bad practice, both unintended and intended, can continue and, in the absence of external counter-controlling mechanisms, can remain hidden and unrecorded. Much can be gained in efficiency, enjoyment and outcome from good relations with family carers and with advocates where services are open.	That services are open to scrutiny.



*'Speak to them. Sit them down. Look them in the eye',*

*'The staff in the kitchen should have locked the detergent away and locked the door',*

They also mentioned putting labels on the bottle or redirecting the person's attention to something else. But the central message was that the participants saw staff as being there to help them to keep safe. In transferring this responsibility they are also assuming a level of trust and that staff will get things right.

Many of the issues uncovered in this skit are covered in other areas. But, additionally, the Senior Practitioner should know those issues laid out in Table 3.

## 2.5 Skit 4

In this final skit, one resident is shown walking into a room and hitting another resident. Staff run to the scene and physically hold the person back and then wrestle them to the ground where they are held.

This skit was the most blatant in terms of a resident harming someone else and it produced strong reactions from amongst the participants.

*'They [the person attacking] were naughty. Very naughty',*

*'That's their job [the staff]. What can they do?',*

*'Put them away. Take them to court',*

*'Need to restrain people to make them safe when it's necessary',*

*'I think you restrain them as a last resort',*

*'It had to be done. A necessary evil'*

The research participants suggested a number of additional strategies that might also have been used by staff:

*'Move the person away', [the one who was attacked]*

*'Tell the person [the attacker] to control themselves',*

*'Should have talked. Stopped pocket money or things they like, like fishing, fresh air...',*

*'If they get upset people get put out the back. They calm them and when they calm down they can come back in',*

*'Get help. Ring family and friends',*

The discussion around this skit produced some of the most important information for this study and for the findings and recommendations that are being made. In skit 2 it was shown that people with disabilities are likely to accept curtailment to their personal freedom in order to achieve safety of their possessions. In this skit we found that the same was true in relation to personal safety. We came, in listening to people, to the profound realisation that people with disabilities often lead lives in which they feel scared and threatened. This is further outlined below.

When we asked if people had experienced the type of restriction seen in the skit the following responses were made:

*'[Staff] Tied a sheet around my neck and dragged me out the door. It wasn't any good',*

*'Someone [staff] kicked me on the leg and hit me like that [demonstrates]. Punches to the stomach. It was wrong. It was nasty. Awful',*

*'I climbed the window. I picked the food from the kitchen. "Get out the kitchen now". Put me to bed. I put food all over my clothes',*

*'Long time ago, 1977. Locked up my toiletries and staff say they're not happy. Keep it locked. Get locked in bedroom. Climbed the window. "Stop climbing the window!. Get inside now! Now!! Cross. A long time ago'.*

And, as important, were those stories relating to the behaviour of other people with disabilities:

*'The person comes up the passageway at [day service] and goes "mm" and gets up and goes up and down. There are people who do things that are a trouble for you. He runs around the room, mucks up, next minute smashes things, banging on the window and two staff got to be in there'.*

*'It's hard at [day centre]. With people it's full-on. Tell staff to make sure they stay in groups. You got to watch you don't get kicked, hit',*

*'Got to watch your back',*

*'I lock myself in my room so the boys can't come in',*

*'At the centre this person screams and hits people',*

*'Scared to go to day centres 'cause people misbehave. [Name] has been pushed by*

*other people. Feel scared. Don't want to be anywhere on my own';*

*'Person runs up and down the passageway causing problems. Everybody has to watch out for him. Someone doesn't like the rain so she causes trouble. Smashes windows. Kicks';*

*'I been pushed over, my wrists broken by the same person. Want to be safe. Don't feel safe. Something should be done to stop that'.*

Perhaps these findings should be no surprise. But they are profoundly worrying. They indicate that many people with disabilities spend their life feeling scared, watching their backs or hiding themselves away to avoid trouble. What is more worrying is that there are so few places in which these threats seem

to disappear and where they can express their own choices. The threat to their personal safety is, for some, a 'majority of life' or predominant experience spanning several settings.

Like anybody else in society, the primary interest of people with disabilities is their safety and security. The context within which this safety has to be maintained is one in which they do not have the autonomy nor possess the means to choose what services or homes they inhabit. Confined by lack of choices, they have to rely on others [usually staff] to set in place the everyday rules to protect them and to use strategies of withdrawal to avoid trouble. People living in such situations are understandably 'edgy' and this can easily express itself in threatening or aggressive behaviours. These are not innate

**Table 4: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware	Characteristics that should feature in recommendations
20	People with disabilities often feel unsafe and threatened.	Solutions that promote safety
21	Given the choice, people would not choose to live, work or frequent settings where they were made to feel unsafe.	Choices that promote safety
22	The environment in which people live has an effect on their own behaviours. People who feel unsafe can use avoidance strategies which themselves may infringe the choices they may wish to make, their rights to freedom of movement or even association. However, they may also lead in some circumstances to aggression as a defence mechanism.	Solutions that prevent people having to sacrifice rights or, because of their reaction, undergo restriction
	People with disabilities are willing to give up some of their own personal freedoms if that means the higher order need for personal safety is attained. If the level of environmental control is too great their lives are rendered unsafe, their freedoms infringed and their life experience diminished.	
23	It is vital to see behaviour as being a communication about lives and environment, and not simply as a personally owned characteristic which defines them by their behaviour. A behaviour of concern is likely to be produced by 'an environment of concern'.	Recognising environments of concern and the characteristics of such environments
	People rely on staff to manage the interactions in congregate settings (whether small or large congregations) and keep them safe. It is hypothesised that the rules required to maintain safety are likely to be more stringent in situations where: the range of people is diverse; the level of attention required to each person is greater than the capacity of the staff complement to proffer such levels of attention; the engagement levels and type, lead to boredom or are disliked; communal areas are not complemented by personal space. Nobody would choose a life defined by such characteristics.	
	Where the level of control required to maintain order in any particular environment is so great as to fundamentally undermine personal freedoms as a matter of course, the environment itself needs to be changed. It is hypothesised that there is a crucial threshold of control over which the restrictions produced by the environment will by definition be restrictive.	

behaviours but should be seen as ‘counter-controls’ or adaptations to the threats they feel to their safety as a routine life experience.

Table 4 sets out some further points about which the Senior Practitioner should be aware.

## 2.6 The voice of people with disabilities – discussion

### 2.6.1 - Discussion

Some readers may wish at this point to move straight to Section 3 if they would prefer to read about the views of family carers. In this current section the focus will be on understanding the complexity of the data so far presented. What follows is necessarily itself a little complex as a result.

Ordinarily the findings of research studies inevitably lead to ‘common-sense’ solutions. These are almost inevitably *binaries*. For example, the findings above would be dealt with in the following way: since people are unaware of their rights there is a need for more training and advocacy; since people are fearful of complaining, policy should make it clear that making a complaint is a right and that services should have penalties imposed where they do not pursue a person’s verbal or written complaint; people with disabilities feel unsafe, and as such, measures to increase security of self and personal goods need to be adopted. Despite a history of exhorting organisations to change and substantial concomitant policy initiatives, change has been slow and many policies lie fallow or simply do not succeed.

It is therefore likely that the source of recalcitrance lies elsewhere. Using study evidence it will be argued below that if the organisational, systemic and environmental constraints of the system cannot be addressed, then perfectly reasonable solutions are not likely to thrive. Organisational problems require fixes to the ‘organisation’; ‘systemic’ problems require a systemic approach and so forth. *Any recommendations must therefore address these systemic, organisational and environmental issues or more straightforward recommendations using the ‘binary approach’ will not be sufficiently robust to withstand the power of the systems to undermine their implementation.* Using research data some of this complexity is described below.

We found out from participants that many people attempted to deal with their fears by avoidance. By staying in their rooms or keeping out of the way, they accomplished safety, but at the expense of their right to freedom of movement, and to the freedom to associate in public spaces.

The settings within which people receive services are often not ones they have chosen. Indeed for some participants it was clearly the case that to experience their service settings would not be their settings of choice. For all of us safety is a primary concern and yet it was clear that a substantial number of participants in our sample felt unsafe in the environments they inhabited. Without the opportunity to experience and choose anywhere different, nor to independently pursue their choices, they have to manage the situation as it is. In many ways participants, were telling us there was no choice of setting and, in this way, the lack of choice and self-determination ‘sieved’ out their rights. For many study participants communal and segregated settings were indicated to create an opportunity structure in which fear and threats to the safety of the person and their goods thrived.

Those unable to understand infringements to their rights, nor to act to be heard or to protect themselves, were unable, without support, to challenge or change this system, hence maintaining the status quo.

As with most organisations, employees primary responsibility is to pursue organisational aims through policy, and their interests are therefore best served by a primary alliance with management and profession. Unable to change the system and themselves under great pressure of work, they cannot think nor act outside the square, thus leaving things as they are. People with disabilities who are unable to speak for themselves are therefore not a problem until such time as their behaviours challenge the system, at which point restrictive practices can be operationalised to draw them into line.

Those able to speak for themselves pose a different ‘problem’ to the system.

We found out from participants that many attempted to deal with their fears by avoidance. By staying in their rooms or keeping out of the way they accomplished safety but at the expense of their right to freedom of movement and to the freedom to associate in public spaces. The privacy of their own room might also afford things they could do, but it limited the richness of experiences from which they might gain were other areas open to them. Avoidance tactics in public domains were about



‘watching one’s back’, keeping a low profile and not upsetting the power relations within the group by complaining or ‘dobbing’. The recognition that it was pointless to complain to staff, or indeed fear of doing so, squared the circle of control by staff woven to maintain the status quo. In other words there were cases in which personal rights were *sieved* by the power relations within the group.

In the absence of the group managing its own affairs, it would defer to staff to arbitrate situations and to conciliate in situations of disagreement or conflict. Many study participants understood the difficulties and pressures under which staff were working and some indicated that they were willing to undergo the imposition of informal rules and restrictions if these were sufficient to keep them safe. This placed staff squarely ‘in control’ giving rise to both informal rules and restrictions as well as those recorded for the Office of the Senior Practitioner.

Staff hold the power not only by making people do something they would not otherwise have done, but by creating an agenda in which people can only choose to do certain things (*cf.* Lukes, 1974). Situations where such differentials in power exist can, at worst, lead to abuse and environments that are defined by staff laziness, inertia and neglect. These situations are likely to go unnoticed where those on the receiving end cannot or do not speak out, where there is insufficient monitoring or where the staff group are complicit in closing ranks.

The above is a worst case scenario of what is possible in such circumstances. More realistically, even where staff try their best, a multitude of factors may sieve rights further: lack of private space will mean public spaces have to be managed; limited staff may defeat their best efforts at giving positive support and time to each client, leaving a large group bored and isolated; such situations may be exacerbated by diverse needs and limited resources. Locked doors or cupboards, whilst wrongly applied to the group when aimed at one person, may represent the only way to manage safety in the absence of a sufficient level of surveillance to assure the safety of all residents.

The informal rules and restrictions that are required to maintain a social order in any one setting may be so great as to severely limit personal freedoms and

further *sieve* each person’s choices and rights.

Where rights are so highly sieved, the environment will have produced behaviours in which people seek to accomplish personal choice *despite* the system. As participants indicated it becomes perfectly reasonable, in this light, for a hungry person to see available communally available milk as his or her own milk; where a person is locked in despite the capacity to move about independently he or she may ‘abscond’ via a bedroom window; a day service where a person is bored becomes one in which he or she shows apathy or chooses not to become involved... So what do we do? Force the milk thief to accept hunger by changing his behaviour to be more acquiescent? Place the person under guard to prevent them experiencing the freedom they enjoy through moving about? Put in place a behavioural programme to make the person look interested in their boring day? Or, alternatively do we see their behaviours as an adaptation to the lack of rights in their environment as *resistance* and as the resource for problem-solving and changing the environment and the behaviour of its personnel?

The sieving of rights and choices means that each person is already acting in an environment where their choices and rights have been compromised and limited. The distance between their experience of the situation and what they find unacceptable therefore narrows. And, since there is no other way when their voices of protest and behaviours of resistance are not seen or heard, they use means to communicate which are, by definition, going to be seen by staff as standing outside of the acceptable behaviour.

Moreover, particularly for people without a voice and for those who cannot accomplish their wishes, without support the preponderance of protest or resistance is likely to be perceived as recurrent ‘behaviours of concern’. Interventions to curb such protest or resistance lead back to further insecurity, hopelessness and fear. The continued imposition of informal and formal rules and restrictions create either dependent behaviours which, over time, lead to acquiescence and institutionalisation or, alternatively, a downward spiral of worsening behaviours as the person struggles to communicate in the increasingly limited ways that will draw attention to their dissatisfaction.

Moreover, particularly for people without a voice and for those who cannot accomplish their wishes, without support the preponderance of protest or resistance is likely to be perceived as recurrent ‘behaviours of concern’

An additional and vitally important further point needs to be made here around social justice. It is possible using systems of control and punishment to force people to do or to comply with things they would not otherwise choose to do. A person can, through fear, learn not to act in a particular way and, through physical or mechanical restraint, be prevented from acting in a particular way. For example, as recounted in one of the family carer interviews reported later the parent told us that,

*‘... instead of isolating him [the attacker] they put SS officers to guard them. Somebody gets up: “SIT!!”, Anyone stand up “SIT!!”. And y’know then one day my son came home one day and he sat and I was talking to the dog, see!?’*

Those unable to figure out what it is to have an ‘intention’ to do wrong cannot perceive they are doing wrong. And if they do not see themselves as ‘doing wrong’ the restrictive actions of staff must seem to them to be hugely frightening and an infringement to their integrity as a person. Recurrent restrictions imposed on someone who is (or sees themselves as) ‘innocent’ is likely to be perceived by them as torture (For a wider discussion of issues see UN General Assembly 2008). In a just society we have to ask whether changing behaviour at all costs is worth the infringements to the rights of people with disabilities and the consequences to them as human beings, much less its economic cost.

### Recommendation

A small minority of people do not understand their behaviour as wrong. There is no intent to cause damage or harm. Those people are also likely to be unable to understand the link between their behaviour and aggressive interventions. In this way, restrictions are likely to be perceived as a form of torture and human rights and social justice dictate they not be used.

### 2.6.2 Some interim conclusions

The discussion above leads to a number of considerations that must provide the framework antecedent to any wider recommendations. The system, organisation and environment must be

receptive to and malleable enough to provide a holding environment that allows recommendations to work. Key areas in this regard are the following:

#### 1. Differences in the ability to secure rights by speaking out

Ward and Stewart (2008) recently point out that in the theory of human rights,

*Individuals hold human rights simply because they are members of the human race and as such as are considered to be moral agents. Moral agents are individuals capable of formulating their own goals and seeking ways of realising them in their day-to-day lives, (p. 3)*

The problem for many people with disabilities is that they are in a position to be least able to accomplish such rights autonomously. Such autonomy might be seen as the ability to make choices from amongst options and to have control over the means to their accomplishment (Boyle 2008). Like the present study, but in relation to people with dementia, Boyle’s review of the literature suggests ‘frustration and distress’ amongst people who cannot verbalise or communicate in ‘standard’ ways (Ragneskog et al. 1998) and that higher levels of agitation in units using physical restraint (Sloane et al. 1998).

Specific studies examining such agitation, stress and fear in different settings have not been undertaken in the disability field. However, the literature comparing residential options indicates amongst other things: more verbal as opposed to physical interventions in smaller community residences compared to institutions (Felce et al. in preparation); more adaptations for limiting movement in institutions (Lowe et al. 1998); more medication in congregate and larger settings (Emerson 2004; Robertson et al. 2005b); and more positive staff:client interaction in settings that are ‘homelike’ (Thompson et al. 1996).

The literature on autonomy and choice has also been shown to differ between different residential options. Several studies have found choice increases as the setting gets smaller (Felce et al. 1998; Golding et al. 2005). No-one should find this surprising. Compare your choices living in your own home to ‘staying in a hotel’, ‘going camping and sharing a tent’ or living in ‘shared accommodation’. As Egli et al. (2002) argue ‘People living in more homelike settings may

be more likely to be expected to make their own choices, to socialise with others in broader society and to be entitled to privacy’ (p. 189). However, even in community residential units it has been found that choices fall way short of those one might ideally expect (Robertson et al. 2001).

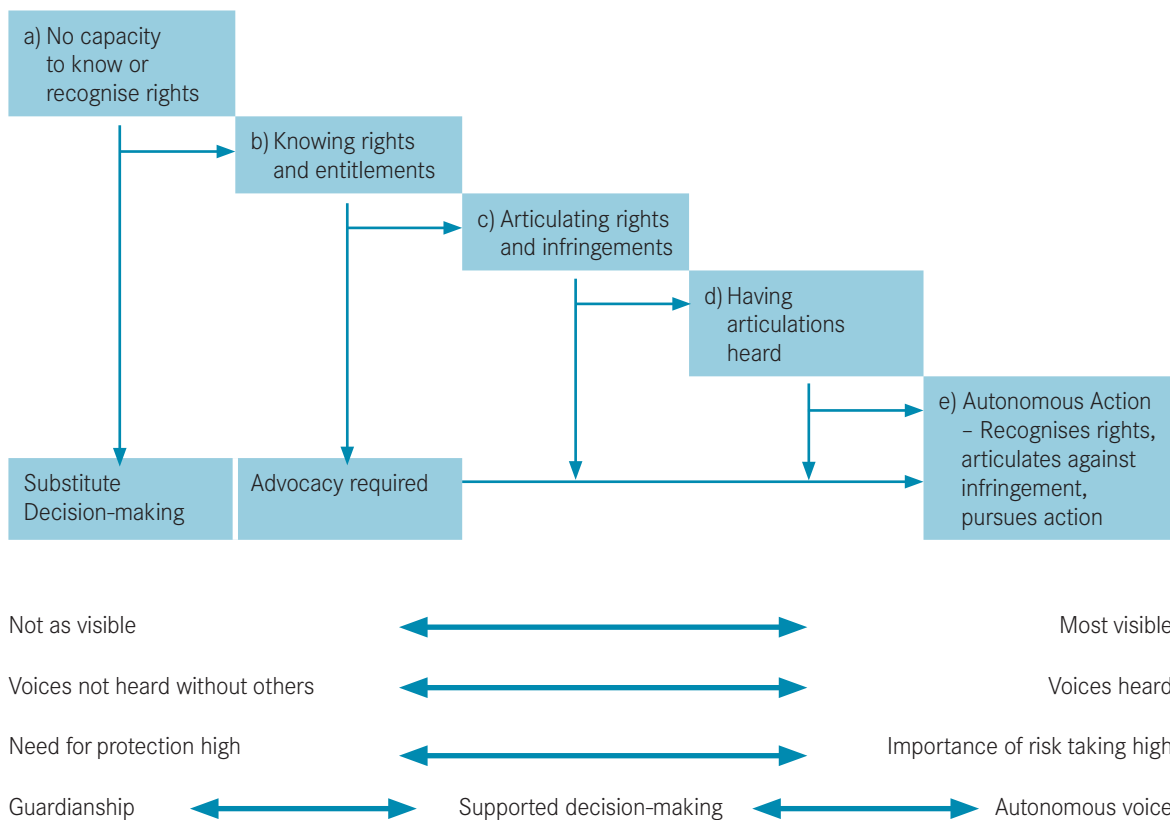
The Senior Practitioner should know that in order to respond to rights those people who care about and for the person should fulfil those roles outlined in Table 5.

However, Boyle’s (2008) call for autonomy through choice requires ‘agency’, that is, the capability to pursue choices. Think about whether you can advocate for yourself in a court; think about how you might communicate in a land you were visiting where you do not know the language; think about how difficult it has been made to make a phone complaint to a modern-day company.

**Table 5: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware	Characteristics that should feature in recommendations
24	Respond to a person’s choices, hope, dreams and aspirations.	Start with hopes, dreams, aspirations and choices
25	Support the person to engage in activities that help them accomplish their choices.	Accomplish choice in support
26	Ensure that the means through which the person accomplishes choices maximises freedom from control, restriction, coercion or neglect.	Human rights, freedoms and not neglected.

**Figure 3: A model of advocacy and accomplishing rights.**



Adapted from: Grant and Ramcharan, 2007a

As citizens like us all, people with disabilities are no different. Some are more able to defend and pursue their rights than others.

The diversity of the population means we all rely at times on an advocate and a usable and fair complaints system. As citizens like us all, people with disabilities are no different. Some are more able to defend and pursue their rights than others. Figure 3 suggests how this works.

Figure 3 clearly demonstrates that the level of substitute decision-making or advocacy will vary by both person and situation. A multitude of advocacy forms are required to cover this diversity. The diagram also indicates that lack of visibility can lead to unseen infringements, to the potential for abuse and to increased risk. The system, as indicated before, therefore additionally needs a system of checks and balances and an independence to the process of advocacy.

### 2. The system of power relations between staff and clients

The findings of this study clearly show that power rests to a substantial degree with direct support staff. Their requirement to meet organisational needs is often at the expense of ‘client’ choice, and they are also unlikely to be able to fundamentally change the service setting. Much more of this will be explored in the section to follow when considering the views of family carers. However the starting point of a ‘positive service’ will always be the person’s dreams, wishes and desires. Furthermore, mechanisms must be found which invert the relations of power. These may be around supporting autonomy and self-determination, re-calibrating acceptable levels

of risk, extending the decision-making group acting with and for the person and, finally, supporting people with disabilities with their circle of support, to themselves be employers so that accountability is to them rather than disability employment agencies.

### 3. Recalculating the equation between rights and restriction

Earlier it was explained that in calculating whether to implement a restrictive practice that present DHS policy, favours an approach which singles out the behaviour as the unit act (see Figure 2 which is reproduced below).

The data from participants with a disability alerts us to the importance of including in this calculation behaviours that are legitimate adaptations to a maladaptive environments. If this is taken into account the equation would be rather more as set out in Figure 4. More of this will be addressed in the discussion section of this report (Section 4).

The Senior Practitioner should therefore be aware that restrictive interventions can be reduced, if it is possible to operationalise the above calculation, by identifying when a behaviour is one of protest and resistance rather than of concern, and which are understandable given disempowering environmental, systemic and interactional situations and circumstances. Many of the themes detailed above are also borne out of the data from family carers. It is to this data that we now turn, prior to extending the discussion stated here in Section 4 of the report.

Figure 2: The basic restrictive intervention equation

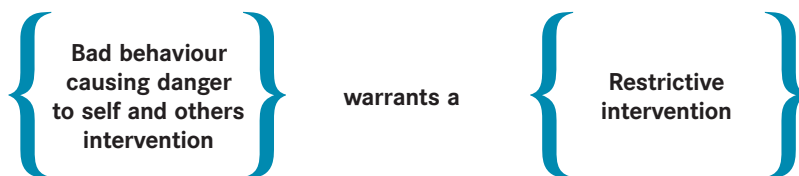
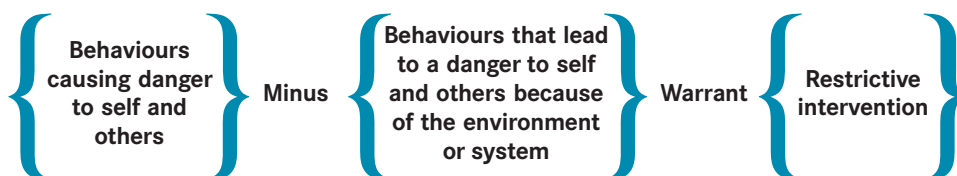


Figure 4: Taking account of behaviours caused or produced by the environment or system



# 3

## The views of family carers

### 3.1 Introduction

In the previous section it was shown that people with intellectual disabilities were willing to give up some of their freedoms for, to them, this was a sacrifice worth making to keep them safe. The people interviewed felt that they had very little control over their environment, so fashioning changes in that respect was not possible. Indeed, some empathised with staff, who interviewees felt were equally powerless to change the context in which they operated.

The data from the eleven family carers interviewed for this study mirror these themes, and extend and elaborate on the data from participants with a disability. The data collected from family carers demonstrates a remarkable number of examples in which the *conditions* for intervention were perceived as a problem and in which the problem did not lie in the pathological behaviour of the individual but, rather, in the environment and circumstances surrounding them. On analysis, these factors were found to fall into a number of categories which are outlined below with examples taken from the transcripts. It should be noted that because of the complexity of the ideas many examples below could fit into more than one category.

In what follows, as each quotation is elaborated upon with a discussion of issues that are clustered into category headings that emerged as the data was being analysed. This leads into a discussion of the key points raised around that category. Further issues for the Senior Practitioner to consider.

### 3.2 Understanding restrictive practices – contextual factors

#### Staffing issues

##### 3.2.1. Staff input (or lack of it)

The following quotes say something about the ways in which staff input might have an effect on a person's behaviour and their safety:

*'Like all of us, we get bored if there's nothing to do... What are staff: minders or carers? Staff should be interacting with the residents... not just domestic work and not interacting.'*

*'locked in his own room... lonely and isolated... Programme said they were an accommodation provider, not educational programmes, counselling, specialist support, staff were on the porch smoking with nothing to do – no engagement.'*

In another example, a young woman, who throws herself around on the floor and has had a broken skull on several occasions and broken other people's bones, has been built a padded area in a house that is shared with three other residents. When asked if it produces freedom, the family carer replied:

*'No. Not at all. It's purely because it can – or what they see as a means of stopping her hurting herself. I actually see it as seclusion... from the rest of the household in there. She doesn't go and sit with others. So when you take her back on Friday [after her visiting the family], she knows that she goes straight into her little cage. And it's sad you know.'*

In each of the above cases any restriction used must be set against the absence of engagement, let alone interaction, as well as positive and planned inputs. Otherwise seclusion is transformed into imprisonment with guarders. A number of points should be noted by the Senior Practitioner in this regard (see Table 6).

##### 3.2.2 Plans not implemented

In many cases, as will be shown later, it was clear that the behaviours that people were displaying were communicating their dislike for what they were being asked to do and where they were receiving a service. Some talked about planning by specialist teams:

*'And we had the BIST [Behaviour Intervention Support Team] involved... They did up a little plan... of what we should be doing across school and home. That didn't work... It wasn't around looking at better ways of communicating and understanding. It wasn't around getting him out more in the community and being around others without disabilities. It was really just about, y'know, what are the triggers for this behaviour and how can we try and quieten him down.'*

*'We did have BIST come out during this [early time] but the recommendations were not realistic... I remember at the time we*



Table 6: Things which the Senior Practitioner needs to be aware

	Things of which the Senior Practitioner should be aware.	Characteristics that should feature in recommendations
27	A padded area for safety is 'seclusion' where it is broken by attempts at inclusion and productive interaction with others.	Seclusion is about safety AND engagement/active support.
	Seclusion of this sort, as a majority experience, is similar to 'imprisonment'. Seclusion as a dominant experience leads to isolation, resentment and to 'behaviours of protest or resistance'.	
28	In circumstances such as these the Senior Practitioner should accord permission for a restriction only where such seclusion is limited and where the person has sufficient positive interactions with others to constitute the action as a restriction and not imprisonment.	Restriction is defined by a stringent limitation in use
29	Families, and people with disabilities should be aware of these issues as a resource for complaint. The DSC, VCAT and Community Visitors should publicise this and take this into account where there are complaints.	Awareness of rights

*all looked at them and thought "That's not really what we can do"... The other thing too was they only came out to see [him] for ten minutes and it was just like they made those assumptions and I don't think they had enough time... I do remember even the school couldn't enforce what they suggested'.*

In these examples the outcome that the support teams were working towards was simply *behaviour change*. The team did not seek to link their approach to *chosen outcomes* for the person. And if the person's communication was saying that they did not like where they were living it begs questions about the extent to which functional behavioural assessment would have identified that as a cause, and recommended changing settings as opposed to changing behaviours to fit the setting itself.

In introducing this section one example was given around the implementation of a person centred plan and the fact that it was simply not implemented. Many families felt encouraged when brilliant, innovative and positive plans were developed that used the person's choice as the starting point and recognised the behaviour as a reaction to environment. However, lack of commitment to action and disciplined case management, as well as inconsistency of action, are amongst a number of factors that mitigate, if not deny, successful outcomes. Here are some subsequent experiences of plans that did not work:

*'So we had this wonderful specialist person sent to plan and everyone came along... everyone went away with all little actions and nothing happened... my argument was that she's a woman whose been with people with disabilities all her life and every time we try and access the community there's a barrier'.*

*'Wonderful plan - but the level of support means he hasn't done these things. He is being baby-sitted. Ten thousand dollars a year in taxi fees, not a lot left over for support. He needs two workers'.*

*'Every year there is an individual plan, and every year there I ask for the same thing, that sometimes this depends on staff as well. Some staff will give him a little bit to do. But mostly he's sitting there doing nothing... We have a big PCP plans now... They do a little at first and then almost back to square one'.*

*'The CEO still does not agree with the Essential Lifestyle Plan... so we've withdrawn him from the service... except employment'.*

*'He had a number of communication assessments... And somebody new would come in with a new idea. And that person would leave. Nothing yet seems to have been followed through'.*

*'The interventions have not had a co-ordinated approach. They are all ad hoc... But they never, never ever follow through'.*

*[At respite] 'Didn't have consistent supervisors, staff. We then had a lot of issues of things of*

**Table 7: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware.	Characteristics that should feature in recommendations
30	Often the restriction that people with disabilities experience is not because they are a danger to self and others but because their behaviour does not fit pre-existent service settings and rules.	Do not impose restrictions to fit persons to the environment
31	Changing the behaviour of a person to fit the setting may require restrictions not required if the setting and/or its inputs were changed.	Change setting before person
32	Behaviours of concern can co-exist even when positive plans are in place. The success of a person centred plan in changing behaviours relies on the person being engaged in things they want and choose to do.	Engagement in accomplishing wishes defines good support
33	It is vital that the outcome of person centred plans be monitored when making any decisions about a restrictive intervention. If agreed courses of action are not being accomplished and the outcomes not achieved then it sets the conditions for behaviours of protest and resistance to arise.	Monitor success of restrictive interventions against it moving people to personal choices
34	No restrictive intervention should be accepted where the outcome is behaviour change on its own. The wider outcome must be stated and the success in moving towards that target should dictate whether the restrictive intervention is indeed working and worthy of extending.	Behaviour change is not sufficient grounds for a restrictive intervention
35	Some system for ensuring better co-ordination between those services and staff involved with the person is required. Lack of co-ordination and consistency of input and aims can seriously endanger the best of plans.	Co-ordination and consistency are vital

*his going missing and he was doing things like beating up other clients. We all had a meeting and they said "Oh. We didn't know that"... they didn't have good information. The new respite are trying... but they have staff turnover too...'*

Given the above findings Table 7 points to further issues about which the Senior Practitioner should be aware.

### 3.2.3 Staff attitudes, perspective and approaches

It was established earlier in the report that the input of staff has a marked effect on the behaviour of the people for whom they provide support. Through the stories presented here, family carers also showed how the attitudes, perspectives and approaches of staff had a significant impact on the way they orientated to and engaged with their clients and, as a result, the client reactions that were produced.

The views held by service providers have significant impacts on the lives of people with a disability. The following quotes show that when the professional

assumes there is nothing that the service can do, then the service does nothing.

*'... and he [the psychologist] said "well ninety percent of these kids... they're not capable of, y'know they haven't got the capacity to understand and therefore I don't give them any counselling... that regular counselling and conflict resolution techniques are not applicable to these children"... Well I honestly think that he doesn't think of them as human...'*

*'In fact after the first year in special school we were just so horrified that what had happened to our daughter... we would say to him that she can play with the track - "no your daughter has no play skills", they would tell us. She can say these things - "no she can't. Your daughter can't talk". And they were firmly of the belief that our daughter was just stupid. That's - I'm sorry to use such blunt language but that's - they were disrespectful of her, they would speak about her in her presence in very disrespectful ways.'*

*'Some staff are just not right... she's sensitive to people who do not like her and she reacts.'*

*'... we then went through the process of getting funding for him to go to school – Psychologist said he couldn't do an IQ test on [son] because he'd have to call him a vegetable.'*

And where the person is categorised as 'beyond help' or 'difficult', the likelihood is that the service will not be working positively with that person to accomplish their aims and to develop their skills. This was repeated frequently in many interviews, and is in the following quote:

*'There was nothing to do in there. Staff wouldn't engage him. Nothing to do. He was left. When he moved in we provided him with toys and that, but they said it's not their job basically to do that, to play with him'*

What is left, hence, is likely to be a lack of inputs, a sole or majority focus on behaviour, and a system set up largely to manage the person within that environment, that is, to warehouse them. Below are some further examples. In the first two quotes staff are acting less as supporters and more to ensure the success of the restrictions they had imposed:

*'So he was actually being shadowed constantly in the playground and that sort of thing. And I guess I would have to say what probably triggers the extreme responses and the lock-up situation.'*

*'... there was certainly some holding down. Because what was happening there when he first went in he absolutely demolished his bedroom... when his anxiety up, something has to break for him to release that tension... now... he'll quietly, without making a big issue, go and grab a light-bulb out of somebody's lamp and go out to our front porch – and there's a big smash on the ground.'*

*'In approaching professionals for advice – we first went to a top psychiatrist who then referred us to a psychologist for the behavioural issues. And under her direction we ourselves used restrictive practice to control some of [daughter's] self-harm. We were holding her. We were using hand-cuffs actually. Tragically.'*

The focus on controlling behaviour is soon seen as a normal pattern of service response. And recording restraints, where this is done, has a focus on behaviour control:

*'Understanding the disability, the trichotillomania has actually been our best bit for helping [son]. If we understand it doesn't make a difference how much we rant and rave... In the past we had time outs and put him in his bedroom and we set clocks and even at one stage one guy told us that y'know [he] had to wipe his own poo-ey pants and all of this. All of that was a complete waste of time.'*

*'the fact they used five point restraints... was not recorded anywhere. It wasn't discussed... they had engaged a martial arts expert to teach the staff how to restrain... the fact that this door had a lock on it... they said [daughter] was locking the door from the inside and [that meant] it was self-seclusion... none of that [was] recorded.'*

*'The only thing that got recorded was the incidents where he would start ripping plaster off the walls and pulling all the electrical wire off the walls. At times I went and saw the damage he'd done and I thought, where were you guys?'*

*'... so they'd got a locum in... doubled the dose of Risperidone, and added a sedative like valium type drug as well. They didn't consult (...), (...), his GP or his psychiatrist who he has – you know a regular. So that's the sort of mentality I've had to deal with.'*

Table 8 shows further issues of which the Senior Practitioner should be aware.

### 3.2.4 Service and organisational issues

It is not meant that the findings of this research criticise disability workers who work hard and often under extreme pressure. As pointed out earlier, their invaluable work is widely recognised, not least by people with intellectual disabilities who see that staff are themselves struggling with difficult situations and limited resources. In that sense many of the problems are not made by staff but located elsewhere in the ways in which organisations are resourced, managed and operate.

This category looks more closely at some of these



**Table 8: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware.	Characteristics that should feature in recommendations
36	In the absence of a positive plan for what the service is setting out to achieve for the person, there is a chance that the service is not active in its support for the person	Active support and engagement to accomplish goals
37	Where there is no positive role, there will be no stated positive outcomes from the service input	Positive views of each person and positive goals
	Where there are no positive interventions, what is left for some people is managing their behaviour to fit the setting. This is unsatisfactory.	
38	The Senior Practitioner should be aware of not just a behaviour plan, but that this plan is one that operates as part of a wider plan in which stated outcomes are set out. Where such outcomes are not being achieved, it may be the setting that is producing behaviours of protest and not pathologically owned 'behaviours of concern'.	BSPs must be part of individualised plans.

service and organisational issues. The research team were surprised at the number of examples in which carers related services being changed, reduced or withdrawn. The following examples illustrate this issue, with the final example represented in detail:

*'And so all of a sudden services that we used with [son] stopped delivering a service to us. The council said "no we can't send a worker because if he needs rectal Valium we're not allowed to give it". And we'd just started using a respite service... and the same thing happened there.'*

*'And then I found the house didn't do things with him. So often he would sit on his own getting more and more withdrawn... Later in the day placement they don't do things with him as well, so now he's very withdrawn.'*

*'[Day service] withdrew their service. He was told very nicely to go. Because some were difficult and they had no idea what to do with him and if he destroyed things and got aggressive they just would not even accept help from the Department.'*

*'Then they said no, we can't even take him out in the car any more because he's not safe in the car even in a special seat - which my husband had made for him... and we are allowed to restrain him, my husband and I... no-one else was allowed to do that. So then the system said "well no we can't look after him any more by taking him out into the community"... and the cost of the system to*

*do that is too high for that to happen regularly so he doesn't get out very much. But what they didn't understand was that if he had this for a little while, he would then realise that he did not have to fight any more.'*

*'But my son is toilet trained and he kept coming home from school with bags with soiled laundry. And I said "why - he's toilet trained, why is - isn't he just allowed to go to the toilet?" I learned that the school locks its toilets at recess and lunch time so the pupils can't access the toilets. And they said - "Oh no, it's not possible to unlock a toilet. Your son has to ask - go up and ask a staff member for the toilet". And I said "well he has a social and communication disability - he can't go up and ask for the toilet, just let him go". That's what we do at home. And they refused to allow him to use the toilet... after I'd done that and I think that - nonetheless my son still kept coming home with soiled laundry. And I said "but the toilets are unlocked aren't they?" "Yes they're unlocked, they're unlocked, that's OK"... And they were making him carry a card around his neck to go up to the teacher, which he couldn't do. So they - I thought how - after all that we'd been through you so determined that he just won't be allowed to go to the toilet. And that really scared me... people will get even with you by doing something nasty to your child. And that made me quite scared and, um. He was - I felt that my boy was being punished for soiling his pants because he went through a stage where he started to eat his stools. And*

*when I went up to school and said “look this is what’s happening, this is” – I’m horrified and we’ve been to the psychologist... it didn’t reflect well on them that my boy had been so traumatised that rather than let someone see that was something in his pants, he would try to make it go away by eating it. And that just – I – that just – I’d lie in bed at night and just cry and cry over that. That just made me ill’.*

In many cases the reasons given for the change to, or withdrawal of the service, were because the person’s behaviours were perceived as too difficult as shown in the following quotes:

*‘But it got to the point where his noises were such that it was no point having him in a classroom full of children... He tantrumed a lot... it wasn’t helping him and it wasn’t helping the school and the other children. So he went down to the special school. ‘One of the reasons he ended up there is because he just seemed to be in the “too hard” basket for anywhere else’.*

*‘We ended up writing lots of letters in desperation to the Department of Human Services, to the Director of Paediatrics... and asking for support for our family and where the support fell down everywhere because of [her] behaviour’.*

*‘... and eventually the school said “look, there’s just not the support to have him here... [without] a one-to-one worker we can’t have him here any more and we can’t have him in our respite care house any more either”. So ostensibly from that day on we’ve had absolutely nothing’.*

*‘He went from [special school] to [autistic centre]. They [the school] basically said that they didn’t want him there. They struggled to deal with challenging behaviour’.*

*‘... kinda... they were very negative tried to get rid of him. Made us come up there with him, “he’s doing this, he’s doing that”’*

In other cases access to the service was allowed only where a restriction was put in place, which was largely a chemical restriction:

*‘... he still fights that [drugs]. And he does not get out in the community any more whether*

*he’s on it or off it... It’s actually in a way the service system saying well we can only, manage him if this is there because – obviously other methods of restraining him have been trialled – such as behavioural management programmes. And they’re not working’.*

*‘went to school for a couple of weeks and then got into trouble... As soon as we’d said we’d take him off medication, every time he got upset they’d suspend him for two or three days and he’d have to stay at home his hours were cut back to less than 12 per week and they said that he was unteachable and therefore did not want to continue with preparation of an education program.*

*‘... as soon as it [the medication] got to 3mg... it could no longer be regarded as therapeutic – they were simply using it as a chemical restraint... [They were told] He was not allowed to go on respite unless he was on some form of chemical restraint’.*

*‘And it was only when the school got involved and said we can’t have him unless he’s medicated in some way that my ex finally agreed. It just helps [son] with his concentration span and things like that’.*

And, in some cases the services were brutally honest about their incapacity to offer anything positive.

*‘They were just managing her. And they actually said that – “we don’t have a program for [daughter]. We are just managing her. We are maintaining her, containing her and restraining her. That’s all we do here”. And I think that’s a direct quote from the principal... And we said “you need a program... Things that she enjoys doing. If you can’t keep that up then she’ll get, ... y’know she’ll get herself into trouble.”’*

*‘I found it quite depressing ringing the schools in my neighbourhood. We have lots of schools around here that we could walk to. None of them wanted my son. Really to the point – they were quite blunt – they just don’t want you. And quite rude. And I think the principals know if they make it sound like it’s not going to be very pleasant experience there you’re not going to pursue it’.*

*‘You really need to have one on one attention and individualised program for a child rather than trying to squeeze a child into something*

Table 9: Things which the Senior Practitioner needs to be aware

	Things of which the Senior Practitioner should be aware.	Characteristics that should feature in recommendations
39	The Department of Human Services should work on the assumption that it is able to provide support services for each and every person with a disability. The same should be true for children in the education sector, as argued later.	There should be a service for each person with a disability
40	Disability Discrimination and Human Rights legislation require that people with disabilities have equal access to services.	Equal access to services is a right
41	Gaining and maintaining access to a service begs questions about the extent to which an unplanned withdrawal, reduction or change of service itself represents a 'restrictive practice' and needs to be recorded.	Withdrawal, reduction or change of service without consultation is a restrictive practice
42	If services are unable to provide an appropriate input to the many because of the behaviour of the few, this begs questions about what additional changes need to be made in order to be able to support a service to manage and thrive despite such challenges.	More support to services which struggle to cater for diversity
43	Finally it begs questions about whether, as well as restrictive practices being something recorded at the individual level, they be the responsibility of the Senior Practitioner to record and to respond to as <i>systemic issues</i> also.	Recording of systemic level restrictions by the Senior Practitioner's office
44	Systemic issues should not only be constructed around access and use but also the extent to which policies and mission statements are in compliance with human rights, disability discrimination and Disability Act legislation.	Policy compliance audits
45	Some services re-badge acts such as seclusion and this can be a problem, since the use of these practices will not be recorded.	Clear definitions to avoid re-badging
46	The interests of service systems should be served by honesty about 'informal restrictions' and about ALL formal mechanisms used to manage behaviour, as well as the difficulties they are facing accommodating a diverse range of clients.	Honesty of services that are struggling to meet client needs
47	All services should be open to scrutiny, at least to parents and to community visitors.	Open door policy for family and advocates.

*that's trying also to accommodate three or four other kids with really specific difficult needs. Because you can't do something for one without it being to the detriment of another'*

An additional point should be made here that some organisations find ways to represent their own interests at the expense of their clients. The following are examples:

*'They'd allocated a dedicated classroom... and a dedicated courtyard area so he could enjoy the outdoors.'*

*'Every time we want to do something we can't do it... it has to be done this way or nothing... Wherever the pay cheque comes from is that is what they do...'*

*'Anyway our son was in that school - he was constantly put into time-out - and put you*

*know in the padded cell... It's a locked room. That the school operates in lock-down. And parents are locked out of this school. You can only go in if the teacher comes to collect you and walks in with you - in retrospect - they didn't want people to see what was going on.'*

*'my son would come home with injuries... He would have cried or that looks like an adult sized hand print on his arm. I think someone must know what's going on. But nobody ever did. He'd be put in to the time-out room - again... And it was like drawing blood from a stone. And that always the shutters would go up... when I read the incident report I just couldn't believe what they had written - It really just put the blame squarely back on him and me as the parent. And that just made me - well very - in the end I reached the conclusion that it is a waste of time*

*complaining. I just want to get my son out of here.*

Because services have their duty of care and cannot be seen to be failing, it is not presently in their interests to say they cannot manage. Some system which supports them to be open and record their troubles may lead to the development and funding of solutions. As it stands protecting their interests necessarily leads to an adversarial approach and, possibly, an even more sinister slide towards closing ranks, hiding behind terminology and even putting up walls to prevent prying eyes.

### 3.2.5 Environment

In working through families' stories it should, by now, be clear that collectively they have a substantial understanding of the precursors to their relatives' behaviours of concern, protest and resistance. Central to many of their concerns are the environments in which the relatives end up, and this is why the category 'environment' plays such a significant role in their accounts. The following selection of quotations helps to further pinpoint these issues:

*'She got a major calcification in the front here... and she has done a lot of property damage. Not a lot at home, but a huge amount since she went into care. Both of these challenging behaviours have disappeared the minute she went into an unlocked facility.'*

*'[Self harm?] She does not self harm herself. Not really self harm. Until lately, moving into the present house' she's doing a lot of this as more and more restrictions are put on her. And it's so unfair.'*

*'[OK. So what we're saying is that many of his behaviours of concern are a product of – is created by his living situation]... Absolutely... [By the services]... Yep... '[residents] come over and touch him, or enter his personal space... And loud noise is another issue for him. So he would say they're too silly or they're too loud, too noisy... But what his data has shown is if he's happy to be in the environment where he is [he'll] spend hours there.'*

*'... there would be fifteen people standing around [her] taking it in turn to hold her down. And they would be doing it for up to an hour.'*

*Holding her on the ground... They had what they called an eight person restraint that they were using... And then of course as soon as [my wife] would arrive she would say "Come on [daughter], let's go home" They'd back off. She'd stand up, she'd walk over and she'd hop in the front seat of [wife's] car and they'd drive home.'*

*'He's not like this at home. Yes we have difficulties but it's not – I never need to manhandle him out into another room and lock him in there... I know he really relishes his freedom at his new school. I definitely have noticed that. And having access to a real curriculum has made an enormous difference to him and his learning.'*

*'They kept changing the taxi drivers because they just would not pick them up. And then we found one called [name] who was just so nice, so easy with the children. I mean, stick the tissue paper under the chair. It doesn't worry him. "Don't do this!! Don't do that!" You're talking to a load of autistic children!'*

*'Maybe she could not cope with the special developmental school and gradually I found her making lots of noises... Now I think there was too many things she wanted to block out so she withdrew into herself a bit.'*

The above examples make a case that behaviours are different in different environments and that the person is trying, through their behaviour, to communicate something of their feelings about that environment. It should always be assumed first that consistent responses in one environment, that differ from another, tell us about the person's relative comfort, safety and happiness in each of those environments.

Some further examples illustrate from the family perspective how their relatives interact with environmental conditions:

*'If we found a good place that had good people looking after him and fun things to do – and [son] got there and said "yeah, see ya later Mum and Dad, I'm staying here for a week" – that would be respite. But we never had that experience...'*

*'[His] room was here and the toilet was here so he couldn't go to the toilet... and the kitchen's here and there's a locked sliding door'*

here... Basically if [son] wanted to go to the toilet he would have to bang on this door to get the attention of staff who might be there or who might be on the patio smoking. Within four weeks of him being there he ended up in hospital four times’.

[house] has a 3.9 metre fence around the courtyard...there are four people living there... it doesn't make sense to aggregate people... It's almost intentional mis-management... detrimental to the health and well-being of not only the residents but the staff who work there.

‘Certainly not good for her as a human being... Basically I think [daughter] is in permanent seclusion as far as I'm concerned... put... occupants in individual houses out in the community. It would be cheaper even with the extra staff... you'd get greater support from family, friends and community people’.

‘One day he hit somebody and he was banned from the shopping centre. It's just one day. We went every Saturday [with son]. One incident [with staff at the CRU] and he's banned... He needs to socialise. You can't lock him up, that kind of bullshit...’

‘When she becomes very stressed and anxious my daughter does become aggressive. And I think that the reason people would react with the time-out... and left there for extended – one time it was forty five minutes. And cried so hard that all the blood vessels around her eyes and face burst and that was really distressing’.

‘Without a doubt there's been effects on [daughter]. Because she didn't get better – she got worse. She lost her language in school. I could weep for the language that she lost in school... Its punitive environment without a doubt caused her development to regress’.

There is something hugely important about the information contained in these transcripts. People, all people, have a conception of when their right to control, choice and autonomy are being infringed. In this sense, controlling behaviours that do not make sense or which do not accomplish an outcome which they choose are a fundamental threat to their integrity as human beings. In other words, there is a fundamental understanding in each person of their human rights. Violation of such rights is likely to produce ‘behaviours of protest’ and ‘behaviours of

**Table 10: Things which the Senior Practitioner needs to be aware**

	Things of which the Senior Practitioner should be aware.	Characteristics that should feature in recommendations
48	Recognise that although some behaviours may remain unexplained or persist (as a behavioural phenotypes for example) it should always be assumed first that consistent responses in one environment that differ from another, tell us about the person's relative comfort, safety and happiness in each of those environments.	Different behaviours in different environments tell us something about relative safety, comfort and happiness
49	The infringement of fundamental human rights leads to ‘behaviours of resistance’ and ‘behaviours of protest’	People recognise infringements to their fundamental human rights and behave accordingly
50	In this model behaviours of concern may equally define the service, rather than being pathologically and unidirectionally attributed to people with disabilities.	Environment, as cause, needs codification to allow for recognition and measurement
	Methods should be developed to support the Senior Practitioner to recognise when a behaviour is resistance, when protest, and when concern.	
51	Only in a system which counter-balances the behaviours of all parties can the balance of power and the rights of parties be understood. In this model interventions which restrict are themselves ‘behaviours of concern’	Equality of arms
52	If interventions, by functionaries of the state, can equally be seen as behaviours of concern, accountability will be built into the system and, moreover, such actions can more easily be distinguished from actions that are abusive and illegal.	See the behaviour of the service as a behaviour of concern



resistance'. To reiterate and elaborate some points already made, Table 10 indicates further issues about which the Senior Practitioner should be aware.

This section has been filled with narratives that are full of angst and they produce accounts which many of us find quite upsetting. Shortly, we will turn to discussion around things that family carers said worked for their relatives. However, this section will be completed by reflecting on one positive experience:

*'[Own home bought by parents] [He] started a few nights ago delivering a newsletter for the Neighbourhood House. He's getting involved in the community he's living in... The house has beautiful garden and he's loving it though he can't use the hoses, and there's a gardener out there. There's herbs in the garden and he's forever giving people herbs. It wasn't one of our priorities. So for [son] there's communication with the community and he's a valued citizen. So while he can never be on his own, I do experiment. The house has been one of those things. I always thought it would take about three years transition. It took [son] three minutes.'*

### 3.2.6 Communication and choice

Much has already been said about the ways in which behaviour is communicating choice. The concept of choice will be argued later to be central to models of rights and their accomplishment. Given the centrality of this point to the discussion to come later, it is sufficient to provide some further accounts of the ways in which such choices are expressed, and to understand something of the ways in which communication expresses an internal mood.

*'Sometimes they'll drive for two hours somewhere and whether they get out at the other end I don't know. I think of all that fuel wasted and is it something [he] would really want to do?'*

*'We didn't have any choice. We didn't have any say in where he went or who he lives with or the fact this place was way away.'*

*'Most of the time and for so many years I can understand that whenever he's having something not right within himself... if he cannot tolerate something he just expresses*

*himself in unacceptable ways, playing up and things like that'.*

*'It's fairly obvious down the track, looking back, a lot of [his] issues were related to inability to communicate. Perhaps frustration with the situation. Pain. Who knows...'*

*'... the home environment there is nobody else with a disability, who is more likely to come over and touch him, or enter his personal space. Which is a key issue for him. So in every situation that has been offered to him, both as a day service and a residential service, that has been a concern'.*

*'And... he's not happy with the day program. Because again they force him to participating in a group situation'.*

*'I think sometimes it may be because of things going on around him... his group does have behaviour problems. Sometimes it may be him, he may not feel well in himself. He may not have slept. But sometimes we cannot find the reason'.*

*'If he started to tantrum or look like he was going to get out control they pushed a button... the heavies all came and stood and made a statement I guess... But as he's got older... it just doesn't work. And [he'll] say "I'm a big, grown up man. Shouldn't hold, shouldn't do" - whatever. He'll actually say it'.*

*'And if you hear [him] he'll talk about all the things that he wants and it's very easy to say "Oh, that's so unrealistic, you're never going to do that" - I just say - I don't say no, I say [son], "I hear you" ... Happy. You know, ha, ha, ha, Mum heard me. I'm really excited, she understands what I want'.*

*'She jumped down from a moving bus. It was a Christmas party... All his snacks were put in the drawer. He jumped down. The next day they had someone with him all the time'.*

*'Even one incident when he was there was that he was starved... He was vomiting... and these people weren't looking after him... They said there was plenty of food but it was only fruit... He was there for six months. He wasn't given choices'.*

*'I think he's been living in seclusion for so long he doesn't know anything else. He has made attempts to escape. So that's his way of communicating'.*

*'Usually the whole idea of restrictive practice is... because if I was eating a piece of toast and I wanted a piece of toast or something and he was excited he might just bite me and I wouldn't see that as something which he should be controlled from doing. Rather I'm meant to be aware of his communication needs and I find it difficult to introduce the idea of restrictive practice because the needs of my son may have to fit into a time frame or something we deem as manageable. I think it has to be a lot broader than that... I see that behaviour issues or anything that might be deemed as restrictive practice is primarily a communication objective of the client.'*

*'If you asked me two years ago, someone with an intellectual disability and choice, I'd actually get on my soap box, and I was really good at it, and I'd say they had NO choice apart from whether she wants her hair pulled back, this pony-tail, that pony-tail... They really don't have that much choice in life. Well, I actually, it's really gone out the window with that. And [daughter] has every choice. Every single thing we do is [her] choice. And it goes back to what colour ribbon she has on her hair... She has that choice every morning.'*

In one respect the quotations speak for themselves. However, an important underlying distinction in this data is between *communication* of choices through behaviour and *pursuing* those choices to achieve outcomes. Both may require additional support to be achieved. The issues of choice have by now been well rehearsed in this report and do not need further explication.

### 3.2.7 Collateral damage

The struggle parents face in trying to do the best for their child, to advocate for their relative over services generally, and in relation to restrictive practices as part of that, was attested to by all parents. Here are just a few reports of how their lives have been affected by their relative's use of services:

*'It takes a lot of my time and my husband's time. I've sat through literally hundreds of meetings.'*

*'Very unhappy with, disillusioned with the system. Yeah.'*

*'It's been really really hard for the boys. They've never complained. I've got these memories of [son] sitting in my car trying to do his VCE... because he couldn't study anywhere else at night... And he would sit in the car in the freezing cold trying to do his assignments.'*

*'A lot of fights I've had about [son] are with my ex where we disagree, like putting him on medication was a huge fight.'*

*'Devastating is not enough... stumble and the DHS wins. It's absolutely hopeless... Years and years of being broken down by the system... That's why I'm giving up.'*

*'We always say we literally went to hell and back. Our social life is zero. We never do anything, we never go out... Even when we go out to parties, we are anti-social because we just have to walk out... Most of the time we got invited once and never got invited the second time. Anyway...'*

*'He became to the point that in his first year at school we couldn't even go out as a family in the community. We couldn't do anything with him. We were prisoners in our home. And because he was so out of control and he'd never been like that before.'*

*'Used to go to meetings. Used to write e-mails and letters. And nothing seems to be working. The mechanisms for justice even with the new legislation aren't working. And they're crippling. Crippling. Time-consuming. Have to find a faster way.'*

*'And at the time, in the six months leading up to him starting school we learned that our daughter was also autistic. And at that time I just felt absolute panic that what could - my son was a real struggle to cope with. I was struggling to be a mother to my daughter as it was without her having the extra needs.'*

*'But we tried for [son] to have his own life. We know it will all fall on his shoulders so we're trying to make it easy as possible for him. We've actually started a circle for [daughter] and we've had one meeting... a formal circle of friends... Not all of them know that part [the restrictions] some are support workers but some of them are friends...'*

*'wrote... and said we couldn't manage the care of our son any more... in a few weeks he*

*had a permanent place in a house out in the middle of nowhere with older – much older people.'*

... because we're a parent, "well, you can kick me, bite me, punch me – do whatever you like to me because I'm not going to leave you because I love you, right?"

Many families are exhausted and traumatised by the endless effort involved in providing care and in continually advocating for their relatives. Certainly, when placed against the experience of other parents, their efforts have to be more sustained and are far more taxing on their health and well-being. Clearly too, there are restrictions concomitant with their caring role that do not feature in the lives of other parents in terms of their social lives, choices and involvement in the community.

Finally, it was also found that the interest in recording interventions is held more strongly by bureaucracies than by families. Indeed, five of the eleven family carers to whom we spoke were still not aware of the requirements of the Disability Act and the work of the Senior Practitioner and were not aware of the links between the recorded restriction and the BSP. Families are more interested in the overall effect of a service. Those families who were aware of the work of the Senior Practitioner and the Act, by-and-large, welcomed the legislation and its intentions. However, a question still remains as to the extent to which there is a link between what the Act will accomplish and what family carers want. Above, it has been shown that there are a significant number of reasons why a disconnect may transpire between the recording and practice requirements of the State and the interests of carers and people with disabilities.

Some final quotes may help to place in context the extraordinary contribution parents make not only to their children with disabilities, but to our society as well.

*'And one day I said... are you upset because you can't get your words out and he just started sobbing and sobbing. And I thought he knows, he knows that he's so frustrated – communication frustrated.'*

*'In a way I sometimes think it's like the stolen generation – where these kids are not seen to be manageable at home with their family – but the system can do better...'*

*'like he's doing crafts that he's never done before... And... they get him to analyse how he's feeling and why he's feeling that way*

*and what he's going to do in response to that feeling... the aim is to habituate good responses... well they've been doing it with some degree of success. He still gets upset... They're not big guys. But they're smart, you know, and they're fearless like you wouldn't believe. Like this big guy's about to explode in their face and they just go "breathe-in" hahaha (laughing) which is important because he doesn't see them as jailers, he doesn't see them as abusers. DHS response is OK let's take that person out of the picture whereas our response is, because we're a parent, "well, you can kick me, bite me, punch me – do whatever you like to me because I'm not going to leave you because I love you, right?"*

### 3.2.8 – Some further issues in constructing the case for a restrictive intervention

The previous section points to the often difficult experiences of family carers and the data suggests that these become particularly acute in circumstances in which parents are in dispute with services or staff. Unfortunately, a good proportion of the family carer participants in this study requested that specific details of their cases were not rehearsed in this document. However, a reduced number, in which permission was granted, are set out below. The first explains a circumstance in school indicating that the experiences are by no means a preserve of adult services.

*'even then when I was having the discussion with this senior person from the Department of Education and the principal, they were trying to tell me that it wasn't – it was permitted by law, what they were doing, under the Disabilities Discrimination Act – and I had to say, look I don't see – I don't care about the Disabilities Discrimination Act – this is an Human Rights issue. And it suddenly – oh we started talking about how the toilets were going to be open. But, as you can imagine I was not very popular in the school after I'd done that...'*

*'We fought and fought... Every time we argued the case we won... was damning of them... [but] staff just ignored it... they [the powers that be] just ignored it.'*

*'They've shut the door now. They wouldn't even pick up the phone. They shut us off... Where do you go? This is our daughter. I'm not*



*allowed to visit my own daughter? What is this all about?'*

*'And it was like drawing blood from a stone. And that always the shutters would go up and no-one would really – oh no-one saw anything. No he might have – I don't know how that happened. One time I got so incensed that I actually – I went to the police and complained... Oh didn't you see the incident report. I said "what incident report, I've never seen and incident report about anything?" so – and incident report was written and when I read the incident report I just couldn't believe what they had written. It was as though my boy had been in the room all by himself and had been, you know, like had bashed his head against the table. And no-one else was there while it happened. When in fact I know that there were three staff members present'*

*'Oh yeah. They haven't even looked at the fact that the client's gotta any ongoing trauma as a result of that. Yeah, for sure... it's the accountability to the incident. What we're talking about is accountability to the incident. You are following a set procedure. As soon as you've done that the document is documented...'*

*'... and this was before I actually witnessed the staff assaulting a client which I could have said was a physical restraint except it was done so brutally and in the Incident Report that staff member wrote he never mentioned any restrictive intervention... it was a blatant cover up... so the incident can be used in a proper way to bring about change and help document a positive and progressive management of people who have disabilities and who are living in CRUs otherwise I don't know where they get the statistics from'*

For a few families in this study and in a few instances, it was found, unless taken to the highest level, and unless it involved the highest level of protest to place an issue, experience or ruling within the public domain, that families did not succeed in having their voices heard. Beneath this level the power held by services and formal authorities was too great to successfully challenge and to lever change, leaving the family carers powerless to make a difference or to be given what they perceived to be a fair hearing.

The intention above is not to create a case against all restrictive practices but, rather, to seek to understand parents views and the basic issues of social justice that underlie such views. In this respect, in another case, a mother spoke of her shock when a new CEO of her daughter's service providing organisation took the position that 'all restrictive practices are bad'. This meant the restrictive practices on her child with Prader-Willi were also 'bad'. The mother was forced by the CEO, through a series of discussions, protests, panels which involved a number of providers, advocates and organisations. It took huge resolve and effort to show how, by extending choice within a restrictive framework, within a good person centred plan and by adopting principles of positive support around accomplishing her child's long term goals and wishes, that the child's life had been transformed for the better.

The important factors in this are in understanding success not just in terms of a model of social justice but by providing a planning framework which works positively to support the person to accomplish their life goals. The additional importance of the long term place of that planning framework is also vital. So far the majority of this report has, drawing on the data, concentrated on establishing the importance of the new categories: behaviours of resistance and protest. Little attention has therefore been paid to the prior circumstances which lead to the service interest in changing a person's behaviour through restrictive practices. These have largely been handled through Incident Reporting mechanisms, which establish the grounds that substantiate an interest in intervention. Several points should be noted in relation to such Incident Reports within contemporary practice:

- Staff reports of difficult situations inevitably lend themselves to staff protecting their own interests,
- The documents themselves stand as an official record that can be challenged, in other words they are implicitly adversarial,
- The focus is necessarily on a discrete behavioural interaction between the person and others, leading to a privileging of behaviour as the primary factor of significance, and the single act at issue to stand out as the criterion for decision-

The intention above is not to create a case against all restrictive practices but, rather, to seek to understand parents views and the basic issues of social justice that underlie such views

making against what might be a substantially unproblematic history,

- In amongst the whole life circumstances and behaviour of the person, the ‘incident’ there carries disproportionate weight often sufficient to convince APOs of the necessity for intervention. This is accentuated where case files, over time, record and accentuate the negatives, providing a misleading history from which the present reader reconstructs the client’s behavioural past.

Previously it was suggested that individualised plans should form the basis for life choices and the focus of support staff to accomplish the wishes, dreams and aspirations of the person. This orientation should be no less evident in the Incident Report. In that report, staff should not only be making recommendations about how the circumstances may have produced the behaviour, but should also be explaining how the incident affects the trajectory of person centred planning and positive support. In this way the report should predominantly examine factors extraneous to the behaviour as antecedent to it and should propose how changes can move the person towards their goals. Having distributed this report to participating carers prior to publication, one also suggested that perhaps there should be a “happiness report” instead of one geared around problems. By taking elements, such as those just outlined as the basis of reporting procedures, honesty can be better served, the focus is the person and their goals, it will not be as adversarial, and any proposed

interventions can be made with the clear knowledge that it is a necessary intervention to accomplish the person’s stated wishes, setting the history of good past experiences against the single incident. To accomplish this will require review of the Incident Reporting mechanisms and a substantial amount of training for staff.

On the basis of what has been said the Senior Practitioner should be aware of those factors set out in Table 11.

### 3.3 Things that work

From what was written in the paragraphs above it should be clear that it is more important to look at the root cause of behaviours and what people are trying to communicate, than to assume that such behaviours of concern immediately warrant a restrictive intervention. But if there have been restrictive interventions, what has worked? Part of the interview with family carers asked them to identify things that had helped in relation to behaviours of concern and these are listed below. Key themes are then set out as appropriate in response to these statements and bold highlighting used to emphasise key terms and values.

*#1 ‘I think that [he] knows someone is making sure he’s safe has been good. He doesn’t hit and carry on in the car any more with us... he doesn’t try to whack his head in the padded area... And he’s happy in bed’.*

Table 11: Things which the Senior Practitioner needs to be aware

	Things of which the Senior Practitioner should be aware.	Characteristics that should feature in recommendations
53	In many circumstances, families have been found to have to argue a case to the very top and then make it a public issue before their voices are heard.	Hearing family carer voices at all levels of the system
54	Families have experienced being locked out, or staff have engineered that they be kept away from their children. Services cannot take the law into their own hands and access to children is a right, not a privilege.	The right to see children unless a Court Order prevents this
55	Organisations inevitably protect themselves. This means the system of reporting incidents becomes adversarial.	Systems of collaboration are by definition not adversarial
56	Incident reports presently privilege the behaviour in the incident. Behaviour, over both a person’s history and around the potential environmental antecedents, as well as the individualised planning framework need to be taken into account, or APOs will have a skewed view in their decision-making.	Review of Incident Reporting Mechanisms

Key themes in #1 – person feeling **safe** leads to better behaviour – By inference the person will **trust** those who make him feel safe.

#2 [medication] ‘... he was sooo manic... they couldn’t even get him to sit down for five seconds, so we ended up back home and so that was that, yeah. And I agreed with them... It depends on the case. With him, he is able to concentrate more. Some of his behaviours have decreased at home. I could not look after him without it. I could be wrong, but I don’t think so... participate more in class and for me it was so I could help to build some skills for him. Because the way he was... he was so non-compliant, you couldn’t do anything for him... I’ve always been big on building on any skills... but we just couldn’t do that. We hadn’t got a foundation and we could not move forward’.

Key Themes in #2 – medication helps concentration implying he gets more from classes, participates more, is building skills, reduces behaviours of concern – by implication the **OUTCOME** has improved with the medication, and it is not just about maintaining him in the class at all costs.

#3 ‘... we haven’t found anything better in terms of equipping parents to know how to reinforce – to do positive reinforcement. How to play down the negative reinforcement. You know what I mean... That’s the best thing that we found. It doesn’t matter, OK we wanted him to do something and he didn’t do it right – OK it’s not his problem, it’s our problem. We’ve got to change the task so that he succeeds and feels better about himself’.

Key themes #3 – **Positive reinforcement** – seeing his failure as our problem – getting to do things he succeeds at – implication that person feels self-esteem from engaging in something.

#4 ‘We actually did manage to organise a day program for [son]. But it was for twelve hours... but this company does provide two staff who are professional, who do an awful lot of planning activities and skill development... And that’s been really helpful. A lot of emotion management work’.

Key themes in #4 – Detailed **planning** of activities, focus on **skills**, working with **emotions**.

#5 – ‘... re-wrote his behaviour management plan... positive behaviour support plan... using the weight of the new legislation in 2007 we completely revised it or repackaged it and got ownership from staff... Take out some bits they don’t like. Added some bits they wanted...’

Key Themes in #5 – **Positive behaviour support**, being in **control** and **owning** the behaviour support plan.

#6 – ‘We’ve found it really interesting or fascinating that we’d put a lot of restraints in before we knew she was Prader-Willi... surveillance is less restrictive for [her] and it allows her to have more privacy. A lot of staff that’s come on board say they’ll give it one try and don’t want to do it at all but after one night supporting [daughter] with surveillance, not one of them... disagrees. ‘Drilled hole in wall and pantry and put a bike chain on the pantry door... helped for couple months... then a complete nightmare when we relaxed – then bike chain, combination lock – within 24 hours she’d sat down and figured out how to do that – several types of locks – Now all support workers have to have a key for the food cupboard. Now we have pretty pink locks that [daughter] chose and we taught her that she would die of other complications... [psychologist]... set up the positive behaviour management. He looked at [daughter’s] choice and how to give [her] choice... If you say to someone you’ve got the surveillance, things locked away it sounds really dreadful. But for [daughter] it’s actually routine. If you break the routine that’s where it doesn’t work... That’s where the autistic part comes in there... So the restriction of the cupboards locked takes away the behaviour. When it comes to [her] food as in choice she has an eating plan... 1200 calories a day. Like tomorrow we’re going out, today I’d restrict her to 900. We break up the food categories... On the side is a ‘barometer’. For breakfast she had... She can actually visually see. She can actually choose what food she has...’

Key themes #6 – Where there is a restriction, offering choices around the restriction – where possible negotiating around how it will work and

then creating a **routine** that works is **knowable and repeatable** with recognisably positive outcomes for the person.

*#7 'When he senses that he's losing control, over his feelings and his body's doing strange things or he's thinking strange thoughts, he senses he's losing control he becomes more obsessive. And I suppose it starts with people who recognise it doesn't make much sense to us... he finds it upsetting so how are we going to respond. Now you learn what the rules are and you learn to work within them'.*

Key themes #7 – Learn to recognise what produces anxiety and loss of control – recognise that the **reasoning and logic** surrounding loss of control may not be available and understood but are nevertheless real to the person.

*#8 'And one of the things that most helped me was being invited to join a support group of older parents who had teenage and young adult...[Who'd]...Been through it.*

Key themes #8 – **Sharing** problems and **learning from others**.

*#9 'Positive behaviour management is the answer to restrictive practices or any restrictive intervention. As long as it has a positive outcome. I just think that's so important. It's not to try everything. That's not the answer. It's a behaviour strategy that's positive with a positive outcome'.*

*#10 'Amused by fire and flames... do a fire intervention thing – met a fireman and coached her over three weeks and that really helped... does it every three months and every support worker has to do the programme if they work with [her]'.*

Key themes #10 – **coaching**, support workers go through training as well to produce a **consistent approach**.

*#11 [new legislation]... what really gives me some comfort is that it's illegal for them to retaliate having made a complaint. Because in the past that actually did stop us'.*

Key themes #11 – Knowing there is a **system**

**of complaints**, knowing the person is safe from retaliation.

*#12 'And one of the comforts of being in a main stream school is to know that there are hundreds of little eyes and ears who can talk, and who will be taken seriously. They might go home and tell their parents if they saw something that they didn't like. And I just think that when you're out in the real world it's just – real world rules tend to apply – people are watching and people conduct themselves differently when they know that they're being watched'.*

Key themes #12 – Knowing everything is **open to scrutiny** and that there are people who are on your side.

What families seem to be aiming at here is adopting themes that are **positive** for the person, positive in approach, positive in their means and positive in outcome for the person with a disability, those close to them and staff – a win-win-win situation. The features of this model are therefore about having a positive plan, positive working practices and positive outcomes.

### 3.4 Final points for discussion

In what has been described above, positive behaviour support features quite strongly. However, it should also be recognised that adopting this as a *modus operandum* is, once again, privileging behaviour as the central issue and area for concern. Looking back at our previous analysis of context, an argument can be made for 'positive support' which would include 'positive behaviour support' but which would also include other areas such as rights, choice-making, control, person-centred planning, positive reinforcement and positive outcomes. Shortly, an effort will be made to piece together the findings from this study into a more robust package designed to inform all those involved in supporting better lives for people with disabilities. It should be noted that the issues identified by family carers have, so far, been reported in discrete categories and presented in summary form in a series of tables in list form. However, these categories do not exist independent of each other. Systems are complex as the following examples seek to show.

**Figure 5: Example of circular logic**



The contexts in which restrictive practices are used are hugely significant to both the type of restriction imposed and the outcome achieved. The Behaviour Support Plan form used for submissions to OSP asks whether it is the ‘least restrictive... as possible in the circumstances’. Much of what family carers talked about in their interview were these circumstances and the antecedent conditions in which the restrictive practices had been used. Many accounts pointed to circular logic and a downward spiral as in the following Figure 5.

Outcomes in this scenario are linked to the vicious circle and downward spiral: an unhappy client who sees the staff as imposing too much on his life and choices, staff working harder to control the absconding, which leads to resultant behaviours of resistance and protest; further controls and so forth. The direct outcome is less access to the community and less chance of accomplishing the ideals of choice and inclusion. But the hidden result is as profound: the relationship between client and staff becomes one of jailer and jailed; the views each holds of the other solidify at the extremes,

‘challenging’ from the point of view of the staff and ‘resentment of staff’ by the client; trust, which is so necessary to good support, is lost; the person is disempowered and their choice ignored. In short, the ‘cost’ of unwanted restrictions is exceptionally high.

The prior condition to this is where power, and the power to define acts, lies with services and staff accepting the concept of ‘absconding’. This immediately implies a person ‘not being where they have been told, or expected, to be’ and ‘leaving without permission’, perhaps even that it is ‘unsafe’. The orientation of staff is therefore based on attitudes of risk reduction and safety to the client. Needless to say, from their point of view, it is better for them to be safe than sorry.

Now consider the mother’s view that her son had a history of ‘choosing to access the community independently’. The resultant circular logic would be as in the Figure 6.

In this scenario the choice is offered to the person. Because of this his own goal, ‘walking properly’, was agreed by him and his circle of support as they

**Figure 6: Example 2 of circular logic**



**Table 12: Comparative outcomes of different intervention approaches**

		Intervention	
		Positive (supporting choice)	Negative (restrictive)
Outcome	Positive	<ul style="list-style-type: none"> <li>• Inclusion</li> <li>• High trust</li> </ul>	<ul style="list-style-type: none"> <li>• Choice</li> <li>• Higher risk</li> </ul>
	Negative	<ul style="list-style-type: none"> <li>• Reduced safety possible</li> <li>• Lots more work and funding</li> </ul>	<ul style="list-style-type: none"> <li>• Safe</li> <li>• Easier to co-ordinate</li> </ul>
			<ul style="list-style-type: none"> <li>• Bad reaction</li> <li>• Trust broken</li> <li>• No choice</li> <li>• No community inclusion</li> </ul>



the controlling environment created more of the very behaviours it was supposed to resolve.

met around his Essential Lifestyle Plan. The person is happy, the staff are engaged in facilitating his life choice, and this builds trusting relationships and a positive environment. In this case, the plan was undertaken with a circle of support and one member agreed to introduce the person to the cycle paths. The parent in this interview said her son was ‘communicating with his legs’. He was happy to stay at places he liked and often walked to his siblings’ houses where he felt comfortable to stay for long periods.

In short, the controlling environment created more of the very behaviours it was supposed to resolve. The case might be summarised as in the Table 12 below which shows the comparative outcomes dependent upon whether the intervention is based on choice versus restriction.

Here is another example in which it is not immediately apparent that there has been a restriction, as defined by the Act, and one that would not therefore be recorded:

Unable to communicate, a young man communicates his need for the toilet at home by making ‘pushing sounds’ and his parents respond immediately, knowing what he is communicating. Since moving to a CRU staff ignore this cue. Now the young man is using the pushing sound to get attention and dirties his pants several times a day. As the mother says, this makes it difficult to go out into the community because they don’t do ‘changing tables for adults’.

In this example the link between a communication cue and toilet is being ignored and there has been no consistency of approach between the family home and his home in the community. Since the young man cannot use the toilet without support there is effectively a restriction being placed on him by omission. Freedom of movement and freedom of access are illusory where the person cannot accomplish these for him or herself. No active restriction applies and this is an example of restriction by omission at best, negligence at worst. The response by the young man represents an *adaptive behaviour to a maladaptive environment* of support. It might be construed as an infringement of his social rights to dignity and self esteem. It is also a behaviour which affects the communication and

interaction between client and staff as well as the outcomes that flow in terms of choice, independence and inclusion.

Here is a third example. A young woman with a significant history of aggressive behaviour towards others has had a wonderful plan written to get her enthused about her day programme. It will involve trips into the community, music which she loves and some craft work, which it is hoped may bring her work. Unfortunately she requires two workers to access the community and this has not been possible to organise. Indeed the level of support for all the activities is too low. The expectations of the client and their family are dashed against the rocks of inadequate funding and, once again, loss of trust in the service system results. It may well have been cheaper to provide the funding to the client and, indeed, her family directly, through an individualised payment from which they could purchase the services of their choice and where they could withdraw payment where the outcomes were not accomplished.

The fact that the plan has failed will not be recorded as restrictive practice, but effectively she is being excluded/restricted from planned activities due to staff shortages. Her access to the community is being restricted, leaving her marooned in a building she does not like, leading to frustration and *behaviours of protest*. Moreover, there is no right to redress as was proven in this case when the family applied for more funding and failed. In cases such as this families advocating on their relatives’ behalfs complain, protest and beg. The stresses for them are substantial and real, and in the end have the effect of grinding families down and leaving their mark on others in the family.

The liberal model warrants decisions by the Senior Practitioner on judging when the positive effect of the intervention outweighs its negative effect. In making this judgement several issues from the three examples are relevant and these are further laid out in Table 13.

The data from family carers and from people with disabilities have now been presented, interpreted and translated into issues about which the Senior Practitioner should be aware. The following discussion formalises some of the recommendations that flow from these findings.



Table 13: Things about which the Senior Practitioner needs to be aware

	Things of which the Senior Practitioner should be aware	Characteristics that should feature in recommendations
57	People with disabilities often experience restriction as an infringement to the integrity of their body and the wholeness of their person, that is as an infringement to their inalienable rights as a human to choose their own path and fate.	Humans have fundamental human rights and will react if these are infringed
58	A behavioural intervention can achieve a great deal in terms of changing behaviour, but if accomplished using negative reinforcement, aversive interventions or physical restrictions the success may be illusory, a result by ' <i>forcing compliance</i> '. In this case, the costs are likely to be too high and they are at the expense of a person's chosen life options and their human rights.	Nobody can have the right to do something wrong. 'Forced compliance' incorporates approaches which infringe the human right to freedom of choice
59	Recurrent and continued infringements using strategies of 'forced compliance' on the person will lead to either complete acquiescence and compliance (ie. institutionalised behaviour) or, alternatively, to <i>behaviours of resistance and protest</i> . APOs need to consider whether the person's behaviour is communicating.	'Forced compliance' leads to institutionalisation or resistance both of which are iatrogenic
60	Interventions are seen as being 'perpetrated' if the person perceives injustice in what is being done to them. If this happens, 'trust' is lost with the perpetrators, mostly staff. It is virtually impossible to regain that trust, therefore breaking the link upon which modern-day disability support should rest.	Staff are perpetrators when their actions are unjust. Unjust actions break trust between clients and staff
61	Long-lasting change in behaviours is achieved, not through restriction, but through <b>positive support</b> . This is support based on the person's choice, in which they agree to plans and actions and a stated chosen outcome is the focus of intervention at all times. Behaviour is JUST ONE focus of this 'choice', but is always judged against the success at meeting the person's chosen outcome.	Positive support based on choice, working to the person's own plan, rights, justice and achieving their goals is vital
62	Producing better outcomes through choice is likely to be cheaper in staff costs in the <i>long term</i> . Distributing support amongst people who love and care for the person in the community will not only save money but will tie the person in to naturally occurring networks of support and natural sources of expectation around their behaviour. Autonomy and independence is ultimately cheaper than recurrent and forced compliance.	Community networks and 'distributed support' are cheaper than behaviour change by forced compliance
63	Good plans based on the person's choice and positive support have to be followed through.	There need to be mechanisms in place to maximise the likelihood that individualised plans work, and a system of redress needs to be available when services fail to deliver the agree outcome
64	The Senior Practitioner should think about the restrictions produced by a service that does not deliver an agreed plan. There should be some system of redress or complaint available (whether through VCAT or the DSC) in situations where an agreed plan is not accomplished. The client and their family should expect services to deliver what has been agreed just as all citizens expect to get the good or service for which they pay. One possible way of empowering the client and their circle of support is through individualised funding in which they can 'take their business elsewhere'.	

# 4

## Discussion and recommendations

### 4.1 A structure for the discussion

In seeking to develop a structure for the following discussion, the 64 items in the thirteen Tables which accompanied the analysis were placed into themes to support the discussion. It is vitally important that what follows is not taken as a prescriptive menu. It is not possible in a report such as this to be exhaustive in setting out how change can be accomplished. Nor is it within the preserve of just a few minds to have covered everything.

Policy-makers, managers, support staff, family carers, people with disabilities and other organisations and advocates are encouraged to themselves:

- Add data and stories to those presented here,
- Think about what the report data and any new stories can tell them about a rights-based approach to support,
- Think about the policies and practices that can lead to social justice, openness, collaboration and better outcomes,
- Think about how to adapt environments and attitudes to espouse positive support,
- Think about how to bring people together to develop new leadership and cultures that accomplish better lives through '*Supporting people to achieve dignity without restraints*'.

In looking through Tables 1 to 13, by far the most common theme was 'power'. Service issues and recognising legitimate causes for behaviours also featured and are reported shortly. It is possible to read each of the categories that follow as the grounds for a report recommendation. As mentioned earlier though, this would produce a list and dilute the reader's view of the most essential matters. The reader should therefore take what follows and think about how each category might be turned into a recommendation and, then, how that recommendation can be operationalised.

By examining the tables it was possible to identify a series of categories relating to power. These have been set out below to highlight the values that need to be accomplished in a system which works to a rights and social justice agenda in relation to the use of restrictive practices (the number against each item is item number in Tables 1–13):

### Power

#### Achieving rights:

- The need for advocacy (1)
- Equality of arms (2, 51)
- Not sacrificing rights 'fundamental rights' for the greater good (22)
- Recognising infringements human rights and freedoms and neglect (26)
- Recognition of the under-reporting of restrictive practices (5)

#### Safety:

- Of personal possessions (9)
- Recognition of where people have to sacrifice rights and choices for the behaviour of the few (13)
- Allowing choice that promotes safety (21)
- Recognising seclusion must be about safety and active engagement and support (27)

#### Visibility:

- Being more visible (3)
- Services and interactions open to scrutiny (19)
- Open door policy for families and advocates (47)

#### Being informed:

- All people being aware, informed and educated about rights (8, 15, 29)
- Staff awareness of effects of their decision-making (18)

#### At the level of interaction:

- Inverting power relations between staff and people for whom they support with their circle of support (17)
- Recognising staff interaction as a potential 'behaviour of concern' (47)
- Recognising power in communal groups (11)
- Trust and respect (16, 17)

#### Positive approaches:

- Choices, hopes and aspirations reflected in support to accomplish these (24, 26)
- Choice of support and services (25)

Think about the policies and practices that can lead to social justice, openness, collaboration and better outcomes

## Services and service system issues

### Social justice:

Equal access to services for all (39, 40)

No withdrawal/reduction/change of service without consultation (41)

Services that cater for diversity (42)

### Individualised planning and interaction:

Individualised plans as part of BSP decision-making mechanism I(38)

Positive views of the person and their goals (37)

Positive support always (36, 61)

### Fundamental values required:

Honesty, especially about hard to serve clients (46)

Working on principles of human rights (57)

Recognition that there is no right to do something that is wrong (58)

Hearing the voice of people with disabilities and family carers (53)

Working with families and people with disabilities collaboratively and co-operatively (55)

Recognising the rights of access and scrutiny of family carers and advocates (54)

Recording systemic issues leading to organisationally restrictive practice (43)

Avoiding re-badging of restrictive interventions (44)

Policy compliance auditing (44)

Review of Incident Report mechanisms at DHS level (56)

## Recognising legitimate causes of behaviour

Change the setting not the person (31)

Recognising environments of concern and characteristics of such environments (4, 14, 23, 50)

Recognising when informal restrictions are a product of environment or the culture (30)

Recognition of the effects that congregate and communal groups have in producing behaviour (10)

Understanding the relative comfort produced in different environments (48)

Solutions that produce honest behaviour (12)

Changing behaviour is not sufficient grounds for a restrictive intervention.

To reiterate, the points above should not be read as a list. As indicated before, systems are complex and, indeed, each issue has its implications and effects on those in other categories and for the ways in which people act and interact. Some of this complexity is examined in what follows.

Participants with intellectual disabilities and family carers perceive **power** within the service system as a crucial element that dictates the complexion of the service they receive. It is possible to control people and force compliance by habituating behaviours initiated under restriction or by making the counter-controls to unwanted behaviour so great that people avoid them. It is therefore critical that the issue of power in the system is addressed, that, where wielded, it is not seen as unjust and that it does not infringe any person's rights.

Moreover, the system and service need to be organised to **protect and defend the rights** of people with disabilities who exhibit differing and varied capabilities to act autonomously in relation to accomplishing such rights and choices.

The policies and characteristics of the service system must therefore demonstrate these characteristics to support specific recommendations for **re-thinking the equation between rights and restrictions**.

Participants with a disability and family carer data suggest that a re-alignment of power and systems to support and protect all rights are required in the following areas:

1. the service and service delivery system,
2. individualised planning which works to the person's choice
3. characteristics of the environment and other legitimate causes of behaviour

The first three sections below consider each of these in turn, and recommendations are set out along the way in blue and to the right hand side of the page.

the system and service need to be organised to protect and defend the rights of people with disabilities

The final section considers how the recalculation of the equation between rights and restrictions can, and should, be managed.

## 4.2 The service system and service delivery – some options

The data and evidence from participants in this study indicates that staff have significant powers to choose how environments are organised, to develop formal and informal rules for how services operate, and to control the behaviour of those within those services. A *consumerist* framework generally means more than just the receipt of and compliance to a service. It also implies rights within the service, some measure of involvement in deciding how it operates, and a system of redress if the service does not meet expectations where the ultimate choice is to take their business elsewhere.

Options around increasing the power and control over the setting therefore range from inverting present systems of ownership and accountability, to fostering some forms of participation, as well as extending systems of rights and redress. These options should not be seen as mutually exclusive.

The inversion of present systems of ownership and accountability are probably best served by an ‘individualised funding’ or direct payments approach. In this approach, funds are provided to the person with a disability, their circle of support or through a broker independent of services to be spent by the person on his or her own services. As such, staff become directly accountable to the person with a disability and their circle of support. The power over how the service works and what staff do is therefore relocated with the person with the disability and those who care for and love him or her. Moreover, the choice of services will be dictated not by ‘off-the-shelf’ packages, that is a controlled supply, but will grow from demand for services that are perceived by those who use them to work best (see Bigby & Fyffe).

A pilot study of direct payments, already undertaken in Victoria amongst people with disabilities able to manage administering such payments themselves, has indicated potentially good results (LDG Group 2007). The emergent evidence from abroad indicates that, on grounds of efficiency and outcomes, there

is merit in seeking to extend such pilots to people for whom services are often more difficult to provide (Duffy 2005; Duffy et al. 2006). Though the demands of the system add to the work of family carers it may subtract from the incessant need to be advocating for services without the power to make them change.

### Recommendation

A potentially good way to empower people with disabilities and their circles of support is to place them in control to choose, purchase and monitor their own services.

Individualised funding represents one good way of achieving this, and it is therefore recommended that further pilot schemes be set up for people who might not be able to administer their own payment.

Where people with disabilities are not themselves employers, staff remain accountable to their employing agencies. It begs questions about whether accountabilities to the person with the disability, allies and advocates might be manufactured, for example through participation in staff appraisal or, alternatively, staff being placed on their own individual plans in which their plan is developed as a form of ‘contract’ to accomplish through their support the outcomes chosen by the people for whom they care.

The participation of people with disabilities in the planning, implementation, management and operation of services now has a long history, much of it linked to the development of a large and robust self advocacy movement (Felce et al. 1998; Whittell & Ramcharan 1998; Grant & Ramcharan 2007a,b). Representation on all decision-making groups should take place as a matter of course and, at service level, people with disabilities should be represented on policy-making groups and in discussions around the operation of their own service both informally and formally. With the right support (Dowson & Whittaker 1993; Goodley 1997) the voice of people with intellectual disabilities, advocates and allies can be heard from local level right the way up to Government.

**Recommendation**

Consumers should have a voice in all aspects of decision-making about their own services. This applies to people with disabilities too. Evidence suggests that this will be dependent upon building, over time, a strong and independent self advocacy movement and the right support to advocates, and participatory approaches that maximise participation of diverse groups and interests.

The need for monitoring of the quality framework for disability services (DHS 2007) and associated standards has been proposed by DHS. Once again, it is suggested that, to ensure the voice of people with disabilities is heard that an independent and fully paid team of people with disabilities and their advocates and allies are empowered to monitor services. From the point of view of the Office of the Senior Practitioner present and future data collection may help to choose how this limited resource can best be used to keep visible those people with disabilities who are least likely to be seen and heard. It might be that some link with the Office of the Public Advocate and the Community Visitors Program may prove useful as hosts for such an independent group.

**Recommendation**

People with disabilities should be empowered to themselves monitor quality frameworks and service standards. Their work should be fully paid, independent and targeted around those services in which people are least visible.

The present system of complaints is just that, a system – Equality of arms can be accomplished only where all restrictions for those who cannot speak for themselves are visible, by whether people with disabilities, staff and others feel free to use the system and by the checks and balances within the system that make it independent of conflicts of interest. The Disability Act establishes a system of

complaint and the Disability Service Commissioner, whose office is independent of DHS. Three family carers welcomed this and the fact that any action by staff as a response to a complaint was subject to legal action.

Further to this, however, families proposed that the complaints system should make sure that people who use a service know how to complain. That being said, the present study indicates that only a minority of people are in a position to do so. Figure 2 presented earlier shows how a substantial number of people with disabilities do not understand their rights, do not recognise infringements and require support to complain. At a service level, this implies the need for a tightening of independent scrutiny, and more advocacy and representation than presently exists. Generally speaking the degree of monitoring and scrutiny to increase the person's visibility should be in inverse proportion to the ability a person has to speak for themselves.

**Recommendation**

A system of social justice requires a balance between claims and counter-claims and an equality of arms. In the present system not as many complaints are being made as could be made. The Senior Practitioner should work with the office of the Public Advocate legal, systems, citizen and self advocacy organisations as well as the Disability Advocacy Resource Unit (DARU) and Self Advocacy Resource Unit (SARU) to extend the visibility of those who are most vulnerable.

Ways of making staff free to advocate should also be examined tying their interest to those of the people they support.

The value system of such monitoring should reflect the standards set by DHS. However, it should also take into account the civil and political rights afforded under the Victorian Charter of Human Rights and Responsibilities 2006 and additionally cultural, social and economic rights, which are as yet not formally recognised. Furthermore, there is an additional necessity to individualise rights,



that is, to make a link between autonomy, choice and preference with the rights framework. This is considered further in the section below.

#### Recommendation

The system of values guiding scrutiny of services should be based on the quality framework and standards but, additionally, the Victorian Human Rights and Responsibility Act. The Office of the Senior Practitioner might make links with the Office for Disability to further operationalise these values.

This report recognises that there is a limit to which the Senior Practitioner can go in establishing change within the service system. However, it should make DHS aware that in structuring and delivering its services that equality of arms, power and mechanisms that can respond to diverse rights are key defining features of any system capable of making meaningful change in people's lives.

### 4.3 Individualised planning and choice – a rallying call

The system of individual planning links the service level changes discussed above with the individual level. The participants with disabilities and family carers involved in this study showed that it is vitally important that the starting point of these plans is the person's choice. Moreover, people with disabilities should act autonomously to accomplish these choices as far as possible, with advocates and allies where they cannot and, be supported to do so within a framework of values that accords with their own choices and within a rights framework. One possible way on individualising rights would be to establish the person's 'non-negotiables' (Smull & Burke-Harrison 1992).

Even for those least able to communicate their wishes clearly it is possible for those close to them to recognise the things that person loves most, their preferences and, by contrast, those things the person does not like and finds stressful. These 'non-negotiables' should be commonly known amongst those who closely support the person and, so long

as they are not impossible, illegal or immoral, should act as a charter of personal rights which cannot be infringed by staff (including a swathe of casual staff who featured in family carer accounts). It is likely that amongst these non-negotiables staff can locate those situations, environments, circumstances and interactions that predispose the person to stress and to behaviours that respond to such stressors.

#### Recommendation

Rights can be individualised by creating over time an individualised list of those things that the person prefers, likes and wants as well as those they find difficult, stressful or distasteful. These should become a charter of personal rights and should be widely known to those who provide support. Infringements would represent a case for complaint. Each BSP should append this individualised charter of rights and state whether it is being in any way infringed.

The participants in this study indicated that services have variously: withdrawn or reduced their level of input; been so over-stretched as not to be able to provide a quality service; used definitions of people as 'no-hopers' as grounds for not providing a service; and had wonderful individual plans drawn up that do not come to fruition. Such moves by services are potentially problematic for the people for whom they provide services and might lead to restrictions that are never seen.

#### Recommendation

Reduction and withdrawal of services by providers which are independent of plans and agreement by the person with disability and their family, should be recorded on any application to introduce a restrictive intervention. They should be taken into account in explaining the behaviour of concern that is the target of the intervention.

To ensure that restrictive interventions are not a result of the failure of services to implement an individual plan, the person with a disability



(supported through the Independent Person Program) and/or their circle of support, advocate or family should have the opportunity to contribute to the plan.

### Recommendation

Any application for a restrictive intervention should be accompanied by a form in which the person, and their advocates and allies comment upon the level of success in accomplishing stated objectives of the person centred plan. Their view should also be recorded in relation to whether they accept that the outcome of the proposed intervention accords with the outcomes stated in the individual plan and whether they perceive the intervention as justified.

The relevance of the individualised plan may have a prospective importance but its importance, is also hugely important as a *retrospective device*. APOs reading Incident Reports, for example will have a skewed view of a person where their assessment is based purely on the reporting of ‘bad behaviour’. When such behaviour is placed within the individual planning framework and organised around the person’s entire history it may take on a completely different complexion. Changing the information presently used by APOs in making their decision is therefore important.

### Recommendation

A Review should be undertaken of Incident Reports and how these forms are used by APOs in constructing a case for intervention.

It is further worthy to note that in making a recommendation for a restrictive intervention the APO is implicitly making some estimation of the ‘risk’ to self and others of the person’s behaviour of concern. Despite efforts to foster a ‘dignity of risk’ culture, many plans and ideas fall victim to organisational and staff fears of litigation and to OHS policies. For people with disabilities this alone has the potential to substantiate significant restrictions on the grounds that the decision protects safety.

This approach is *punitive*. In an example given earlier, if the ‘absconding’ had not been replaced with the concept ‘accessing the community by choice’ *despite the risk*, then the system would have moved back to the lowest common denominator to produce safety at all costs.

It is suggested that further consideration is given to the ‘*reconfiguration of risk*’. One idea with some potential is to start with the position that the risk has to be calculated against benefit. The work of Beauchamp and Childress (2001), in relation to medical and research ethics, may be of use here. In their four principles approach to ethical practice or, for the purposes of our argument, ‘restriction’ should:

- Respect ‘autonomy’, that is the right to choice and self-determination of the individual to make with their advocates and allies informed choices
- Demonstrate ‘beneficence’, which balances the benefits of the intervention against its risks and costs. These benefits should not only be seen as accruing to the person but be in the ‘public good’ also
- Act with ‘non-maleficence’, which involves avoiding harm that is disproportionate to the benefits
- Achieve ‘justice’, which entails recognition of an approach that is fair and just by being similar for all.

### Recommendation

By ensuring that risk and benefit are considered together the restrictive practice can itself be seen as a behaviour of concern, which has to be counter-balanced by the stated benefit and against the behaviour of concern it is designed to address. This not only ensures a system in which both rights and risks are put to the test, it also establishes a system of proportionality and justice. More research on the *reconfiguration of risk* is required.

In looking at the features of those interventions that family carers had found useful it is clear that they share the single common feature of being positive in

their approach. Such approaches include: ensuring the person feels safe, listening to the person first, and understanding when they feel they lose control and become anxious and distressed; being able to share their problems with others in support groups or informal discussion; knowing that each person providing support comes with a consistent approach; knowing there are no ‘closed doors’ either literally or in terms of making a complaint; helping the person to see either life has improved, using systems of positive reinforcement and positive behaviour support, offering choices around the restriction and staff being accountable for their actions. Together with positive plans aiming at positive outcomes, these represent more than just positive behaviour support. They represent, to coin a term, *positive support* itself.

#### Recommendation

The principles of positive support are hugely significant in defining the experience of people with disabilities and should be adopted as an important principle for the operation of services and as being important to any restrictive interventions that are planned.

Particularly in situations where there is disagreement between the service wishing to restrict and the person, their advocates or allies, it is possible that a board with a make-up reflecting the stakeholders could be convened to make decisions by examining the ways in which they fit the concepts above. In this way, the interests of any single party in their assessment of risk, is counter-controlled by the duty to demonstrate benefit and justice.

#### Recommendation

It is recommended that if people with disabilities and their advocates and allies have the right in the submission to the Senior Practitioner to challenge the service application for a restrictive intervention, that it be referred to a panel constituted out of the range of stakeholders which can arbitrate a decision based on balancing risk with benefit of intervention. The same channel of complaint should also be available where services are perceived to be restricting the person because of withdrawal of service or other factors.

Several points should be made in relation to this approach. Firstly, one of the most difficult issues around restrictive practices is finding an overarching model that accommodates not only danger to other, but also danger to self. The balancing of risk and benefit covers both, and allows the benefits of restriction that prevent self harm to be suitably taken into account.

Secondly, since restrictive practices are more likely to be applied to people who cannot speak for themselves, it is likely that the system will produce extra scrutiny and a system of checks and balances which accords a voice to the person, their advocates and allies. However, there is also a danger that the rise in work associated with such cases may mean that informal practices replace the formal permission required by the Senior Practitioner. This makes all the more important the principle of ‘openness to scrutiny’ in which services (except where accorded legal rights) cannot refuse entry to families, appointed advocates and friends.

#### Recommendation

To ensure visibility, services should work on the principle of being open to family, recognised advocates and friends, except where they apply for such a restriction to be enforced.

#### 4.4 Characteristics of the environment – the grounds for further research

The data in this study around the environment/behaviour nexus makes a strong hypothesis about the relationship between the two. Yet with few exceptions (Cooper & Picton 2000) the literature shows that community living has little effect on the level of ‘challenging behaviours’ (*sic* ‘behaviours of concern’) (Conroy, et al. 1991; Mansell 1994; Conroy et al. 1995; Emerson et al. 2000; Stancliffe et al. 2002; Young 2006). Indeed, two studies suggest they increase (Lowe et al. 1998; Felce et al. 2000) and another researcher has reported that such behaviours increase if person centred planning is introduced (Robertson et al. 2005). In the latter study the authors hypothesise that freedom of choice and autonomy to act increase the opportunity structure for such behaviours and the expression of individuality. However, although the overall frequency and severity of behaviours of concern did not change in these studies, some studies have found on individual items that externalised threatening behaviours decreased in community settings (Fortune et al. 1995) and internal self abuse behaviours also fell (Rose et al. 1993; Fortune et al. 1995).

As discussed earlier, the overall outcomes of smaller residential options are better than for larger ones and those in which there is a homogenous group, for example, only people with behaviours of concern. Moreover in smaller residences there were less controlling and restricting measures with less medication and more verbal, as opposed to physical, interventions. More research seems warranted on the link between the levels of behaviours of concern and the level and types of restrictions in place in the environment. This study would indicate that the two are linked, but this hypothesis is open to further testing given the strong links proposed by the data in this study.

The views of people with disabilities and family carers collected in this study have challenged us to reconsider the ways in which we all calculate the fitting adjustment between personal freedom and public good. From the point of view of project participants, professionals should not simply see each behaviour as a ‘behaviour of concern’ first.

Rather they should actively seek an explanation of behaviours as behaviours of protest or resistance. Their view is that at least two additional categories should be considered and dismissed before professionals identify the behaviour as being one of ‘concern’:

- Behaviours that are a response to environment, system or understandable in terms of human interaction
- Restrictions that are produced as a result of inaction, where rights and choices are not actively supported and pursued.

#### Recommendation

APOs should be prompted to meaningfully assess whether a behaviour is one of ‘protest’ or ‘resistance’ rather than of concern. The following equation provides a guideline to the Senior Practitioner about how this might work.

The approach is one which significantly relocates the emphasis of, and funding to, services away from behaviour and towards positive supports. This is easier said than done. Within disability services the concentration on behaviour and its change has been the dominant paradigm for 150 years, at least since the time of Seguin and other nineteenth century social reformers. The resultant dominant paradigm sought to mimic the pathway to a productive adult life experienced by the majority population who, from a pragmatic point of view, are educated and trained to move into the employment market. In terms of productive economic lives and the ‘good life’ the fact is that the approach has simply not produced these outcomes to a great enough degree. Moreover, the moves towards inclusion remain illusory, as many remain segregated from wider society and congregated amongst other people with disabilities throughout their lives.

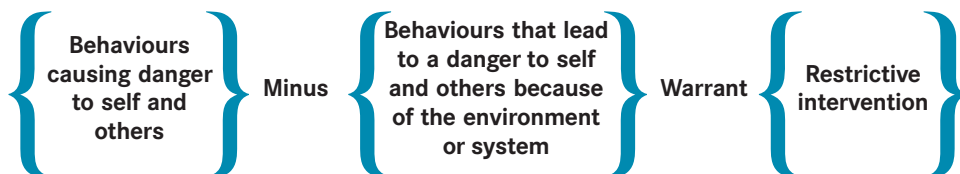
The latter point is not insignificant to this study. We spoke to family carers whose children were still at school and found that many of the points raised around adult services were equally applicable in the schools settings. A lifetime of recurrent restrictive practices is likely to significantly affect the person’s

self perception, their self esteem, their capacity for independent decision-making and choice, as well as to leave its mark. From a social learning perspective, unresolved problems from the past prevent the person moving forward and are thus hugely significant in their lives. Particularly for people with whom explanation and counselling are difficult, a history of perceived punishment is not a history that is, easily resolved. Joined up Government, that is, working across Government departments, is never easy but it seems important that DHS and the OSP, with their responsibility for adult services, make some contact with the education sector, and the Office for Disability to develop core values around rights and restrictions in schools, disability service and the wider community.

**Recommendation**

The OSP should work collaboratively with the Department of Education and Early Childhood Development and the office for Disability to develop core values based around a human rights approach that can be commonly applied in schools, communities and disability services around rights and restrictions.

A further issue is that ways of recognising and measuring the systemic, environmental and interactional factors that produce behaviours have not been codified sufficiently, making their identification and use rather difficult. This study has identified a significant number of such factors as re-rehearsed below:



The model is **vitaly important** for a further reason. Despite making a very strong case from the voice of people with disabilities, this report is **not** saying that **all** behaviours are a product of the environment or system or of the interactions with others.

What it is saying is that, by taking these into account, social justice can be better served for, at the heart of these arguments lies the importance of autonomy and personal choice and the primacy of support which responds to that agenda, that is to a **'positive support'** agenda. Simply by comparing the life circumstances of people with disabilities with others in society, we can see that the conditions in which they experience their lives are different. They tend to go to different schools, to do different things during the day, to live in groups, to have worse health care and to have less access to the community. In many respects they are simply 'in a different queue' to mainstream society. Since the conditions they experience differ so too does their response.

**Recommendation**

Additional research is required to identify, quantify and codify behaviours of protest and resistance so that they may be more easily used by those who need to understand the cause of much behaviour and reconstruct the evidence about what constitutes a least restrictive alternative by taking such factors into account.

# 5

## Conclusions

A qualitative study necessarily uses small numbers, but losses in the potential for generalisation are offset by several gains. We believe that the data from participants in this report helps us to understand how they view and understand services and the place of restrictions they experience in service settings. We believe that the data helps us to understand better what values people hold and how these values relate to their social actions, behaviours and responses in the environments they live, work and breathe. We believe that the data furnishes us with a view of causation which lays bare the route to emotional responses and behaviours, in ways not otherwise possible. Moreover, if a service system is to meet diverse needs, then our understanding must cover this diversity and not structure services around statistical models of central tendency alone. Whilst statistics have their place, *each and every* experience should be an important locus for the development of a responsive service. Finally, whilst some of the conclusions drawn have required the use of long chains of plausible inference, they do so no more than many other research methods and create a path to future research of both a qualitative and quantitative nature.

We believe we have demonstrated that many behaviours are adaptive responses to maladaptive environments. We believe, in this study, that we have demonstrated well the categories we have chosen to call behaviours of ‘resistance’ and ‘protest’ that respond to these environments. We believe that social justice is served by distinguishing between these categories from behaviours of concern in seeking to justify restrictions to personal freedoms. We believe the data indicate the necessity to find solutions that deal with fundamental differences in power between service providers and those who use the services and their allies. We believe the data strongly supports the need to have diverse strategies for advocacy and protection based on maximising choice and autonomy for diverse groups, and that solutions should be based on a positive support model.

We believe the data does all these things, though it is also the case that it has done so on small samples. In seeking to deepen our understanding it may be useful to extend the collection of data around the new concepts induced (cf. the grounded

theory, Glaser & Strauss 1976). But it is equally important to convert the ideas of ‘behaviours of resistance and concern’ into usable categories for practice. If the arguments in this study are accepted, this should be the next stage of research.

The solutions and recommendations proposed in this report are limited by the inventiveness of the authors in suggesting from a repertoire of available options those solutions which best fit the data. Needless to say that inventiveness would be even better served by wide-ranging consultations and discussions.

### Recommendation

If some of the central findings of this report are accepted by the Senior Practitioner, it is suggested that the range of potential solutions would benefit from further consultation with people with disabilities their advocates and allies, families and members of the service sector. To get people to work in unison necessitates that change is a product of consultation and participation and agreement. It is therefore suggested that this report be used as a basis for a consultation exercise to elaborate further some the potential solutions that exist.

Finally, it should be said that this report is based on a series of values. These values incorporate the important statements in the Quality Framework and associated standards published by DHS. However, as noted to be important in the Disability Act, they are also based upon the relevance of the human rights agenda and legislation to people with disabilities.

We hope that this report contributes to identifying and defining what J.S. Mill (see Introduction) describes as the elusive ‘fitting adjustment between individual independence and social control’ and to the Senior Practitioner’s aspiration to support people to achieve dignity without restraint. In doing so we propose that this adjustment has to be made on the grounds of human rights and social justice, and have provided some news lenses through which such justice can be recognised. Having exhausted all options around rights and social justice, the decision to restrict freedom cannot be taken lightly but, in some instances, it is a decision that has to



be taken. The price we pay for freedom requires that this sometimes be the case. However, by heeding the positive support approach and recommendations in this report, it is suggested that such cases will be substantially reduced and freedom for many of our fellow citizens with disabilities will result.

## References

- APRAIS (2005) *In the name of treatment: A parent's guide to protecting your child from the use of restraint*. Baltimore MD, APRAIS (The Alliance to Prevent Restraint, Aversive Interventions and Seclusion, Baltimore, MD.
- Beauchamp, T.L. & Childress, J.F. (2001) *Principles of Biomedical Ethics (5th ed)*. Oxford: Oxford University Press.
- Bigby, C. & Fyffe, C. (Eds) (2008) *Achieving their own lives: The implementation of individualised funding for people with intellectual disability*. Proceedings of the Third Annual Roundtable on Intellectual Disability Policy, Friday 24th October 2008.
- Bonner, G., Lowe, T., Rawcliffe, D. & Wellman, N. (2002) Trauma for all: A pilot study of the subjective experience of physical restraint for mental health inpatients and staff in the UK, *Journal of Psychiatric and Mental Health Nursing*, 9, (4) 465-473.
- Boyle, G. (2008) Autonomy in long term care: a need, a right or a luxury?, *Disability and Society*, 23, (4) 299-310.
- Conroy, J. W. (1995) The Hissom outcomes study: a report on six years of movement into supported living. *The well-being of people with developmental disabilities in Oklahoma* (Brief Outcome: no. 1). Ardmore, PA: Centre for Outcomes Analysis.
- Conroy, J. W., Lemanowicz, J. A., Feinstein, C. S., & Bernotsky, J. M. (1991) *1990 results of the CARC v. Thorne class members* (Report no. 7). Philadelphia: Temple University, Developmental Disability Centre.
- Cooper, B., & Picton, C. (2000). The long-term effects of relocation on people with an intellectual disability: Quality of life, behavior, and environment. *Research on Social Work Practice*, 10, (2) 195-208.
- Cunningham, J., McDonnell, A, Easton, S. & Sturmey, P. (2003) Social validation data on three methods of physical restraint: view of consumers, staff and students.
- Department of Human Services (2007) *The Quality Framework for Disability Services in Victoria: Better Services, Better Outcomes, Stronger Communities*. Melbourne: Disability Services, DHS.
- Department of Public Welfare (2006) Elimination of restraints through positive practices, *Mental Retardation Bulletin*. Pennsylvania: Commonwealth of Pennsylvania.
- Duperouzel, H., & Fish, R. (2007) Why couldn't I stop her? Self injury: the views of staff and clients in a medium secure unit. *British Journal of Learning Disabilities*, 36, 59-65.
- Dowson, S. and Whittaker, A. (1993) *On one side: The role of the advisor in supporting people with learning difficulties in self-advocacy groups*. London: Values into Action in association with the King's Fund.
- Duffy, S. (2005) Transforming the allocation of resources for care, *Journal of Integrated Care*, 13, (1) 1-11.
- Duffy, S., Waters, J., Hatton, C. & Lockwood, S. (2006) *Evidence on self-directed support. Submission to ODI of findings on economic sustainability*. Unidentified place: In Control.
- Egli, M., Feurer, I., Roper, T., & Thompson, T. (2002) The role of residential homelikeness in promoting community participation by adults with mental retardation. *Research in Developmental Disabilities*, 23, 179-190.
- Emerson, E. (2002) The prevalence of use of reactive management strategies in community-based services in the UK. In D. Allen (Ed.), *Ethical approaches to physical interventions* (pp. 15-28). Kidderminster: BILD.
- Emerson, E. (2004) Cluster housing for adults with intellectual disability. *Journal of Intellectual and Developmental Disability*, 29, (3) 187-197.
- Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., et al. (2001). The prevalence of challenging behaviors: A total population study. *Research in Developmental Disabilities*, 22, (1) 77-93.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Hillery, J. (2000) The treatment and management of challenging behaviours in residential settings. *Journal of Applied Research in Intellectual Disabilities*, 13, 197-215.
- Felce, D., Lowe, K., Perry, J., Baxter, H., Jones, E., Hallam, A., et al. (1998) Service support to people in Wales with severe intellectual disability and the most severe challenging behaviours: processes, outcomes and costs. *Journal of Intellectual Disability Research*, 42, (5) 390-408.
- Felce, D., Lowe, K., Beecham, J., & Hallam, A. (2000). Exploring the relationships between costs and quality of services for adults with severe intellectual disabilities and the most severe challenging behaviours in Wales: A multivariate regression analysis. *Journal of Intellectual & Developmental Disability*, 25, (4) 307-326
- Felce, D., Allen, D., Perry, J., & Meek, A. (in prep). Resettlement outcomes for people with severe challenging behaviour moving from institutional to community living. Cardiff, Wales: Welsh Centre for Learning Disabilities
- Finnegan, P. & Clarke, S. (2005) *One law for all: The Impact of the Human Rights Act on people with learning difficulties*. London: Values Into Action.
- Fish, R. & Culshaw, E. (2005) The last resort?: Staff and client perspectives on physical intervention. *Journal of Learning Disabilities*, 9, (2) 93-107.
- Fortune, J., Heinlein, K. B., & Fortune, B. (1995). Changing the shape of the service population. *European Journal of Mental Disability*, 2, (8) 20-37.
- Glaser, B. G & Strauss, A. L. (1967) *The discovery of Grounded Theory: Strategies for qualitative research*. Chicago: Aldine.
- Golding, L., Emerson, E., & Thornton, A. (2005). An evaluation of specialized community-based residential supports for people with challenging behaviour. *Journal of Intellectual Disabilities*, 9, (2) 145-154.
- Goodley, D. (1997) Locating self-advocacy in models of disability: Understanding disability in the support of self advocates with learning difficulties. *Disability and Society*, 12 (3) 367-79.
- Grant, G. & Ramcharan, P. (2007a) *Valuing People and research: The Learning Disability Research Initiative*. London: Department of Health.
- Grant, G. & Ramcharan, P. (2007b) *Valuing People and*

- research: *An easy words and picture report*. London: Department of Health.
- Harris, J. (1996) Physical restraint procedures for managing challenging behaviours presented by mentally retarded adults and children.
- Intellectual Disability Review Panel (IDRP) (2006) *Annual report of the IDRP for the year ending June 2006*. Melbourne: IDRP.
- Jones, P. & B. S. Kroese (2007) Service users' views of physical restraint procedures in secure settings for people with learning disabilities. *British Journal of Learning Disabilities*, 35, (1) 50.
- Lambrechts, G., Petry, K. & Maes, B. (2008) Staff variables that influence responses to challenging behaviour of clients with an intellectual disability: A review. *Education and Training in Developmental Disabilities*, 43, (4) 454-473.
- LDG Group (2007) *Evaluation of the Direct Payments Project: Final Report*. Melbourne: Community and Individual Support Group, Disability Services, Department of Human Services
- Lowe, K., Felce, D., Perry, J., Baxter, H., & Jones, E. (1998) The characteristics and residential situations of people with severe intellectual disability and the most severe challenging behaviour in Wales. *Journal of Intellectual Disability Research*, 42, (5) 375-389.
- Lukes, S. (1974). *Power: A Multi-dimensional View*. London: Macmillan.
- Mansell, J. (1994) Specialized group homes for persons with severe or profound mental retardation and serious problem behaviour in England. *Research in Developmental Disabilities*, 15(5), 371-388.
- Mill, J. S. (1999) *On Liberty*. Peterborough, Canada: Broadview Press, (original published 1859).
- McVilly, K. (2008). *Physical restraint in disability services: current practices; contemporary concerns and future directions*. A report commissioned by the Office of the Senior Practitioner, Department of Human Services, Victoria, Australia.
- Nunno, M. A., Holden, M. J., & Tollar, A. (2006). Learning from tragedy: A survey of child and adolescent restraint fatalities. *Child Abuse & Neglect*, 30, 1333-1342.
- O'Brien, J. (1991) Against pain as a tool in professional work on people with severe disabilities. *Disability, Handicap and Society*, 6, (2) 81-90.
- Office of the Senior Practitioner (2007) *From Seclusion to Solution*. Melbourne: Department of Human Services.
- Office of the Senior Practitioner (2008) *Supporting people to achieve dignity without restraint*. Melbourne: Department of Human Services.
- Office of the Senior Practitioner (2008b) *Annual Report 2007/8*. Melbourne: Department of Human Services.
- Paterson, B., Bradley, P., Stark, C., Saddler, D., Leadbetter, D., & Allen, D. (2003) Deaths associated with restraint use in health and social care in the UK. The results of a preliminary survey. *Journal of Psychiatric and Mental Health Nursing*, 10, (1) 3-15.
- Peter, D. (1999) The Client Role: a help or a hindrance? *Disability and Society*, 14, (6) 805-818.
- Ragneskog, H., Gerdner, L.A., Josefsson, K. & Kihlgren, M. (1998) Probable reasons for expressed agitation in people with dementia. *Clinical Nursing Research*, 7, (2), 189-206.
- Ramcharan, P., Robertson, A., Strong, R. & Nankervis, K. (2009) *Restrictive practices in the lives of people with disabilities*. Melbourne: RMIT.
- Ray, N.K., Myers, K.J. & Rappoport, M.E. (1996) Patient perspective on restraint and seclusion experiences: a survey of former patients of New York State psychiatric facilities. *Psychiatric Rehabilitation Journal*, 20, (1) 11-18.
- Robertson, J., Emerson, E., Hatton, C., Elliott, J, MacIntosh, B., Swift, P., Krijnen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., & Joyce, T. (2005a) *The impact of Person Centred Planning*. Lancaster: The Institute for Health Research.
- Robertson, J., Emerson, E., Hatton, C., Gregory, N., Kessissoglou, S., Hallam, A., et al. (2001) Environmental opportunities and supports for exercising self-determination in community-based residential settings. *Research in Developmental Disabilities*, 22, (6) 487-502
- Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D., Meek, A., et al. (2005b) Treatment and management of challenging behaviours in congregate and noncongregate community-based supported accommodation. *Journal of Intellectual Disability Research*, 49, (1) 63-72.
- Robins, C.S., Sauvageot, J.A., Cusack, K.J., Suffoletta-Maierle, Frueh, B.C. (2005) Consumers' perceptions of negative experiences and "sanctuary harm" in psychiatric settings. *Psychiatric Services*, 56, (9) 1134-1139.
- Rose, K. C., White, J. A., Conroy, J., & Smith, D. M. (1993). Following the course of a change: a study of adaptive and maladaptive behaviours in young adults living in the community. *Education and Training in Mental Retardation*, 28(2), 149-154.
- Sequeira, H. & Halstead, S. (2001) 'Is it meant to hurt , Is it?' Management of violence in women with Developmental disabilities. *Violence Against Women*, 7, (4) 462-276.
- Sequeira, H. & Halstead, S. (2002) Control and restraint in the UK: Service User Perspectives. *The Journal of Forensic Practice*, 4, (1) 9-18.
- Sigafoos, J., Arthur, M., & O'Reilly, M. (2003) *Challenging behaviour and developmental disability*. London: Whurr.
- Singh, N. N., Lancioni, G. E., Winton, A. S., Curtis, W. J., Wahler, R. G., Sabaawi, M., et al. (2006) Mindful staff increase learning and reduce aggression in adults with developmental disabilities. *Research in Developmental Disabilities*, 27, (5) 545-558.
- Sloane, P.D., Mitchell, C.M, Preiser, J.S., Phillipps, C., Commander, C., & Burkner, E. (1998) Environmental correlates of resident agitation in Alzheimer's disease, Special Care Units, *Journal of the American Geriatrics Society*, 46, (7) 862-869.
- Smith, G. M., Davis, R. H., Bixler, E. O., Lin, H.-M., Altener, A., Altener, R. J., et al. (2005) Pennsylvania State Hospital

- system's seclusion and restraint reduction program. *Psychiatric Services*, 56, (9) 1115-1122.
- Smull, M. W. & Burke Harrison, S. (1992) *Supporting people with severe reputations in the community*. Alexandria, VA: National Association of State Mental Retardation Program Directors.
- Stancliffe, R. J., Hayden, M. F., Larson, S. A., & Lakin, K. C. (2002) Longitudinal study on the adaptive and challenging behaviors of deinstitutionalized adults with mental retardation. *American Journal on Mental Retardation*, 107, (4) 302-320.
- Thompson, T., Robinson, J., Dietrich, M., Farris, M., & Sinclair, V. (1996) Interdependence of architectural features and program variables in community residences for people with mental retardation. *American Journal on Mental Retardation*, 101, (3) 315-327.
- United Nations (2006) UN Convention on the Rights of Persons with Disabilities. New York: United Nations.
- UN General Assembly (2008) *Torture and other cruel, inhuman or degrading treatment or punishment. Note by the Secretary General*. Promotion and Protection of Human Rights Instruments. New York: UN.
- Victorian Charter of Human Rights and Responsibilities Act (2006) VIC, Act No. 43/2006
- Ward, T. & Stewart, C. (2008) Putting human rights into practice with people with intellectual disability, *Journal of Developmental and Physical Disabilities*, 20, (3) 297-311.
- Whittell, B. & Ramcharan, P. (1998) The All Wales Strategy, Self advocacy and participation. *British Journal of Learning Disabilities*, 20, (1) 23-26
- Young, L. (2006) Community and cluster centre residential services for adults with intellectual disability: long-term results from an Australian-matched sample. *Journal of Intellectual Disability Research*, 50, (6) 419-431.







