

**REPORT**

**TO**

**HONOURABLE WARREN PITT M.P.**  
**MINISTER FOR COMMUNITIES DISABILITY SERVICES AND SENIORS**

**CHALLENGING BEHAVIOUR**

**AND**

**DISABILITY**

**A TARGETED RESPONSE**

**Hon W.J. Carter Q.C..... July 2006**

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# TERMS OF REFERENCE

## **Terms of Reference for Development of Options to Provide a Targeted Service Response for Adults with Intellectual/Cognitive Disability and Who Exhibit Severely Challenging Behaviour**

*Intellectual disability* is defined as a person with a score of approximately two standard deviations below the mean on an individually administered intelligence test and displaying a lack of competency in at least two of the following skill areas before the age of 18 years: communication; self-care; home living social/interpersonal skills; use of community resources; self-direction; functional academic skills; work; leisure; or health and safety.

*Cognitive impairment* is described as a delay, reduction or abnormality of cognitive functions such as learning, reasoning, memory, problem solving, decision-making, organisation, perception, intellect and/or attention. It is likely to be experienced by people with a disability with diagnoses such as autism or other pervasive developmental disorders or acquired brain injury.

*Challenging behaviour* is defined as culturally abnormal behaviour/s of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.

A small group of adults with an intellectual/cognitive disability exhibit *severely challenging behaviour* that represents a *significant risk of harm to themselves, others or the community*. People who exhibit this severely challenging behaviour require intensive support and management. It is desirable to examine options for provision of this intensive support and management. This examination is based on the principle of ensuring the rights of the cohort are uppermost and protected, and guide the range of response options.

Accordingly, Bill Carter QC and the Directors-General of Communities and Disability Services Queensland and of the Department of Housing as Co-Chairs (the Panel) are requested to:

- review existing provisions for the care, support and accommodation of people with an intellectual/cognitive disability who represent a significant risk of harm to themselves or the community;
- by way of written report on the review provided to the Minister for Communities, Disability Services and Seniors, develop options and make recommendations on legislative framework and service requirements for the provision of both voluntary and involuntary care to the cohort;
- by way of interim advice as considered appropriate or necessary by the Panel, detail any response that may be implemented under the current legislative framework if and when a response is identified during the investigation; and
- identify where restrictive practices are currently used and the problems that these may pose.

In examining options, Panel should have regard to:

- the human rights principle within section 9 of the *Disability Services Act 1992* (Qld) and the proposed Part 2 of the *Disability Services Bill 2005* (Qld);

- Australia’s international human rights obligations;
- recognition that, while some members of the cohort may be well-supported in a community-based environment, others may need a more structured and protective service response best delivered in a secure environment; and
- inclusion of the following key features:
  - a legal framework integrating legal principles, and safeguards, and support models for the cohort;
  - capability to provide care and support in a secure environment
  - a list of principles and objectives under which compulsory treatment is to be provided;
  - the process for approving a facility where compulsory treatment can occur;
  - professional assessments, including psychological and psychiatric assessments, of the individual;
  - recommendations concerning appropriate support or treatment (including appropriate accommodation);
  - authorisation of recommended restrictive practices, including definitions of restraint and seclusion, the situations in which it can be applied, and relevant reporting requirements;
  - monitoring of implementation and use of restrictive practices or “secure” accommodation;
  - review of original authorisation to ascertain the continued need;
  - rights of review of decisions where authorisation is disputed; and
  - a process for transferring people with a sole diagnosis of intellectual/cognitive disability currently ordered by the Mental Health Court to be detained in an authorised mental health service into the support options in appropriate cases.

In providing the reports, consideration is also to be given to structural and systems options, current or proposed, in other jurisdictions, in particular Victoria and New Zealand, as well as the need for the options to be robust in their legality but discrete in their application. Also, the options may be either mutually exclusive or inter-related.

Options generated do not need to provide specific service specifications or financial modelling as to implementation or on-going costs associated with the model.

The Investigation is not to involve public hearings. To inform the investigations and any options, Bill Carter QC and the Co-Chairs must consult with and may receive written submissions from key stakeholders.

The Panel is to note the Minister is required to report back to Government on the investigation within 12 months.

## **ABBREVIATIONS**

<b>No.</b>	<b>Abbreviation</b>	<b>Name</b>
1	AG	Adult Guardian
2	AQ	Autism Queensland
3	ASD	Autism Spectrum Disorder
4	AS&RS	Accommodation Support and Respite Service
5	BSC	Basil Stafford Site
6	BYDC	Brisbane Youth Detention Centre
7	CC	Challinor Centre
8	CJC	Criminal Justice Commission
9	CMC	Crime Misconduct Commission
10	CSTDA	Commonwealth State/Territory Disability Agreement 2002-2007
11	CYFOS	Child and Youth Forensic Outreach
12	DChS	Department of Child Safety
13	DSA1992	Disability Services Act 1992
14	DSA2006	Disability Services Act 2006
15	DSQ	Disability Services Queensland
16	DVO	Domestic Violence Order
17	DFYCC	Department Families Youth and Community Care
18	GAAT	Guardianship and Administration Tribunal
19	IBST	Intensive Behaviour Support Team
20	IS&H	Innovative Support and Housing
21	MHA	Mental Health Act 2000
22	MHU	Mental Health Unit
23	NGO	Non Government Organisation
24	QH	Queensland Health
25	QPS	Queensland Police Service
26	QCIDD	Queensland Centre for Intellectual Disability Disorder
27	RCO	Residential Care Officer
28	SAS&RS	Specialist Accommodation Support and Respite Service
29	VLRC	Victorian Law Reform Commission

## **ACKNOWLEDGEMENTS**

The completion of this work and the Report would not have been possible in the time (14 April -31 July 2006) without the support, encouragement and assistance of many people.

My initial written request to many sector organisations, government agencies, non-government organisations and public officials to make submissions was enthusiastically accepted and prompted a string of other responses from relevant bodies and individuals who wished to contribute to this work. In particular I wish to acknowledge the many parents who shared with me their family life with one who has intellectual disability / cognitive impairment and whose behaviour must have been for them at times a very challenging experience.

To all of those who in any way made a contribution I express my sincere thanks and gratitude.

Closer to home I thank the many DSQ personnel who assisted, supported and encouraged me. In particular I especially thank my colleagues Ms Linda Apelt, Director-General DSQ and Ms Natalie McDonald, Director-General Department of Housing.

Finally I thank Ms Kelly Weekley and Mr Simon Grant of DSQ who were assigned to assist me and to respond to my many requests for assistance. They did much more than that. I was able to draw upon their significant professional skills whenever necessary. Regular consultation with them was invariably to my advantage.

Ms Kathy Totham willingly and in good spirits assumed the almost impossible task of reading many pages of handwritten material and converting it into this Report.

To all, my sincere thanks.

Hon. W.J. Carter QC  
31 July 2006.

## **EXECUTIVE SUMMARY**

The progressive deinstitutionalisation of the intellectual disability sector in Queensland which commenced in the late 1970's was effectively completed in the mid to late 1990's. Challenging behaviour was a feature of institutional life. Information now available from one respected source establishes that in 1989 70% of residents at Basil Stafford Centre and 54% of residents at Challinor Centre exhibited various forms of challenging behaviour.

The literature clearly supports the view that the transition from institutional to community living relieved to some extent the incidence of challenging behaviour but it remains a matter of considerable concern to those engaged in service delivery, including families and government and non government service providers and carers. Such behaviours can constitute a serious risk of injury to the person the subject of the disability, those with whom the person lives and those with responsibility for the care of persons with intellectual disability.

The *Disability Services Act* 1992 and the recently enacted *Disability Services Act* 2006 require that disability services should be delivered to persons with a disability in accordance with the human rights and service delivery principles set out in the Act.

Challenging behaviour which is exhibited not only by persons with intellectual disability but also by those with mental illness and in some cases with physical disability not only may put at the risk of injury the particular person and others but also it potentially deprives the person of access to the community and in some cases denies that person the opportunity to engage in the normal affairs of community living. It is therefore a matter of considerable significance. It needs to be addressed in a way which enhances the prospects of the person's personal development and enhances that individual's opportunity to establish a quality life. Services and service delivery should be designed and implemented to achieve that objective.

In 1977 the Intellectual Handicapped Services Branch was created in the Department of Health and in 1989 it was incorporated into the Department of Families. The first Disability Services Act was enacted in 1992 and Disability Services Queensland (DSQ) as a separate department was established in 1999.

Since 1989 the various agencies concerned with Intellectual Disability attempted to systematically address the issues of concern in relation to challenging behaviour; by the Intellectual Handicapped Services Branch/Division in 1989; during the early/mid 1990's by the establishment of behaviour support teams and more recently by the Intensive Behaviour Support Teams (IBSTs); in 1997/8 by Queensland Health (QH) and in 2001/3 by the Ipswich Regional Office in DSQ in association with professionals at The Park Mental Health Service at Wacol. For a variety of reasons none of these initiatives succeeded in establishing a systemic service modality which was effectively responsive to the needs of the many persons who demonstrated challenging behaviour some of whom presented as a serious risk to themselves and to others. The Ipswich initiative 2001-2003 was a professionally generated attempt to develop an interagency and collaborative model which would be effective and responsive to the needs of the particular client group in the region. It terminated in December 2003 as a result of a decision in DSQ which was said to have been based on the lack of allocated resources and funding, the fact that the proposal fell outside the priorities determined by the DSQ Business Plan 2003, that the Innovative Support and Housing Project was considered to be the major project for this cohort and that the development of a proposal at The Park Mental Health Service was in conflict with DSQ's commitment to community based services.

There are lessons to be learned from these earlier initiatives and the development of the proposals in this Report have been greatly assisted by the contributions made earlier by the persons who were committed to seriously attempting the preferred solutions to what has to be considered a major concern in the delivery of human services.

Current service delivery in relation to this problematic issue is largely crisis driven. A family may have suffered “burn out” or have reached the point at which family care was no longer viable; an escalating episode of disturbed behaviour may have proved to be beyond a service provider’s capacity to manage; contact with the criminal justice system in one way or another may have been the precursor for required intervention by DSQ. Most, if not all of these cases end up with DSQ. Crisis management, invariably stressful and inevitably expensive not uncommonly has been marked by a perceived lack of interdepartmental co-operation and an insistence on bureaucratic “gatekeeping”. Although in numerous cases the relevant disability and the challenging behaviour emerged in infancy/childhood a lack of early intervention and ongoing effective and relevant interventions by a variety of government agencies has demonstrated the urgent need for a whole of government approach to this issue characterised by inter departmental/agency collaboration in the best interests of the individual person. These problems are compounded by a lack of emergency and other suitable accommodation and a serious shortage of suitable experienced and well trained professionally developed professional and residential carers. Recently developed Innovative Support and Housing models have been ineffective in responding to the problems arising from challenging behaviour. The Mental Health Court in respect of those members of the cohort who are the subject of investigation by the Court in relation to fitness to plead and unsoundness of mind issues is seriously concerned at the lack of capacity in DSQ to appropriately house such persons who have intellectual disability but not a mental illness.

The present crisis driven culture which is essentially reactive and which now heavily infests the present DSQ experience is unsustainable. It has to be replaced by a professionally driven proactive service modality which will reflect world best practice and which by means of appropriate interventions and support mechanisms in the community can provide for the person with intellectual disability the real opportunity of living in the community, exercising his/her human rights appropriately and so ensuring that the conditions of everyday life for the person are the same as, or as close as possible to the conditions of everyday life valued by the general community.

***What is proposed involves a fundamental process of reform, renewal and regeneration of the DSQ and disability sector’s response, which will provide an efficient, cost effective and financially sustainable outcome for the proper care and support of persons with intellectual disability and challenging behaviour across Queensland. Its adoption and development by DSQ will have the capacity to place DSQ and the Queensland sector in a position of leadership, both nationally and internationally, in ensuring the proper support and care for such persons.***

***Based on the evidence of best practice, the published research literature and the consultation with experienced persons in the intellectual disability sector both persons within DSQ and respected persons outside of the Department and overseas, I state my strong view that a targeted service response for the proper care and support of the persons within the cohort must reflect unambiguously the following operational principles which must be regarded as being of basic and fundamental importance:***

- ***An individualised and flexible approach which provides for and specifically addresses the person's specific needs and the circumstances of the individual case is the unequivocal key element in the proper care and support for the person with intellectual disability and challenging behaviour;***
- ***A co-ordinated and cooperative working relationship between DSQ and QH to the extent that a comprehensive multi-disciplinary assessment of the individual person requires both general health and psychiatric assessments.***
- ***A comprehensive multi-disciplinary assessment process in respect of the particular person with a view to the development of an individualised positive behaviour support plan for that person.***
- ***An ongoing effective interaction between the assessment process and the intervention process within the community which will require co-ordination and individualised plan management at regional level so as to ensure the effective maintenance and integrity of the total process in the best interests of the individual person;***
- ***This process of assessment, intervention and coordination and individual plan management will operate collaboratively across the whole sector and will be available to and accessible by both DSQ and NGO service providers;***
- ***The incorporation of the above into a Queensland Centre for Best Practice in Positive Behaviour Support under the leadership and management of a high profile and highly regarded practitioner supported by a suitably qualified Reference Group. The Leader should have an academic appointment;***
- ***The Centre for Best Practice will develop as a Centre of Excellence in ensuring the proper care and support of persons with intellectual disability and challenging behaviour. It will also develop as a valuable research facility and itself become a valued research resource. Its role will include community development and education. Its functions are set out more fully in this Report;***
- ***The immediate establishment of suitable accommodation to enable an immediate and effective response in those cases which require emergency management;***
- ***The urgent and planned development of a range of accommodation options which respond to the need for secure care, transitional accommodation arrangements and community living for the target group;***
- ***The recruitment and development of suitably qualified allied health and other support staff specifically for persons with intellectual disability and challenging behaviour and ensuring their ongoing training and professional development;***
- ***The incorporation of the Centre into and as a distinct specialist segment within DSQ;***

- ***A legislative framework which will ensure that the use of any restrictive practice in the case of a person with intellectual disability and challenging behaviour is independently approved and properly regulated and which will provide adequate legislative support as required.***

The functions of the Queensland Centre for Positive Behaviour Support are:-

- **to advise on, develop and ensure the maintenance across Queensland of consistent and best practice service options for all persons with intellectual disability and challenging behaviour which expressly apply the human rights and service delivery principles expressed in the *Disability Services Act 2006*.**
- **to facilitate the establishment, maintenance and ongoing review of a system of Positive Behaviour Support for persons with intellectual disability and challenging behaviour, which is based on comprehensive assessment and targeted individualised intervention in the community and the plan management and coordination of those services.**
- **to continually monitor and review the quality of service delivery across Queensland to persons with intellectual disability and challenging behaviour.**
- **to liaise with and develop a positive working relationship with the relevant professional bodies engaged in the delivery of services to persons with intellectual disability and behavioural issues, such as, the College of Psychiatrists, the College of General Practitioners, the Australian Psychological Society and other like bodies such as QCIDD.**
- **to develop and maintain the required early intervention strategies in respect of young children with intellectual disability and challenging behaviours and to ensure and maintain as a permanent ongoing feature of service delivery a continuum of care and positive behaviour support for this client group through increasing maturity and teenage years and young adulthood and for that purpose to coordinate government, non-government, relevant community agencies and professional bodies in responding to the individual needs of young persons in this group.**
- **to develop as a professional research resource to the disability sector in Queensland and to government and for that purpose to develop a research facility which will monitor best practice nationally and internationally and ensure that the details and all relevant data in respect of the Queensland experience is collected and retained.**
- **to do what is necessary to ensure that suitably educated and skilled professionally developed expertise is available to efficiently service the individual needs of person with intellectual disability and challenging behaviour in Queensland and for that purpose to liaise with and develop a professional working relationship with (a particular tertiary academic institution).**
- **to develop and provide the relevant professional development and expert training for those who will work in the disability sector specifically as day to day professionals, carers and support personnel for those persons in Queensland with intellectual disability and challenging behaviour.**

- to liaise with all relevant government departments and agencies, NGO service providers and disability peak bodies in the community with a view to establishing a whole of government and sector response and the effective collaboration and cooperation of all bodies concerned in any respect with the well being and development of those in Queensland with intellectual disability and challenging behaviour.
- to develop as a valued community resource which can provide professional advice to any person, agency or government department which is concerned with the needs of any person in Queensland with intellectual disability and challenging behaviour.
- to provide a system of information sharing with and advice to the community generally and ensure that the community is better informed in relation to issues concerning persons with intellectual disability and challenging behaviours.

The Centre has been designed to provide a systemic, specialised and focussed response to challenging behaviour whether that behaviour is sourced to intellectual or cognitive disability, Autism Spectrum Disorder, Acquired Brain Injury or physical disability, all of which are included in the definition of “disability” in the *Disability Services Act 2006*.

**This proposal has been constructed in response to the perceived need to lift this multi-faceted and troublesome issue out of its vague and presently ill defined regional/departmental location into a specialised area of interest requiring a special focus and a specialised response.**

The Leader of the Centre should be a high profile practitioner with a national / international reputation and based on the QCIDD Model it should also have a university appointment. The key role of the Centre will be to monitor, resource and professionally inform service delivery, to undertake and to provide to government and the whole of the sector quality applied research and advice and to ensure best practice. Another key role is to establish close liaison with the relevant university faculties and schools so as to ensure that learning is relevant and that under graduate and post graduate students are introduced to and are well equipped to resource the disability sector. The vocational training of graduates in behavioural issues as well as direct care givers through the Centre will ensure that those whose daily task it is to provide quality service to clients are best equipped to support the daily life of persons with intellectual disability. The multi disciplinary roles of the Centre require that it be the creative thinker, innovator and facilitator of best practice to the whole of the disability sector. Then policy development at every level will not only be truly professional and relevant, one can rest assured that the whole sector and government will be properly resourced and supported in providing a service of excellence. Because of its specialist role the Centre should be led by one who is closely affiliated with the University/academic sources of applied learning. The Centre’s training brief in respect of the sector’s professional and direct care staff will then also be executed at the required level of excellence.

Whilst the Centre will not itself engage in service delivery it will be the driver of quality service delivery across the sector by constantly monitoring and reviewing service delivery and resource the sector with the product of applied research from national / international sources.

The key initiative will be a process of comprehensive individualised assessment by a multi disciplinary team in association with the person, parents/guardian and carers and the development of an individual Positive Behaviour Support Plan. The execution of the Plan will be the subject of targeted interventions in the daily life of the person in the community. In the regions those processes will be the subject of constant monitoring, coordination and plan management by a dedicated officer who will report to the Regional Director and also to the Centre Leader.

The delivery of quality Positive Behaviour Support requires not only quality and well trained staff but needs to be made available in the preferred environment. That is why there is a need to ensure that the accommodation support is of such a kind as to maximise the prospects for enhanced development of the person.

In terms of accommodation there is an urgent need for housing those who are often the subject of crisis and who are unable to return to their prior accommodation. The major facility should be developed at the Basil Stafford site as part of a total redevelopment of that area. Emergency accommodation should be conveniently available so as to ensure ready assessment of the person the subject of the crisis. Smaller facilities may also be available at other places such as Townsville and Maryborough.

There is a small minority of persons who may require secure care because of the nature and extent of the disturbed behaviour and the fact that it can create the serious risk of injury or harm not only to the person but also to others, including persons in the community. For that purpose the current "Purpose Designed Housing" project intended for the Basil Stafford site should be expanded and reviewed in terms of its design so as to ensure the availability of secure care with a varied level of security available to satisfy the circumstances of the several cases as they arise. In this context DSQ should as soon as possible be in a position to respond to the requirements of the Mental Health Court which has the jurisdiction to make a forensic order in respect of a person with intellectual disability only who has committed an indictable offence. The present power of the Court is limited to ordering that that person be detained in a mental health service which objectively and in the mind of the Court is a totally unacceptable outcome.

The provision of appropriate accommodation for such persons is urgent. Not only will that course assist judicial decision making it will also ensure the availability to that person of the service regime recommended by this Report namely comprehensive assessment, the development of an individualised positive behaviour support plan and intervention strategies developed to ensure as far as possible to personal development of the individual. This form of specialist accommodation will also assist bail decision making in the Magistrates Court.

The Innovative Support and Housing Model should be retained and developed but only after close review of its operation so far which is on any objective assessment less than optimal. The views of Emerson, Clapton, Stanhope and McVilly expressed in November/December 2003 should be revisited before any further development is undertaken and in reviewing the operation of the project consideration should be given to its design, entry and exit criteria and the level of professional behavioural support required to sustain it as part of a continuum of care and support for those with intellectual disability and challenging behaviour.

In respect of community accommodation close regard should be had to the research which strongly suggests that large or clustered accommodation facilities are more likely to be counter productive in addressing behavioural issues and that greater emphasis be given to more dispersed, smaller and more intimate design which provides separate and private space at the same time providing the capacity for social

interaction as the individual desires. The provision of Community Access is in need of urgent review and the work of some NGO's in this respect can provide a useful template.

The implementation of the various proposals recommended in this Report will be a major undertaking. It has to be emphasised that the various proposals are essentially systemic and integrated and together constituted an holistic response. At the same time it is understood that their implementation will need to be phased in, if accepted. However, in the longer term a much more cost effective system can be expected.

The central and dominant strategy is the establishment of the Centre for Best Practice in Positive Behaviour Support. Its key function is to drive service delivery, innovative and creative thinking, best practice, critical analysis and the pursuit of continual improvement and excellence. Its detailed design and resource requirements is of fundamental relevance. Chapter 6 asserts that the development of the Centre, the appointment of the Centre Leader and the development of its infrastructure, which will be essentially specialist, is a matter of priority. This and the other urgent requirements are identified in Chapter 6 under the heading Phase 1. Obviously there are priorities and in terms of relative importance, some perceived variations. This however should not distract from the integrity of the whole.

The Centre should be located away from the Basil Stafford site and away from any DSQ departmental infrastructure. The Report suggests an appropriate location would be near a city office precinct in which it can itself develop its core specialist roles.

Because the report emphasises the need for reform, renewal and regeneration of effort in the provision of services to those with intellectual disability/cognitive impairment and because this requires a specialist and integral response it is clear that an examination of the existing DSQ infrastructure suggests the need for review. The strategic innovative creative role which the Centre for Best Practice must pursue unambiguously requires its separation from service delivery and related issues. Again the service delivery components of the Model should be delivered in close contact with the relevant persons in the community where they will be living. This emphasises a special role for Regional Management in association with the need for coordination and plan/case management by the Best Practice Broker/"Trouble Shooter" who will report to the Centre Leader and the Regional Manager. The Report in Chapter 6 identifies the principles which govern the development of the preferred departmental design which can more effectively respond to the needs of persons with intellectual disability and challenging behaviours. A more efficient structural arrangement will ensure a more efficient and professional response.

A new legislative framework is required for those cases where in the development of a positive behaviour support plan for the individual person following comprehensive assessment and the identification of the necessary intervention strategies, there is the need to make use as required of any restrictive practice.

"Restrictive Practices" will be defined to include detention, chemical and mechanical constraint, physical constraint and seclusion. The same legislative scheme will apply in relation to any defined restrictive practice. The principles which are fundamental to the legislative scheme are:-

- 1. The human rights and service delivery principles set out in part 2 Divisions 1 and 2 of the Disability Services Act 2006 are to be applied expressly to the extent that the same are relevant to this issue.**
- 2. Since the legislative focus is on the development of the individual person, and the services to be delivered have to be designed and**

**implemented for the purpose of developing the individual and enhancing the person's opportunity for a quality life, restrictive practices can only be justified as part of a specific individualised positive behaviour support plan which will be of benefit to the individual and which will assist in the achievement of that objective.**

- 3. Any such plan for the care and support of the individual person must be developed by the appropriate specialists in association with the individual and where necessary his/her parent or guardian.**
- 4. Approval for such a plan, if it contains provisions for the use of restrictive practices must be given by an independent body consisting of persons with the requisite skill, knowledge and/or experience and such approval shall operate only for a limited time, at which time it shall be reviewed and the continuance or otherwise of the restrictive practice considered anew in the light of the material to be provided to the independent body. (GAAT)**
- 5. Whilst the approval remains in operation, the use of the approved restrictive practice(s) shall be monitored by an independent person(s) who shall report to the independent body upon each review. (Community Visitor Program)**
- 6. That the use of restrictive practices be prohibited except as approved by GAAT in accordance with the above.**

The obvious and preferred location for the legislative provisions is in the Disability Services Act 2006. Since there must necessarily be a lapse of time before the legislative provisions can become operative there is a need to address concerns which arise because of the status quo. The required lapse of time is occasioned by the close interaction between the permissible use of a restrictive practice and the development of a positive behaviour support plan consequential upon multi disciplinary assessment and the fact that the latter process is related to the development of the Centre for Best Practice which will take time to develop.

There is a concern that across the sector there has been an historical resort to the use of restrictive practices which have been seen as a necessary intervention in the perceived best interests of the person and of others including members of the general community. This use of restrictive practices has not to date had any legislative support and accordingly exposes both family members and direct care givers and service providers to allegations of acting unlawfully. Given that the long term legislative scheme will have as its core feature a prohibition on the use of any restrictive practice unless its use is independently approved by the Guardianship and Administration Tribunal (GAAT) as part of a Positive Behaviour Support Plan, there must necessarily be a change in service delivery culture. There is therefore a strong case for the introduction of such a scheme to be postponed which will present the opportunity for a process of community education and the adjustment of historical practices.

In the interim the legislation will provide defences to the offences of assault (Sections 245, 246 of the Criminal Code) and unlawful deprivation of liberty (Section 355 of the Criminal Code) if the use of a restrictive practice in the delivery of disability services as defined by *Disability Services Act 2006* is reasonably necessary to protect the person with a disability or any other person from the risk of injury or harm.

In the event that the Honourable the Minister for Health is agreeable this Report recommends amendments to the *Mental Health Act 2000* to address the concerns expressed by others including the Mental Health Court, in relation to the making of forensic orders in the case of the person with intellectual disability but who is not mentally ill.

## **RECOMMENDATIONS**

### **A. Core Recommendations**

1. That a targeted service response for the proper care and support of the persons in Queensland with intellectual disability / cognitive impairment and challenging behaviour must reflect unambiguously the following operational principles which must be regarded as being of basic and fundamental importance.
  - ***An individualised and flexible approach which provides for and specifically addresses the person's specific needs and the circumstances of the individual case is the unequivocal key element in the proper care and support for the person with intellectual disability and challenging behaviour;***
  - ***A co-ordinated and cooperative working relationship between DSQ and QH to the extent that a comprehensive multi-disciplinary assessment of the individual person requires both general health and psychiatric assessments.***
  - ***A comprehensive multi-disciplinary assessment process in respect of the particular person with a view to the development of an individualised positive behaviour support plan for that person.***
  - ***An ongoing effective interaction between the assessment process and the intervention process within the community which will require co-ordination and individualised plan management at regional level so as to ensure the effective maintenance and integrity of the total process in the best interests of the individual person;***
  - ***This process of assessment, intervention and coordination and individual plan management will operate collaboratively across the whole sector and will be available to and accessible by both DSQ and NGO service providers;***
  - ***The incorporation of the above into a Queensland Centre for Best Practice in Positive Behaviour Support under the leadership and management of a high profile and highly regarded practitioner supported by a suitably qualified Reference Group. The Leader should have an academic appointment;***
  - ***The Centre for Best Practice will develop as a Centre of Excellence in ensuring the proper care and support of persons with intellectual disability and challenging behaviour. It will also develop as a valuable research facility and itself become a valued research resource. Its role will include community development and education. Its functions are set out more fully in this Report;***
  - ***The immediate establishment of suitable accommodation to enable an immediate and effective response in those cases which require emergency management;***
  - ***The urgent and planned development of a range of accommodation options which respond to the need for secure care, transitional accommodation arrangements and community living for the target group;***

- *The recruitment and development of suitably qualified allied health and other support staff specifically for persons with intellectual disability and challenging behaviour and ensuring their ongoing training and professional development;*
  - *The incorporation of the Centre into and as a distinct specialist segment within DSQ;*
  - *A legislative framework which will ensure that the use of any restrictive practice in the case of a person with intellectual disability and challenging behaviour is independently approved and properly regulated and which will provide adequate legislative support as required.*
2. That the functions of The Queensland Centre in Positive Behaviour Support shall be:-
- to advise on, develop and ensure the maintenance across Queensland of consistent and best practice service options for all persons with intellectual disability and challenging behaviour which expressly apply the human rights and service delivery principles expressed in the *Disability Services Act 2006*.
  - to facilitate the establishment, maintenance and ongoing review of a system of Positive Behaviour Support for persons with intellectual disability and challenging behaviour, which is based on comprehensive assessment and targeted individualised intervention in the community and the plan management and coordination of those services.
  - to continually monitor and review the quality of service delivery across Queensland to persons with intellectual disability and challenging behaviour.
  - to liaise with and develop a positive working relationship with the relevant professional bodies engaged in the delivery of services to persons with intellectual disability and behavioural issues, such as, the College of Psychiatrists, the College of General Practitioners, the Australian Psychological Society and other like bodies such as QCIDD.
  - to develop and maintain the required early intervention strategies in respect of young children with intellectual disability and challenging behaviours and to ensure and maintain as a permanent ongoing feature of service delivery a continuum of care and positive behaviour support for this client group through increasing maturity and teenage years and young adulthood and for that purpose to coordinate government, non-government, relevant community agencies and professional bodies in responding to the individual needs of young persons in this group.
  - to develop as a professional research resource to the disability sector in Queensland and to government and for that purpose to develop a research facility which will monitor best practice nationally and internationally and ensure that the details and all relevant data in respect of the Queensland experience is collected and retained.
  - to do what is necessary to ensure that suitably educated and skilled professionally developed expertise is available to efficiently service the individual needs of person with intellectual disability and challenging

behaviour in Queensland and for that purpose to liaise with and develop a professional working relationship with (a particular tertiary academic institution).

- to develop and provide the relevant professional development and expert training for those who will work in the disability sector specifically as day to day professionals, carers and support personnel for those persons in Queensland with intellectual disability and challenging behaviour.
- to liaise with all relevant government departments and agencies, NGO service providers and disability peak bodies in the community with a view to establishing a whole of government and sector response and the effective collaboration and cooperation of all bodies concerned in any respect with the well being and development of those in Queensland with intellectual disability and challenging behaviour.
- to develop as a valued community resource which can provide professional advice to any person, agency or government department which is concerned with the needs of any person in Queensland with intellectual disability and challenging behaviour.
- to provide a system of information sharing with and advice to the community generally and ensure that the community is better informed in relation to issues concerning persons with intellectual disability and challenging behaviours.

#### B. Early Intervention and Prevention

3. That there be developed a whole of government strategy which will ensure a continuum of care and support for all persons in Queensland with disability/cognitive impairment and challenging behaviour from early childhood through the child's years of formal education to those of increasing maturity and adulthood through a process of inter-departmental co-operation and collaboration.

#### C. Accommodation and Facilities

4. That what is known as the Basil Stafford Centre site be the subject of total planned redevelopment and renewal.
5. That the Centre for Best Practice in Positive Behaviour Support be located away and separate from the Basil Stafford site and from any identifiable DSQ departmental office or facility.
6. That there be provided at the redeveloped Basil Stafford site 6 emergency or crisis accommodation units suitably designed and appointed and that as part of or nearby to this accommodation an office facility for the Brisbane / Ipswich assessment units be provided. Smaller facilities may also be necessary at Townsville and Maryborough.
7. That the Purpose Designed Housing Project (also referred to as the "Places of Safety" project) be progressed urgently and that it have the capacity at first to accommodate at least 20 persons requiring secure care in a range of architecturally designed housing of various designs and styles and of various levels of security. This purpose designed accommodation of various sizes should be provided in different locations on the redeveloped Basil Stafford site. Similar secure accommodation may also be required at other places e.g. Maryborough and Townsville.
8. The Purpose Designed Housing Project must have the capacity to accommodate those presently detained in a mental health service but who are not mentally ill and also the capacity to respond to the requirements of the

Mental Health court in respect of persons who have intellectual disability but who are not mentally ill.

9. That before the redesigned Purpose Designed Housing project be progressed there be an immediate comprehensive assessment of each of the persons whom it is intended to accommodate in order to ensure that the accommodation is designed so as to more appropriately respond to the individual needs of those persons.
10. That the provision of accommodation in various designs for persons with intellectual disability, whether with challenging behaviour or otherwise be the subject of a Capital Works Development Program which will have the capacity to more appropriately respond in the future to the individual needs of those in the client group.
11. That in planning for immediate and future accommodation requirements the present tenancy arrangements and all matters relevant to the establishment of co-tenancies be the subject of comprehensive review.
12. That the Innovative Support and Housing Project which is to provide transitional accommodation be comprehensively reviewed before further development occurs and that entry and exit criteria and the level of professional support required be reassessed in the light of this Report and of the independent advice provided to DSQ in November / December 2003.
13. That DSQ urgently facilitate a review of the way in which community access is provided to persons with intellectual disability and challenging behaviour and in the course of so doing consult with those NGO's which specialise in the provision of this disability service.
14. That Disability Services Queensland and Queensland Health engage collaboratively in determining the preferable option(s) for accommodating those persons with intellectual disability only who are and have been for many years accommodated and cared for at Baillie Henderson hospital.

#### D. Staffing Issues

15. That the Centre for Best Practice in association with external agencies of international reputation ensure the proper training and professional development for all specialist staff and direct care providers across the sector.
16. That specialist staff who are required to work with those persons whose challenging behaviour is most difficult in the accommodation providing higher levels of secure care, be specially trained and their conditions of employment be reviewed.
17. That DSQ take all necessary steps to ensure the employment of the required number of psychologists and other allied health professionals necessary to properly service the needs of those requiring specialist support.

#### E. Implementation

18. That the implementation of the Report's proposals be executed as soon as possible and in accordance with a phased process of the kind suggested in the Report. Since the core legislative proposal is necessarily tied to the implementation process, the development of the total reform be executed within a period of 2 years.
19. That the Honourable the Minister consider a realignment of DSQ's functions and structure (as proposed in Chapter 6) in a manner consistent with the development of the proposed Centre of Excellence within DSQ.

#### F. Legislation

20. That the Disability Services Act 2006 be amended to provide legislative support for the use of any restrictive practice identified as part of the development of

the Positive Behaviour Support Plan for the individual in accordance with these principles:-

1. The human rights and service delivery principles set out in part 2 Divisions 1 and 2 of the Disability Services Act 2006 are to be applied expressly to the extent that the same are relevant to this issue.
2. Since the legislative focus is on the development of the individual person, and the services to be delivered have to be designed and implemented for the purpose of developing the individual and enhancing that person's opportunity for a quality life, restrictive practices can only be justified as part of a specific individualised positive behaviour and support plan which will be of benefit to the individual and which will assist in the achievement of that objective.
3. Any such plan for the care and support of the individual person must be developed by the appropriate specialists in association with the individual and where necessary his/her parent or guardian.
4. Approval for such a plan, if it contains provisions for the use of restrictive practices must be given by an independent body consisting of persons with the requisite skill, knowledge and/or experience and such approval shall operate only for a limited time, at which time it shall be reviewed and the continuance or otherwise of the restrictive practice considered anew in the light of the material to be provided to the independent body. That independent body should be the Guardianship and Administration Tribunal (GAAT).
5. Whilst the approval remains in operation, the use of the approved restrictive practice(s) shall be monitored by an independent person(s) who shall report to the independent body upon each review. This should be done as part of the Community Visitor Program.
6. That the use of restrictive practices be prohibited except as approved by GAAT in accordance with the above principles.
21. That pending implementation of the core legislative provisions the amendment of the Disability Services Act 2006 provide defences to the offences of assault (S245 of the Criminal Code) and of deprivation of liberty (S355 of the Criminal Code) by declaring it to be lawful for any service provider to use a restrictive practice if it is reasonably necessary, to protect the person or any other person from the risk of injury or harm.
22. That, subject to the approval of the Honourable the Minister for Health, consideration be given to the amendment of the *Mental Health Act 2000* in relation to the Mental Health Courts power in making a forensic order in respect of a person with intellectual disability to order that the person be detained other than in a mental health service.
23. That the Honourable the Minister refer to the Honourable the Attorney-General and Minister for Justice and the Honourable the Minister for Health the question of how best the Criminal Justice System should deal with those alleged offenders with an intellectual disability (but no mental illness) who are charged with a simple offence only and who may be unfit to plead or otherwise entitled to have the issue of criminal liability determined in the light of an apparent mental infirmity.

#### G. Dual Diagnosis

24. That the Centre for Best Practice have regard to the Recommendations in the Report of the Dual Diagnosis Project 2002 (QCIDD) and consider the same for implementation in the light of this Report.

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**CHAPTER 1****INTRODUCTION**

The Minister for Communities, Disability Services and Seniors the Honourable Warren Pitt MP seeks to identify appropriate options for providing a targeted service response for persons with an intellectual/cognitive disability who exhibit severely challenging behaviours that pose a significant risk of harm to themselves, others with intellectual disability, their carers and / or the community and seeks recommendations for any appropriate legislative framework which may be necessary.

It needs to be understood that the focus of the report is those with intellectual/cognitive impairment. As a matter of convenience only I have in the body of the Report used mainly the phrase “intellectual disability”. This should not be understood to mean that those with cognitive impairment or disability are excluded.

Below I will refer both in generic and specific terms to the nature and extent of the target group. I hasten to point out, however, that whilst the development of the appropriate service options for the target group should be the subject of specific examination, one should begin with the assumption that those in the target group should not be regarded as intransigent or that their opportunities for establishing “a quality life” (s21 of *Disability Services Act 2006*) are incapable of enhancement. Rather the contrary assumption is true, indeed, demonstrable and the development of an appropriate service option must proceed on that basis.

Any tailored service response and legislative framework must have as its key objective the ultimate attainment by each individual, or as many as possible, of the living skills which are “the same as or as close as possible to, the conditions of everyday life valued by the general community.” (s23 (a) of *Disability Services Act 2006*). The particular service response which this Report proposes has to be seen as an integrated and collaborative continuum which begins with a comprehensive assessment of the persons needs which seeks to identify the source of the behaviour, then develops the proper care, and positive behaviour supports which benefit the person, allows progress through a process of transition if necessary with the ultimate objective being that each individual person can come to enjoy “a quality life” in the community and have their fundamental “right to respect for their human worth and dignity as individuals” fully recognised and respected - (s19(2)(a) *Disability Services Act 2006*).

Very early in the life of this project I came to realise that challenging behaviour and its damaging consequences was not the product of adulthood only but was a matter of major concern in the life of the person at a much younger age and over a span of years before attaining the age of 18. The person of concern at aged 18 was the same person who had exhibited the same challenging behaviour in childhood and in his/her earlier teenage years. That fact has significant implications for this Report which will later appear.

Furthermore it also became apparent that the preferred service response for the target group has to be developed and implemented within the wider context of the services which DSQ and its funded service providers deliver to persons with intellectual disability whether they exhibit challenging behaviour or not. The two, in terms of appropriate services, are not mutually exclusive. The objective for each is precisely the same.

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**A brief historical context**

In his 1963/4 Annual Report Dr Stafford then the Director of Health and Medical Services wrote –

**“there is no need for the majority of mentally subnormal persons to be in our special hospitals”.<sup>1</sup>**

The language of his day has undergone significant change but Dr Stafford’s central theme resonates loudly and clearly in this day and age. His simple assertion was then that the majority of those with intellectual disability (the “mentally subnormal persons”) should not be accommodated, cared for and supported in a mental health service (“our special hospitals”). Perhaps he had in mind, when implying that a minority should be, those persons with intellectual disability who also have a diagnosable mental illness – what the language of today would call “a dual diagnosis”.

In 1966 the Government of the day took the critical step to separate the care and support of those with intellectual disability from those services which focussed on the medical treatment of persons with mental illness. Government had provided accommodation services for both adults and children with an intellectual disability in certain institutional settings such as Challinor Centre, Basil Stafford Centre, Wolston Park, Baillie Henderson and Mossman Hall, which were largely mental health care facilities.

In 1968 the Ipswich Special Hospital was designated “a training centre for people with an intellectual disability.” That section of Wolston Park Hospital which accommodated children with an intellectual disability were designated the Basil Stafford Training Centre.

The move away from caring for those with intellectual disability in a medical model of care and towards de-institutionalisation received some impetus in 1978 when the then Minister for Health outlined a new model for residential care, in the form of smaller residential centres, for accommodating and for caring for those with an intellectual disability. New caring professions were established. In this context 16 villa type houses were constructed at the Basil Stafford Training Centre. Nursing staff were replaced with Residential Care Assistants, now Residential Care officers (RCOs) and the Certificate in Residential Care was commenced. Shortly thereafter community based villas were opened in Toowoomba, Maryborough and Rockhampton. At the same time an Alternative Living Service (ALS) commenced in private rental accommodation in Ipswich and Brisbane.

So too did the administrative structures undergo change. An Intellectual Handicapped Services Branch had been created within the Health Ministry in 1977. It was not until 1989 that Intellectual Handicapped Services departed the Health Ministry and became merged into the then Department of Families. From 1982 the government’s commitment to the principles of Normalisation and of the Least Restrictive Alternative had been confirmed in a Parliamentary White Paper with its greater emphasis on community residential care facilities rather than on institutions. The first specific legislative intervention, the *Disability Services Act*, was not enacted by the Queensland Parliament until 1992. This was a direct consequence of deinstitutionalisation and the move towards community living and the proposals for funding non-government organisations (NGOs).

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<sup>1</sup> AS&RS Document 30 March 2006.

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The 1990's however, proved to be a turbulent time in the delivery of services to those with intellectual disability, in particular, at the Basil Stafford Centre (BSC). Early in 1990's this government facility had become the focus in the media and by way of complaint to the then Criminal Justice Commission (CJC) of long standing allegations of abuse and neglect of its clients by persons engaged as residential care officers. In 1994 the CJC engaged the Honourable D.G. Stewart to inquire. His report was published in March 1995. He found that –

- Staff of the Centre were directly or indirectly implicated in allegations of assault, client abuse and neglect;
- Conventional methods of investigation undertaken by the State government, the QPS, and the CJC itself, had experienced difficulty in identifying wrongdoers or in stemming the tide of allegations of abuse and neglect;
- The alleged occurrences of assault and client abuse were seen to be linked to what the Stewart Report called an 'insidious institutional culture' characterised by a regime of non-reporting of such behaviour and the fear of reprisals and harassment being visited upon those who 'broke ranks'.<sup>2</sup>

The major recommendation in the Stewart Report was that BSC be closed. At the time of the Stewart Inquiry and Report (1994-5) 122 persons with intellectual disability, all of whom had severe levels of intellectual disability, were accommodated and cared for at BSC. 17 of these were children.

In 2000 the CJC undertook a review of the Stewart recommendations. By then some improvements had been achieved. There were 69 clients still living at BSC but the process for relocating them into community facilities was in place. New recruitment procedures were introduced and an enhanced training regime for RCO's had been instituted; a more efficient and revised staff : client ratio had been established; there were more stringent requirements for the reporting of incidents and more aggressive attempts were being made to terminate the employment of those whose conduct was unacceptable. At the same time the community based Alternative Living Service (ALS) was in the course of further development and facilities such as the Loganlea Accommodation Support Service (LASS) had recently been developed, and a like facility at Brackenridge was contemplated. Government funded NGO's had come to provide a key role in service delivery. In December 1999 Disability Services Queensland (DSQ) was established as a separate Department and remains so.

After the announcement of a new Business Model for DSQ in 2003, the Accommodation Support and Respite Service (AS&RS) was established as a separate directorate within DSQ with responsibility for the management and development of the relevant accommodation and support services under the auspices of DSQ. It has recently undergone a substantive review.

It is obvious therefore that DSQ is still in a developmental phase and its present status as a separate and independent government agency is a reflection of the massive changes which have taken place, in the last 15-20 years, perhaps slowly but nonetheless progressively, over the life of several Governments in the development of appropriate care models and facilities for those with intellectual disability.

The Ministerial focus now on issues relating to this particular target group has to be seen as a further and necessary step in the provision of proper accommodation and support and in the personal development of those with intellectual disability who have

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<sup>2</sup> CJC Review of the Implementation of Recommendations: The Basil Stafford Centre Inquiry Report: May 2000.

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and do exhibit disturbed behaviours which may seriously impact on the well being of the persons themselves, their carers and other members of the community.

This is a critical time for DSQ. Its place in the delivery of comprehensive quality services to those with intellectual disability can only be enhanced and its status as a leader in the delivery of proper professional services to those in the target group firmly established, if there is established within DSQ a valid and truly professionally integrated process which will support the development of the individual person and at the same time ensure the safety of others, but above all which will respect and give full recognition to the rights of the individual person. I believe that the detailed service and legislative responses in this report achieve that objective.

***This point has to be strongly emphasised at the outset – the present state of affairs in relation to the target group cannot be sustained any longer. The proper response to their care and support is now urgent. This requires an immediate and substantial rejection of the present crisis-driven culture which heavily infests the present DSQ experience. Its urgent needs are – a robust political will, a fundamental renewal of DSQ practices and culture and the urgent availability of considerable resources to allow a process of reform, renewal and regeneration to commence.***

***I am now aware that at least since the late 1980's this issue has been the subject of discussions, meetings, so called strategic policies and paper writing – but little effective action over the life of various Governments of different political persuasions. The “talking” time has surely passed. It is now the time to act. Previously unearthed valuable and professionally based material within DSQ and from other sources has become available which sets out, consistently, the necessary care models and/or positive behaviour support strategies to address this problem.***

***I am encouraged by the fact that my tentative conclusions which had independently developed prior to becoming aware of this material coincide in all material respects with what had written by others well before the commencement of this project.***

***For instance in April 1989 Dr Attwood in a paper entitled – “An Alternative Approach to reducing Challenging Behaviours: A Model for the Community” - wrote:***

***“In conclusion a specialist intervention team with a small crisis admission/assessment unit has considerable potential in supporting people with challenging behaviour in community based services. Although the costs of adequately funding such a team are high, the savings of such a team are considerable. If each member of the team in one year helps to keep two intellectually disabled people at home with their families or in ordinary accommodation in the community, the government is actually spending less money than paying for these two people to live in a special government unit. Thus the approach is not only an effective way of reducing the incidence and disruption caused by challenging behaviour, it is also a cheaper and more normalised alternative to providing specialist units.”***

***Dr Attwood wrote that in the context of his time. Seventeen years later although the context is historically different and the size of the cohort has necessarily enlarged, the fundamental problem remains and the core solution proposed in this Report is essentially no different from that proposed in his paper. Dr Attwood's comments on the cost-effectiveness of the proper options are endorsed. They are well understood and are repeated in the body of this Report.***

This investigation and Report in respect of the cohort is very timely. It is significant that at the same time a recent review of the DSQ service delivery arm, AS&RS is in the early stages of its implementation. So too the development of proposed improvement strategies for a preferred approach to assessment and prioritisation of disability service delivery and funding is well under way.

The preferred service delivery option for this cohort has necessarily to be considered for implementation in the same context. The core feature of the AS&RS review is a desired change of culture at the level of service delivery. The core feature of the Programs review is the desired development of improved strategies for the improved design, management and funding of disability service programs; as this Report will demonstrate the core feature of this report is the urgent need for reform of all key elements of services in the provision of Positive Behaviour Support to those with disturbing behaviours.

Not only for DSQ but for the whole sector the need for change is seen to be essential. In the best interests of persons with intellectual disability not only must the need for change be embraced but also the implementation of the desirable changes have to be well managed.

### **Human Rights Principles**

One cannot begin to address the issues which emerge in the provision of the proper care and support of persons with intellectual disability or to propose options for a meaningful service response and legislative framework unless one places at the forefront the principles which underpin the fundamental human rights of every individual person whether that person has an intellectual disability or not. On 10 December 1948 the General Assembly of the United Nations adopted and proclaimed the Universal Declaration of Human Rights to which Australia is a signatory. The opening paragraph of its Preamble asserts that –

**“recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom justice and peace in the world”.**

That declaration applies with all of its force to persons with intellectual disability as well as to those without.

When government and its public service agencies are so often overborne by a whole host of troublesome issues requiring problem solving responses, usually in an environment of finite resources and competing priorities, it is easy to disregard such principles as having aspirational value only and for them to become submerged, if not ignored, in the pragmatism which attends day to day decision making. No doubt conscious of the risk that lip service only might be paid to these matters of fundamental principle inherent in the recognition of the individual's human rights, the Queensland Government positively and without equivocation addressed that risk in the *Disability*

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*Services Act 2006* (DSA 2006) by legislating and mandating, as a matter of law, the statutory obligation to have regard to human rights principles in the delivery of “disability services” to those with intellectual disability. It is no longer in Queensland a matter of choice. It is a matter of statutory obligation. Sections 18-33 of DSA 2006 speak for themselves.

Accordingly Section 19 of the Act which became effective 1 July 2006 enacts –

**“Principle that people with a disability have the same human rights as others**

- (1) People with a disability have the same human rights as other members of society and should be empowered to exercise their rights.**
- (2) People with a disability have the right to—**
  - (a) respect for their human worth and dignity as individuals; and**
  - (b) realise their individual capacities for physical, social, emotional, cultural, religious and intellectual development; and**
  - (c) live lives free from abuse, neglect or exploitation; and**
  - (d) participate actively in decisions affecting their lives, including the development of disability policies, programs and services.**
- (3) When using disability services people with a disability have the right to—**
  - (a) services supporting their achieving quality of life in a way that supports their family unit and their full participation in society; and**
  - (b) receive services in a way that results in the minimum restriction of their rights and opportunities; and**
  - (c) receive services in a way that respects the confidentiality of their information; and**
  - (d) receive services in a safe, accessible built environment appropriate to their needs; and**
  - (e) pursue grievances about services without fear of the services being discontinued or recrimination from service providers; and**
  - (f) support to enable them to pursue grievances about services; and**
  - (g) support, and access to information, to enable them to participate in decisions affecting their lives.**
- (4) People with a disability have the right to receive services, and information necessary to support rights, in ways that are appropriate having regard to their disabilities and cultural backgrounds.**
- (5) Subsections (2), (3) and (4) do not limit subsection (1).**

These statutory imperatives cannot be ignored. To ignore them in delivering services to a person with intellectual disability is not only to ignore matters of fundamental principle; it is to act contrary to what the law requires.

The need to ensure that human rights principles are mandated by legislation is driven by the fact that the target group – those with “challenging behaviours”, or who are said to have “high and complex needs”, are vulnerable persons. Just a decade has elapsed since the very damaging Stewart Report which highlighted the systemic abuse of individuals, where “thump therapy” and other forms of abuse were a regular feature

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of the “care and support” delivered to some in a government controlled facility. Fortunately much has changed for the better but there is still an identifiable mindset on part of some that those with intellectual disability who fall into this group are seen as a “problem”, as difficult if not impossible to manage, a nuisance, worthless, unloved, “not mad – just bad”, and that the public moneys used to fund their support could be better spent. (Opening Doors to Citizenship: June 2004: Office of the Public Advocate Queensland)

The enlightened and socially responsible legislative principles encapsulated in the Disability Services Act 2006 are the classic antidote to this poisonous mindset. Compliance with these legislative imperatives is therefore not negotiable. Not only do they bind all concerned in delivering disability services, they provide a robust foundation for policy development, for service delivery at all levels and provide the yardstick or measure against which performance, whether at government level or in the workplace, is to be measured.

To insist on these standards is not to set an impossible task or an unattainable objective. One can identify in some of the developmental work of DSQ and in that of some funded non-government organisations (NGOs) instances where the required standards are maintained as a matter of course or serious attempts made. The concern is to ensure that these legislative requirements are embraced at all levels and, that they increasingly become pervasive and systemic. Excellence is then not merely a working objective; it is and will remain a permanent achievement.

Therefore in “develop(ing) options and mak(ing) recommendations on a legislative framework and service requirements”, this Report will have specific regard to legislative requirements, such as Section 21 of the DSA 2006, which provides –

**“Services should be designed and implemented so that their focus is on developing the individual and on enhancing the individual’s opportunity to establish a quality life”.**

and to the United Nations Declaration on the Rights of Persons with an Intellectual Disability 20 December 1975, such as clause 9 –

**“Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.**

The Report will necessarily address the reality that some clients in the target group demonstrate unprovoked violence and other seriously inappropriate behaviours which, in other circumstances, would have been dealt with by the Criminal Justice System as a matter of course. In some of the case studies in Chapter 2 the persons were charged with indictable offences and ultimately found their way to the Mental Health Court. Others did not. The present purpose is to emphasise that the evidence establishes that in many instances a range of persons have become the unwitting victims of the aggressively violent or other inappropriate behaviour by individuals in the cohort. I refer to members of the persons immediate family, other persons with intellectual disability with whom the person may be living, the person’s carers, including RCOs and others engaged in professional work with the client and, not

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uncommonly, members of the public who, for all practical purposes are total strangers to the person.

This troublesome issue raises two main questions which are inter-related, firstly the dominant need to identify, with the assistance of the relevant professional expertise the reasons for such disturbed or inappropriate behaviour so as to facilitate the personal development of the individual by appropriate care and support and to enhance his / her quality of life and secondly, the obvious need to protect those close to the person and others in the community, who are strangers to the person, from any harmful consequences of the behaviour.

The second matter has traditionally been seen as the easiest to deal with or to respond to. Locking the person up or applying some other form of coercive practice, whether as a punitive measure or otherwise, was commonly the accepted response and the one usually resorted to. The literature would regard such a response as archaic and no longer acceptable. Best practices are now undoubtedly directed to addressing the first and dominant need referred to. As section 21 of the DSA 2006 requires, services should be “designed and implemented” to develop the individual by seeking to address the causes of the behaviour as part of a comprehensive strategy designed to identify the specific characteristics and needs of the individual person.

That is not to say that the protection of the other persons referred to is no longer relevant. It clearly is and, provided that there are in place appropriate safeguards, restrictive practices for the purpose of protecting others are justifiable. Such was the common response from those consulted for the purposes of this Report.

The important point in this context which requires emphasis is the need to satisfy apparently competing interests – the need to develop the individual and the enhancement of his/her quality of life and at the same time the appropriate use of restrictive practices which will protect others as required. Properly balancing the protection of the rights and best interests of the person with intellectual disability and safeguarding and protecting others from the risk of injury or harm is one major focus of this Report. To be restrictive of persons in the target group is to be discriminatory yet the overall objective has to be the personal development of the individual person. The two can only be reconciled if the capacity to restrict lawfully is used only for the purpose of or integrated with the purposeful strategies designed to develop the individual and enhance quality of life.

In this context one must acknowledge the work of the Victorian Law Reform Commission and the reference in its Report: *People with Intellectual Disabilities at Risk: A Legal Framework for Compulsory Care* to the developments in Therapeutic Jurisprudence in the US. This innovation is defined as “the study of the use of the law to achieve therapeutic objectives” (see Pgs 46-47).

At the same time one needs to be mindful of the caveat issued by Justice Vincent of the Victorian Supreme Court that:

**“Once a community starts to decide for itself that it will incarcerate an individual not for something that he had done but because of something it is feared he might do the community is moving into dangerous waters.”**  
(VLRC Report, page 4 note 128.)

**“Disability”**

The DSA 2006 defines a disability as follows:

- (1) A disability is a person’s condition that—
  - (a) is attributable to—
    - (i) an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment; or
    - (ii) a combination of impairments mentioned in subparagraph (i); and
  - (b) results in—
    - (i) a substantial reduction of the person’s capacity for communication, social interaction, learning, mobility or self care or management; and
    - (ii) the person needing support.
- (2) For subsection (1), the impairment may result from an acquired brain injury.
- (3) The disability must be permanent or likely to be permanent.
- (4) The disability may be, but need not be, of a chronic episodic nature.

The definition is extensive and the range of persons to whom “disability services”, as defined in section 11, are delivered or for whom funding under the Act may be provided to a funded service provider, extend significantly beyond those who are persons with intellectual disability. Those with cognitive impairment are included in the Terms of Reference which define “cognitive impairment” as follows:

**Cognitive Impairment is described as a delay, reduction or abnormality of cognitive functions such as learning, reasoning, memory, problem solving, decision-making, organisation, perception, intellect and/or attention. It is likely to be experienced by people with a disability with diagnoses such as autism or other pervasive developmental disorders or acquired brain injury.**

Autism Spectrum Disorder (ASD) is usually included within the scope of cognitive/neurological impairment and Acquired Brain Injury (ABI) is specifically included in the definition of “disability” by sub-section (2).

Intellectual and psychiatric disability, as well as ASD and ABI, are all represented in the target group. Challenging behaviour, as defined, is a manifestation of each.

In the course of this consultation with the various peak bodies, I was invited to consult with groups who represent those persons with physical impairment but who likewise demonstrate disturbing behaviours of the same general kind which can be as challenging as those seen in the case of intellectual disability or cognitive impairment. I refer to the Spinal Injuries Association and the Cerebral Palsy League. Both those with spinal injury and those with cerebral palsy fall within the definition of “disability” in s11. In respect of cerebral palsy, the case is often characterised as a “dual diagnosis” where the cerebral palsy is associated with intellectual disability.

Challenging behaviour often occurs in these cases of physical disability – verbal abuse, violence and threatened suicide are not uncommon. In some of these cases the person’s support in the community is assisted by DSQ funding.

At present DSQ, pursuant to a community consultation, is reviewing its programs and policies and focusing on system improvement in the area of needs assessment, prioritisation, service and funding approaches to ensure that persons with the greatest

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need have access to support services. The needs of those with physical disability are included in that Review.

This Report will focus on the issue of challenging behaviour in respect of the cohort defined by the terms of reference. Although DSQ does not engage in service provision to those with physical disability, the fact that such persons may be properly included in the “challenging behaviour” category should not be lost sight of.<sup>3</sup> The legislative scheme in DSA 2006 is designed to support those with a disability, including a physical disability.

### **Challenging Behaviour – why the issue is so significant**

The literature abounds with references to “challenging behaviour” in the context of intellectual disability. Other terminology, which refers to a person having “high and complex needs” or “very high support needs”, is usually a reference to a person with intellectual disability who demonstrates challenging behaviours or in some cases “seriously challenging behaviour”.

The term “challenging behaviour” itself provokes considerable comment and there are those who will argue its appropriateness or otherwise. It has, however, become a fixture in the disability language and literature and is now so entrenched that any theoretical discussion about its use, meaning or content is a pointless exercise. Those with experience of intellectual disability know what it means, have witnessed it, have at times been the victim of it and spend a significant amount of time and effort in seeking to properly manage it.

Emerson’s definition (1995) in his well known text “**Challenging Behaviour**” is the most widely used. He defines it (pg3) as:-

**“culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be place in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in a person being denied access to, ordinary community facilities”.**<sup>4</sup>

Such behaviours include aggression, destructiveness, self-injury, consuming inedible objects, non compliance, persistent screaming, regurgitating food and smearing faeces on property or person. The list is not exhaustive. These have potentially serious and damaging consequences for the person him/herself, family, other carers, others with intellectual disability and at times members of the community.

Merely to define challenging behaviour therefore is to emphasise its significance for the lives of the individual person and others and that of the wider community. It is hardly surprising that there is a widely held expectation that the management of challenging behaviour should be a government priority. It is a difficult issue; it involves the risk of harm to others; the management of it is resource intensive; it is generally beyond the capacity of the family, despite heroic effort, to cope into the longer term; they desperately need access to the resources of government to be able to deal with it.

But the real significance of challenging behaviour lies in the impact which it has in the life of the very person with intellectual disability. At best, that person’s access to community living and its facilities is restricted and limited; at worst, such access is denied. Exclusion from its facilities and rejection by the community of the particular

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<sup>3</sup> DSQ does provide funding for physical disability.

<sup>4</sup> Emerson: Challenging Behaviour, 2<sup>nd</sup> edition 2001, page 3

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person must surely represent the most destructive and damaging affront to the human dignity of that person. Such exclusion is wholly inconsistent with Section 27 of the DSA 2006 which promotes competency, positive image and the self-esteem of the person with that disability.

Therefore for the benefit of the person and the community the issue demands a response. Properly framing that response is itself a challenge, but one that has to be met. To fail to respond is to fail to comply with a clear legislative intent.

### **Whole of Government Issues**

Disability Services Queensland and other providers of services to those with intellectual disability necessarily interact with other government bodies and agencies – the Department of Child Safety, Education Queensland, Queensland Health, Department of Housing, the Criminal Justice System, Department of Justice and Attorney-General through the offices of the Adult Guardian and the Public Advocate, Corrective Services and Police. In some cases this interaction is productive and collaborative. In others it is less so; in some, interaction is a source of conflict.

There are some pressure points at present which need to be identified and addressed because the legislative and service options which this Report proposes require that contentious matters be eliminated. The practical impact and content of these can be seen in some, if not all, of the case studies in Chapter 2.

A collaborative whole of government response is essential.

Whatever its source, intellectual disability can be recognised in infancy and those many parents whose child is affected by, for example, Autism Spectrum Disorder well know that the management of their child's consequential disability will be a lifelong obligation. Some will manage successfully. Many others will find it more difficult to cope and will need community/government support. A significant proportion will seek out DSQ or a DSQ funded service to provide management and service requirements for their child/adult offspring. This will often be the case with those who are included in the cohort and are the focus of this Report. Challenging behaviour however, is not an issue reserved for adulthood.

Since DSQ does not generally assume statutory obligations for the person until one attains 18 years of age, it is relevant to inquire as to what has been the earlier experience of that child – at home and in the education system. The experience is that it is not uncommon that by age 14 – 17 many with intellectual disability who exhibit challenging behaviour have “dropped out” of school, may be the subject of a Child Protection Order and may already have made contact with the Juvenile Justice System. It is therefore relevant to inquire about the quality or otherwise of their education, their level of community support and what efforts, if any, have been made to address the recognisable and disturbing behaviours which are seen as a feature of increasing social dysfunction.

The issue therefore of managing challenging behaviour will almost invariably have been a concern before the person becomes the subject of interest under the DSA. Education Queensland, the Department of Child Safety and in some cases the Juvenile Justice System will almost inevitably have had some contact with the person.

The quality of the response from those agencies in the case of this person is therefore a relevant inquiry.

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It is the regrettable fact that some of the most difficult cases in the care of DSQ at present are young men – in their late teens and early adulthood. DSQ is also aware of cases of seriously challenging behaviour in juveniles which will soon require DSQ support.

Whilst this Report focuses on the required response for the adult members of the cohort, that will necessarily present an incomplete picture. The issue is much wider for the obvious reason that challenging behaviour is not the sole preserve of adults. The issue needs to be addressed much earlier. The literature leaves one in no doubt that effective early intervention is essential if the life of that person with intellectual disability is to have a chance of real quality.

The requirement for an effective and collaborative response between relevant agencies is surely obvious. It cannot be achieved by bureaucratic “gatekeeping”.

During this process of consultation investigation and report writing I have had the privilege of having some of the many parents of young persons with intellectual disability and challenging behaviour share with me their experiences of living with/caring for/attempting to deal with their own children in their own homes and at the same time seeking out/looking for/urgently requesting some effective and positive support, usually of a relevant government agency or professional body.

Their collective mixed emotions range from an obvious and deep seated love for a seriously disabled child on the one hand to, on the other, an equally deep seated sense of anger and frustration and fear based on an apparent inability by the relevant “support” government – based agencies to effectively respond to their needs and concerns and the seeming inability of such agencies to provide an efficiently responsive and consistent level of support for their disabled child or family member.

The most recent group of 6 women with whom I met – 4, the mothers of young men/boys, 1, the sister of 2 brothers with intellectual disability and 1, the foster parent/carer of a teenager who had already experienced the juvenile justice system – all with challenging behaviour.

One young mother commented: “I hate to go shopping with my son. When he plays up unexpectedly, I feel people pointing at me and saying – you are a bad mother”; another said: “My son is at special school. The other day they rang up and said that because he was so troublesome, they are going to exclude him – can they do that at a special school?” Yet another: “I ring Child Support; they say ring DSQ. I rang DSQ they said ring Child Support”.

The lack of any real effective response to their need for support and the limited availability of any consistent and efficient service response to the needs of their young children/young adults is a convincing symptom of a fragmented process of service delivery which only seems anxious to provide some response in times of crisis. These mothers seemingly are at a loss to understand what they perceive to be a lack of official concern about their needs. One can only question whether the decision makers have any real or intimate understanding of what these young mothers have to tolerate on a daily basis.

This Report seeks to address the problems which emerge constantly on account of the lack of any process of proactive early intervention.

This Report will deal more specifically with the interaction between DSQ and Queensland Health, in particular Mental Health Services, as well as with Police, Department of Housing and parts of the Criminal Justice System. The purpose in this

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Introduction is to emphasise that the target group is not and will never be the sole obligation of DSQ.

A more effective response will only be possible with a more collaborative effort on part of all government agencies with human services responsibilities. The fact that this Report focuses mainly on the appropriate DSQ response for the target group should not detract from the need to address the issue from a whole of government perspective. I will return to this issue in the body of the Report.

A more collaborative effort however should not be limited to one which focuses only on government agencies. It should extend across all service providers including DSQ and NGO's.

Early intervention has a two-fold application. It refers not only to intervening early in the life of a person. It also refers to the need for intervention early in the cycle when the disturbed behaviour shows signs of escalation. The service response model which this Report proposes has to be seen to be generally responsive across the disability sector so that each service provider can take advantage of it. Although DSQ will be the initiator of this service every person with intellectual disability and challenging behaviour will be able to access it as required. The circumstances may be that an individual person who was thought to be stable in behavioural terms may commence to exhibit behaviours of concern and accordingly "early" intervention is the required response. In short the strategy can be preventative and this may best be achieved either by DSQ, any other NGO service provider or parents accessing an effective intervention of the kind proposed here. An NGO may confront an emergency. That service provider by means of an appropriate reference may access the service option provided. So too if the situation falls short of a present emergency.

That is real collaboration and should also operate between service providers. After all the real objective is the betterment of the individual person.

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**CHAPTER 2****A STATISTICAL REVIEW AND CASE STUDIES****THE TARGET GROUP**Disability services

DSQ funds and provides disability services to Queenslanders with a range of disability types, as defined under Section 11 of the DSA, and as agreed under the Commonwealth State/Territory Disability Agreement 2002-2007(CSTDA). Those people receiving a service include, but also extend beyond, people with an intellectual/cognitive disability. The disability service types are Accommodation Support, Community Support, Community Access, Respite, Advocacy, Information & Alternative Forms of Communication and Other Support.

Support services to people with an intellectual/cognitive disability can be delivered in one of two ways. The service may be delivered through DSQ provided services which involve staff employed by DSQ to provide direct support to the person with an intellectual/cognitive disability and/or their family. Alternatively, support can be funded by DSQ and provided through other services or agencies in the community. These non DSQ provided services are often, but not limited to, specialist disability support services provided by non-government organisations (NGOs). In some special circumstances the non DSQ provided services include services within mental health facilities.

The most recently available CSTDA service user data, obtained from the National Minimum Data Set (NMDS), indicates that of the 16,432 service users in 2004-05, the number of DSQ funded services accessed through DSQ provided services was 5,674 (34.2%) and the number accessed through other DSQ funded service providers was 13,197 (80.3%)<sup>1</sup>. These statistics represent the number of people receiving a service of some description, it does not describe whether those services fully or partially meet the needs of the individual or whether other services, if they were available, may be more appropriate for the individual.

Target group data

Data is not systematically collected and analysed on the characteristics of the target group for this review. As a result in order to get an indication of the size of the cohort and their characteristics AS&RS and DSQ Regions were approached to provide the necessary information. In addition, during the course of the review, Queensland Health in their submission provided statistical estimates of people residing within their facilities who may be considered as being a part of this cohort.

The information provided by Queensland Health at this time is more basic and does not allow a detailed demographic breakdown. Queensland Health submits that “a

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<sup>1</sup> Service user data are estimates after use of a statistical linkage key to account for individuals who received more than one service during the collection period. Totals may not be the sum of the components since individuals may have accessed more than one service type category and agency sector during the collection period. The number of ‘services accessed’ represents the number of service type outlets a service user accessed over the data collection period. This number is difficult to interpret and should be used with care. It is not a measure of the number of ‘episodes’ of services received.

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detailed analysis of data is required to ascertain the exact number of this cohort in Queensland Health facilities". This would need to be undertaken as a matter of urgency in any further developmental or financial modelling work undertaken by Government should the recommendations of this report be accepted. On further investigation some of the data provided by Queensland Health does not fit within the Terms of Reference for this review. However, the data of relevance relates to:

- 35 patients in public mental health facilities. These people do not have a diagnosis of mental illness but have a sole diagnosis of intellectual/cognitive disability and are residing in either acute facilities or dual diagnosis units. Some, but far from all, will have a Forensic Order under the Mental Health Act requiring them to be accommodated within a mental health facility; and
- 10 patients in acute (Princess Alexandra Hospital) or slow stream acquired brain injury units (Jacana and Casuarina Lodge) who demonstrate severely challenging behaviours.

Additional data was also sourced from both the Mental Health Review Court and Queensland Health regarding the number of people with an intellectual disability subject to a Forensic Order under the Mental Health Act. Whilst this data also needs to be examined in more detail it does give an indication of the numbers of people with a sole diagnosis of intellectual disability who are subject to a Forensic Order and either accommodated within a mental health facility or subject to a limited community treatment order.

According to the Mental Health Review Court data there have been 26 Forensic Orders made for individuals with a sole diagnosis of intellectual disability since the 2001/02 year. In 2001/02 one order was made for this cohort, seven in 2002/03, five in 2003/04, three in 2004/05 and ten in 2005/06.

Queensland Health records indicate that there are 23 Forensic Order patients with a sole diagnosis of intellectual disability, 10 of which are inpatients within mental health facilities. Their records indicate an additional 12 Forensic Order patients with a dual diagnosis of intellectual disability and mental health, five of which are inpatients within mental health facilities.

Whilst these numbers and the numbers referred to within the DSQ survey data differ they indicate a small cohort (less than thirty) of Forensic Order patients with a sole diagnosis of intellectual disability.

The survey data from DSQ funded or provided services provides more of a picture of the target group at this time.

#### DSQ funded target group features

Through the survey of AS&RS and DSQ regions a group of 312 people with complex and challenging behaviour was identified as currently receiving DSQ provided and/or funded services and whose challenging behaviour was either being managed by the use of restrictive practices or was at risk of requiring restrictive practices. These people were further categorised by the severity of the restrictive practices required:

Sub-group 1	<ul style="list-style-type: none"> <li>• the person's current accommodation is periodically or continually secured. Secured access to the community may include locked bedrooms, front doors or yard gates. This does not necessarily include locked fridges or cupboards;</li> <li>• other restrictive practices may also be being implemented such as unplanned or planned physical restraint techniques, restraint devices, or daily medication to alter behaviour eg. Anti-psychotic medication; and</li> <li>• the person does <u>not</u> currently access the community.</li> </ul>
Sub-group 2	<ul style="list-style-type: none"> <li>• the person's current accommodation is periodically or continually secured. Secured access to the community may include locked bedrooms, front doors or yard gates. This does not necessarily include locked fridges or cupboards;</li> <li>• other restrictive practices may also be being implemented such as unplanned or planned physical restraint techniques, restraint devices, or daily medication to alter behaviour eg. Anti-psychotic or psycho-tropic medication ; and</li> <li>• the person is currently supported to access the community or may access unsupported when they are not exhibiting challenging behaviour.</li> </ul>
Sub-group 3	<ul style="list-style-type: none"> <li>• the person's accommodation is not locked except at night for safety; and</li> <li>• other restrictive practices are being implemented such as unplanned or planned physical restraint techniques, restraint devices, or daily medication to alter behaviour eg. Anti-psychotic or psycho-tropic medication.</li> </ul>
Sub-group 4	<ul style="list-style-type: none"> <li>• the person has never been subject to securing of accommodation or restrictive practices, however there is a high risk (eg. As a result of the person's escalating challenging behaviour) that restrictive strategies may be required in the future; and/or</li> <li>• the individual is currently not receiving secure accommodation or restrictive practices but has in the past and will most likely require such intervention in the near future. (E.g. the person goes in and out of crisis where they are admitted to a secure hospital facility for a period of time and then return to their residence in the community).</li> </ul>

This snapshot of the potential target group represents approximately 1.9% of the total DSQ service user population as it was in 2004-05. As the population of service users will have increased since that time the percentage figures are overestimates and should be interpreted with some caution: they are indications only. Of the target group, 132 (42.3%) are receiving services from DSQ provided services which is approximately 2.3% of the total DSQ provided service user group from 2004-05. Approximately 180 people (57.7%) people from the target group are accessing services through a non DSQ provided service which represents around 1.3% of services users accessing support through non DSQ provided services in that same year. Thirteen of the cohort recorded within this survey as accessing services through non DSQ provided service providers are in a mental health facility (13) or a correctional facility (2). Whilst these individuals have been included in the data

analysis it does not necessarily mean that they will in future require the level of secure care that they are receiving in those facilities.

The relatively higher representation of people with challenging behaviour accessing DSQ provided services is not unexpected given that these services focus exclusively on people with intellectual and cognitive disabilities and other non DSQ provided services support the wider range of eligible disability types such as people with physical and sensory disabilities. In addition, DSQ also has a focus on supporting clients with the highest level of needs.

The cohort of interest to this review clearly represent a very small proportion of overall DSQ funded service users but nevertheless are in need of highly specialised services.

### Regional distribution

Specialist disability services are delivered through 10 regions across Queensland. Table 1 outlines the locations in which people from the target group are receiving services and the distribution of total service users throughout the State in 2004-05 as a point of comparison.

In DSQ provided services the majority of the target group are concentrated in three regions, Greater Brisbane Region (47 people - 35.6%), Moreton Region (44 people - 33.3%) and Darling Downs/South West Queensland Region (22 people -16.7%). Only small numbers of the cohort receive a DSQ provided service in other regions. By contrast, target group members who access non DSQ provided services are distributed more evenly in regions across the State. The largest number access non DSQ provided services in the Gold Coast Region (42 people - 23.4%) and Moreton Region (41 people - 22.7%), followed by Greater Brisbane Region (24 people - 13.3%) and Wide Bay/Burnett Region (20 people - 11.1%) and). The remaining smaller numbers access non DSQ provided services across a spread of regional areas.

**Table 1: Target Group and State wide numbers by service sector and DSQ region**

DSQ Region	DSQ-provided service				Non DSQ-provided service				Total	
	Target Group		NMDS 04-05		Target Group		NMDS 04-05			
	No.	%	No.	%	No.	%	No.	%		
Darling Downs/ South West Qld.	22	16.7%	549	9.8%	12	6.7%	905	6.9%	34	10.9%
Far North Queensland	-	0.0%	356	6.3%	5	2.8%	472	3.6%	5	1.6%
Fitzroy/Central West Queensland	9	6.8%	324	5.8%	7	3.9%	541	4.1%	16	5.1%
Gold Coast	3	2.3%	718	12.8%	42	23.4%	1389	10.5%	45	14.4%
Greater Brisbane	47	35.6%	1513	26.9%	24	13.3%	6427	48.7%	71	22.8%
Mackay/Whitsunday	-	0.0%	101	1.8%	7	3.9%	393	3.0%	7	2.2%
Moreton	44	33.3%	924	16.4%	41	22.7%	775	5.9%	85	27.2%
North Queensland	3	2.3%	521	9.3%	14	7.8%	969	7.3%	17	5.4%
Sunshine Coast	2	1.5%	563	10.0%	8	4.4%	1222	9.3%	10	3.2%
Wide Bay-Burnett	2	1.5%	351	6.2%	20	11.1%	718	5.4%	22	7.1%
<b>Queensland</b>	<b>132</b>	<b>100%</b>	<b>5620</b>	<b>100%</b>	<b>180</b>	<b>100%</b>	<b>13197</b>	<b>100%</b>	<b>312</b>	<b>100%</b>

Of particular note in this regional breakdown of data is the disproportionately large representation of the target group accessing both service sectors (DSQ provided and non DSQ provided services) in the Moreton Region. Whilst accounting for 16.4% of DSQ provided service users and 5.9% of non DSQ provided services across the State, people residing in this region made up 33.3% and 22.7% of the target group respectively. It is highly likely that the relocation of people from the Challinor and Basil Stafford Centres to accommodation arrangements in this region over the past 15 or so years is a contributing factor to this anomaly. Other regions of interest include the Sunshine Coast Region with smaller than expected representation in the target group (3.2%), the Gold Coast Region, with disproportionately high representation by non DSQ provided service users (23.4%) and Greater Brisbane Region with lower than expected non DSQ provided services representation (13.3%).

### Gender and Age Structure

Gender distribution in the target group (Table 2) supports the general trend described within the literature with a larger number of males than females within the cohort<sup>2</sup>. Approximately 3 out of every 4 individuals within the cohort are male (73.4%), whilst the proportion of males accessing total specialist disability services is 56.7% and for females is 43.3%. The widely acknowledged higher prevalence of intellectual disability among males partly explains this trend, however, given the large size of the gender difference, it is clear that other factors contribute to the higher representation of males in a group requiring the use of restrictive practices.

**Table 2 – Gender by Service Sector**

<b>Gender</b>	<b>Number</b>	<b>Percent</b>
<b>Male</b>	229	73.4%
<b>Female</b>	83	26.6%
<b>Total</b>	<b>315</b>	<b>100%</b>

The age data for this cohort also reflects the findings described in the literature regarding increased prevalence of challenging behaviour being found in the younger age groups and lower prevalence over 45 years of age<sup>3</sup>. The majority of the people within the target group are aged between 17 and 45 years (74.3%). Whilst the Terms of Reference for this review relate to adults with an intellectual/cognitive disability, the seventeen year olds have been included in the data analysis as they will undoubtedly shortly require DSQ support.

<sup>2</sup> Di Terlizzi, M., Cambridge, p., & Maras, P. (1999). Gender, ethnicity and challenging behaviour: a literature review and exploratory study. *Tizard Learning Disability Review* 4, 33-44.

<sup>3</sup> David Allen, Success and failure in community placements for people with learning disabilities an challenging behaviour: An analysis of key variables. *Journal of Mental health*, 8(3), pp. 307-320.

**Table 3 – Gender by Age Structure**

Gender	Age Groups (years)						Total
	0 - 17yrs	18- 25	26 – 35	36 – 45	46 – 55	56 +	
Male	4	56	56	57	40	14	227
Female	-	27	17	15	19	5	83
<b>Total Target Group</b>	<b>4</b>	<b>83</b>	<b>73</b>	<b>72</b>	<b>59</b>	<b>19</b>	<b>310 (of 312*)</b>
<b>% of Target group</b>	<b>1.3%</b>	<b>26.6%</b>	<b>23.4%</b>	<b>23.0%</b>	<b>18.9%</b>	<b>6.0</b>	<b>99.2%</b>

\*Note: 2 NGO clients age unknown at time of data collection

### Severity of restrictive practices

As mentioned at the start of this chapter, individuals are included in the target group on the basis of meeting criteria relating to the use of, or risk of use of, restrictive practices in managing their challenging behaviour. The four sub-groups are based on different “levels” of restrictiveness currently in place. Sub-groups 1 and 2 include people who are currently restrained through the use of a locked/secured residential environment. Sub-group 1 is considered more restrictive than Sub-group 2 because as a result of the risk presented to the community these people do not access the community. People in sub-group 2, on the other hand, experience similar environmental restrictions, but do participate in community access activities with support when their challenging behaviour does not present a major risk to themselves or others. Individuals in sub-group 3 do not currently reside in secured accommodation, however, other forms of restrictive practices (such as the use of physical restraint techniques, restraint devices or mood stabilising medication) are in use and they do access the community either with or without support. No restrictive practices are in use among people in Sub-group 4, however, such practices may have been used in the past or the person’s challenging behaviour is such that this may be required in the future.

Over half of the target group (169 people – 54.2%) are in Sub-group 3 (see Table 4). Sub-group 4 has 69 people (22.1%) and Sub-group 2 has 65 people (20.8%). A very small number (9 people – 2.9%) are in the most secure category Sub-group 1.

**Table 4 - Sub group by Service Sector**

Service Sector	Sub-group								Total	
	SG 1		SG 2		SG 3		SG 4			
	No.	%	No.	%	No.	%	No.	%	No.	%
<b>DSQ-provided service</b>	1	-	22	-	94	-	15	-	132	42.3%
<b>Non DSQ-provided service</b>	8	-	43	-	75	-	54	-	180	57.7%
<b>Total Target Group</b>	9	2.9%	65	20.8%	169	54.2%	69	22.1%	312	100%

Whilst it would appear unusual that eight people within the most secure category would be being managed by non DSQ service providers, four of these are in mental health facilities and 2 are currently within a correctional facility. The other two may not be accessing the community at the present time as a result of the current seriousness of their challenging behaviour.

**Table 5 - Sub group by Region**

Region	Number in Sub-group				Total number in Sub-groups C1 & C2
	C1	C2	C3	C4	
Darling Downs/South West Queensland		2	19	13	2
Far North Queensland		1	1	3	1
Fitzroy/Central West Queensland		4	8	4	4
Gold Coast		2	33	10	2
Greater Brisbane	5	24	34	8	29
Mackay/Whitsunday	1	1	5	13	2
Moreton	1	12	59	7	13
North Queensland	1	7	2	4	8
Sunshine Coast	1	2	3	7	3
Wide Bay-Burnett		10	5		10
Queensland	9	65	169	69	74

Table 5 displays the distribution of clients by sub group across DSQ Regions. Not unexpectedly, the largest number of the most difficult individuals within the cohort (in the C1 and C2 sub groups) is living in the Greater Brisbane Region. This region includes Wacol where The Park Centre for Mental Health is located and the Basil Stafford site. The Moreton Region has the next highest number of clients within the C1 and C2 sub groups (13) followed by Wide Bay-Burnett (10) and North Queensland (8).

### Diagnosis

Table 6 gives an indication of the diagnoses for the target group. It should be noted that a significant number of people within the target group have multiple diagnoses (e.g. a diagnosis of Autism Spectrum Disorder (ASD), intellectual disability and a mental illness). A significant proportion of the target group (84.9%) has a diagnosis of intellectual disability. Approximately a quarter of the target group (26.3%) identified as having a diagnosis of ASD and over eighteen percent (18.2%) of the target group has a diagnosed mental illness. 31.4% of the target group has a range of other diagnoses such as acquired brain injury, Down Syndrome, neurological disorders, and hearing or speech impairments.

All nine members of the target group in the most secure category have an intellectual disability, with some of the group having an additional diagnosis.

**Table 6 - Target Group by Diagnosis**

Diagnosis	Sub-Groups				Total	Percent
	1	2	3	4		
Mental Illness	3	12	32	10	57	18.2%
ASD	3	28	31	20	62	26.3%
Intellectual Disability	9	52	152	52	265	84.9%
Other	1	21	59	17	98	31.4%
<b>Total*</b>	16	93	274	99	These totals do not necessarily sum as some individuals have more than one diagnosis	

\*2 Clients diagnosis is currently unknown

### Contact with the Criminal Justice System

As outlined in Table 7, about one-third of the target group (37.2%) has experienced some form of recent contact with the police as a result of their challenging behaviour. Of significance is that 8 of the 9 people (89%) in Sub-group 1 have had contact with the police compared to smaller percentages in other Sub-groups (Sub-group 4 – 46.1%, Sub-group 2 – 44.9% and Sub-group 3 – 27.8%). Interestingly the majority of the individuals having contact with the police (67.2%) are at the lower levels of restrictive practice use (Sub-groups 3 and 4). The relatively large number of people in Sub-group 4 most likely reflects the potential for these people to be the subject of restrictive practices in the future. The data may also indicate a pattern of police contact precipitating the use of more restrictive strategies over time (e.g. locking of accommodation) to manage challenging behaviour.

Only 20 of the target group (6.4%) have a Forensic Order in place. Not unexpectedly, the Sub-group with the highest percentage of people with a Forensic Order is Sub-group 1 (22.2%), followed by Sub-group 2 (9.2%), Sub-group 4 (7.2%) and Sub-group 3 (4.1%). This pattern may suggest that for some individuals in the target group, in particular Sub-groups 2 and 3, that regular police contact leads to restrictive practices being imposed to prevent recurrences of the behaviour. Alternatively, the issuing of forensic orders may be more related to factors such as the seriousness of the offence and/or the number of repeated offences.

**Table 7 - Sub-Group by Police Contact and Forensic Order**

Police/ Forensic Contact	Sub-group				Total	
	1 No.	2 No.	3 No.	4 No.	No.	%
<b>Police Contact</b>	8	30	47	31	116	37.2
<b>Forensic Order</b>	2	6	7	5	20	6.4%

\*2 clients' forensic history is currently unknown

### Living Arrangements

The living arrangements of target group members (Table 8) is characterised by over half of the group (58.2%) residing in group home arrangements either as part of a DSQ provided service (36.5%) or supported by an NGO (21.7%). Around 1 in 6 people (15.1%) live in a family home. As mentioned previously, thirteen people currently live

in a mental health facility while 2 of the group are detained in a mainstream correctional facility and one other resides in a hospital ward. One in 6 of the group (17%) live alone while around one fifth of the group (21.1%) live with others without a disability. The majority (61.9%) live in arrangements with other people with a disability.

**Table 8 – Accommodation Type by Living Arrangement**

Living Arrangement	Accommodation Type									Total
	Family Home (incl foster & host family)	Group Home - NGO	Single Accom - NGO	Group Home - DSQ	Single Accom - DSQ	Boarding House/ Hostel	Correctional Facility	Mental Health Facility	Hospital	
Alone	-	-	33	-	18	-	-	1	-	53 - 17%
Others without a disability	47	-	2	-	-	14	2	-	1	66 - 21.1%
Others with a disability	-	68	-	114	-	-	-	12	-	193 - 61.9%
<b>Total</b>	<b>47 15.1%</b>	<b>68 21.7%</b>	<b>35 11.2%</b>	<b>114 36.5%</b>	<b>18 5.8%</b>	<b>14 4.5%</b>	<b>2 0.6%</b>	<b>13 4.2%</b>	<b>1 0.3%</b>	<b>312 - 100%</b>

\*Clients currently or soon to be in IS&H arrangements are counted across a range of accommodation type categories.

Table 9 outlines the accommodation arrangements of people within the different Sub-groups. Of interest across Sub-groups 1 to 3 is the relatively high percentage of single accommodation (14%) while the majority reside in group home situations (182 people – 58.2%). As would be expected, all 13 people currently accommodated in a mental health facility are from Sub-groups 1 to 3.

**Table 9 – Accommodation Type by Sub-group**

Sub-group	Accommodation Type									Total
	Family Home (incl foster & host family)	Group Home - NGO	Single Accom - NGO	Group Home - DSQ	Single Accom - DSQ	Boarding House/ Hostel	Correctional Facility	Mental Health Facility	Hospital	
1	-	1	1	1	-	-	2	4	-	9 – 2.9%
2	8	20	6	15	7	-	-	8	1	65 – 20.8%
3	19	34	18	84	10	3	-	1	-	169 – 54.2%
4	20	13	10	14	1	11	-	-	-	69 – 22.1%
<b>Total</b>	<b>47 15.1%</b>	<b>68 21.7%</b>	<b>35 11.2%</b>	<b>114 36.5%</b>	<b>18 5.8%</b>	<b>14 4.5%</b>	<b>2 0.6%</b>	<b>13 4.2%</b>	<b>1 0.3%</b>	<b>312 (100%)</b>

### Summary of data implications

On the basis of this snapshot of the potential target group there are likely to be approximately 10 people at any one time requiring such a secure level of care and support that they would not receive access to the community until it is deemed safe for them to do so with appropriate support. The ongoing aim would of course be to progress these individuals to a less secure form of support, where possible.

There is a second group (approximately 65 individuals) who would need restrictive practices to ensure that they did not leave their homes without appropriate support and a larger group (approximately 170) who may require restrictive practices on occasions to managing their challenging behaviour. They may or may not require support to access the community.

The final group (approximately 70) are a group who need intensive intervention around their behaviour to ensure that they don't progress to the use of restrictive practices in the future.

The data can be used to provide guidance as to where more secure living arrangements and intensive positive behaviour support for the cohort may be required. On the basis of this survey data it is likely that more robust living arrangements will be required in the South-East of the State located either in the Greater Brisbane or Moreton Regions or situated in a position allowing ready access to both these regions.

It is also likely that the capacity for similar living arrangements, albeit for smaller numbers of individuals, may be required in the Wide Bay-Burnett and North Queensland Regions.

### **CASE STUDIES**

In order to get a better indication of the target group I have included a number of case studies of a range of individuals within the cohort. The following twelve case studies give a feel for the life experiences, seriousness of challenging behaviour and the complexity of the support needs for some of the people within this cohort. The case studies describe for each individual, their diagnosis, life experiences (where possible), the characteristics and impact of their challenging behaviour, their current support and accommodation arrangements and the contact and interactions that they have with their family members. On looking at these cases one can only wonder whether the outcome and quality of life for some of this cohort would have been different if they had an opportunity to experience different care and support responses at particular stages in their lives.

#### Case Study A:

A with autism spectrum disorder, moderate intellectual disability, complex behaviour disorder. A also has a diagnosed mental illness, namely schizophrenia. A has difficulties in processing information, problem solving, reasoning and impulse control. A engages in sexual aggression towards females triggered by auditory hallucinations, absconding, and physical aggression towards others, which includes the use of knives.

A is an only child and has no other relatives living in Australia. Due to high levels of physical aggression A's mother reported difficulty in managing A's childhood behaviour. She received little support or assistance from external services or from A's father. Throughout childhood A experienced a lack of stimulation and attention and was deprived of stimulation and emotional and physical nurturing. A was subjected to physical and sexual abuse by A's father which remained unreported by a clinically depressed mother.

A's educational experiences were also disrupted. A's learning and behaviour problems became evident during A's first year of schooling. A proved unable to form peer relationships and demonstrated absconding behaviour and physical aggression. A was transferred to a special school at the age of seven years. A continued to engage in challenging behaviour in all environments and this intensified as A grew older.

A began receiving medication to manage A's behaviour and treatment was supervised by a psychiatrist at a local mental health service. The police first became involved in A's behaviour management around this time.

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, A's violence towards teachers and students escalated to include dangerous acts such as property destruction, banging other children's heads against walls and striking a student with a hammer resulting in placement at the special school being ceased. At this time A was admitted to the district Mental Health Unit (MHU) for physical aggression towards younger children.

A was transferred from the MHU to a provincial mental health service and was trialled on a range of medication, including antipsychotic medication. That same year A was transferred to the Security Patients Hospital (SPH) after committing multiple physical assaults on staff and patients, including attacks on a female nurse and female patient with a knife. A was detained at the SPH under the involuntary treatment provisions of *the Mental Health Services Act 1974-1984*. A was diagnosed with moderate mental retardation and superimposed functional psychosis of a sado-masochistic type. remained a patient at the SPH for approximately three years. During this time A's medication, including medication to be administered in response to behavioural outbursts, was reviewed and altered on a number of occasions.

Following a series of brief home visits and extended leave, A returned to the care of parents in 1987. A's physical aggression escalated to episodes of sexual assaults towards others including an episode where seriously assaulted mother. Day services with a non-government service provider which A had been attending for a number of years were terminated due to serious violence by A towards others including the use of wood and a hammer as weapons.

Up until this point in life A had a network of social acquaintances and relationships with other service clients. These relationships were reportedly severed due to A's physical and sexual attacks on those people familiar to .

In 1989 A was transferred to another mental health unit after parents refused to continue care. was diagnosed with schizophrenia with associated poor self control and sexual impulses. A remained an inpatient for several weeks after which was admitted to a closely supervised area within the Basil Stafford Centre. Strategies for managing A's behaviour included one to one staffing, removal to an area separate from other clients during the day and the stationing of a staff member outside A's bedroom each night. Subsequent to this, A received funding for 15 hours a week of community access and was referred to Family Planning and attended sex education sessions on a weekly basis. These strategies had little long-term positive impact on A's behaviour.

Whilst at the Basil Stafford Centre A attacked others on four occasions over two months and continued to demonstrate inappropriate sexual behaviour and sexual assault upon staff and co-tenants. A was assaulted and/or threatened by other co-tenants on 26 occasions.

In 1999 A was charged with common assault after strangling the neck of a female patron at a cinema when under the supervision of a staff member. A appeared before the Mental Health Court, was found to be unfit to stand trial and was regulated under the *Mental Health Act 2000*. was subsequently referred to the local mental health unit for ongoing management and treatment, while continuing to reside under close supervision at the Basil Stafford Centre.

Between 1997 and 1999, A's medication was reviewed on at least seven occasions. In 1999, A was admitted to a MHU on three separate occasions for incidents of physical aggression and auditory hallucinations. The following year

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was again admitted, but psychiatrists at the MHU requested that A not be admitted to the MHU again as (despite previous diagnoses) did not present with a mental illness and the stability of the MHU was being compromised by admission.

A's mother passed away . A attended the funeral but did not fully comprehend mother's death or the purpose of the funeral.

In June 2000 A was again regulated under the *Mental Health Act 2000* following charges of assault. was subsequently released under a forensic order and accessed outpatient mental health services. In 2003 A relocated to an alternative residence within the Basil Stafford Centre with three other men with challenging behaviour. continued to access the community through a non-government service provider. In mid June 2004 the intensity of A's challenging behaviours increased in response to anxiety related to a co-resident.

A comprehensive review of A's situation in 2005 led to relocation to current residence with one other man who also presents with high support needs and challenging behaviour. A has indicated a preference for living with this co-resident. The residence is a refurbished self contained villa in the grounds of Basil Stafford at Wacol. Each resident has own bedroom, shares kitchen and living areas and has access to an outside area surrounded by a high fence. A spends much of time using trampoline or gym equipment, looking at family photos, watching television or doing domestic duties which enjoys. appears contented in this situation and is supported by experienced staff. There are well advanced plans to construct a purpose built home for A and co-resident which will afford them both more space and privacy.

A remains under a forensic order which is reviewed six monthly. The order sets out conditions including that must reside within current secure residence, must take medication and be accompanied by staff when in the community. In January 2006 A absconded and assaulted two female staff members. Since this time community access has been extremely limited. It is anticipated that community access will be gradually reintroduced. A's medications are supervised by the psychiatrists at the local Mental Health Service and A receives additional mental health support from the Forensic Liaison Services.

A's father died in April 2006. A has adjusted well to the death with no apparent ill effects. The Adult Guardian has recently been appointed guardian for advocacy matters relating to A's behaviour management and risk assessment plans.

### Case Study B:

B with autism spectrum disorder, moderate intellectual disability, complex behaviour disorder, and a history of mental health disorders. B does not, however, have a diagnosable mental illness.

B's mother was 11 years old when her father committed suicide. There is a history of family dysfunction. B's parents separated in early childhood and B's mother reared the children alone. The family unit was chaotic and relocated 15 separate times.

In 1974 the local Department of Family Services Suspected Child Abuse and Neglect (SCAN) team became involved with the family following allegations of child abuse and neglect of B and older brother.

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B's mother demonstrated an erratic parenting style with an apparent favouritism towards the . She showed little affection towards the other children, including B. B's mother was unable to cope with behaviours and was paranoid and distrustful of services. In an attempt to control B's behaviours her response was to chain B to chairs or to the dog, and to forbid B from speaking.

B had a strained relationship with sisters and would frequently attack them. B appeared to have a close relationship with one of brothers and actively participated in activities with . However, this brother committed suicide after a prolonged period of depression. B did not attend the funeral. Family members appeared to have a poor understanding of B's developmental disabilities and learning impairments.

B attended mainstream preschool and then special school. From an early age B displayed increasingly severe challenging behaviour consisting of physical aggression (use of weapons), stealing food items, sexually inappropriate behaviours, and property destruction (interfering with electrical equipment). (1983) struck a horse after falling off it, lit fires and sexually harassed other students at special school.

Between 1985 and 1989, ongoing SCAN team involvement led to a care and protection order being taken out and B no longer being cared for by mother. staff from the special school, the Department of Families and Intellectual Disability Services assisted B to transition to Basil Stafford Centre. In the time that followed B participated in six sessions of Human Relations education with topics including relationships, sexuality and the human body. B's pattern of behaviours at this time included smearing faeces on objects, destroying furniture, urinating on floors, hurting family pets and physical aggression.

In 1992 B was referred to the Psychiatric Unit at a Brisbane Hospital and was later transferred to a facility for people with an intellectual disability. was then accepted by a nearby special school where structured behaviour plans were developed to improve B's social skills and capacity to cope with negative emotional states. However, B exhibited increasing incidents of extreme behaviours such as touching others on the genitals and injuring others with a knife. also made bizarre vocalisations such as "big bitch" and "kill granny" prior to the onset of challenging behaviour. Later in 1992 was suspended from special school for assaulting the school principal. During time at the facility, B frequently attacked co-residents and required a series of admissions to the mental health unit at a major city mental health service.

While residing at the facility between 1992 and 1994 B was referred to Commonwealth Rehabilitation Services which provided specialist management of individuals with psychological and behavioural disorders to access employment opportunities. B also attended counselling sessions at Intellectual Disability Services on a weekly basis for 12 months, regarding emotional expression and problem solving. B continued to display sexualised behaviour towards female staff and violently attacked a co-resident.

In April 1994 B was readmitted to Basil Stafford as the facility was closed and other suitable accommodation could not be found. B displayed increased anxiety, agitation, and disturbing behaviours such as fire setting and stealing of food items. A trial placement in a private residence in 1994 was terminated after one month because B attacked a co-resident with a broken cup causing severe injuries to the resident's face. B was admitted to a mental health unit for two weeks observation regarding violent

and sexual behaviour. Psychiatrists assessed [redacted] as not having a psychiatric disorder but requiring a stable, structured, and consistent living environment.

B was again admitted to Basil Stafford in October 1994 where [redacted] has resided ever since. In 1997 B was accepted into a Behaviour Awareness Group at the Dual Diagnosis Unit, Wolston Park Hospital. B completed the 12 session program and actively participated in the behavioural strategies. Since 1998, records indicate that B's medication has been reviewed regularly and the impacts of changes monitored closely. B continues on a range of mood stabilising medication.

B currently resides with one other man with high support needs and challenging behaviour. The residence is a villa in the grounds of Basil Stafford with shared kitchen and living areas and separate bedrooms. B has access to an outside area surrounded by a high fence and open access to [redacted] trampoline outside the yard. B enjoys using [redacted] trampoline, watching television and spending time with staff. The environment allows B to spend time alone as required. B will move into a new, larger residence in the same area once it is constructed, which will afford [redacted] further privacy.

B currently receives six hours of supervised community access per week where [redacted] does [redacted] own banking. Early in 2006 B attacked a staff member in a shopping centre after a community visit. This has led to limitations on the time and range of community visits.

B has had no regular contact with [redacted] mother or siblings for several years. Staff working with [redacted] in [redacted] current residence are taking steps to re-establish contact, in consultation with B.

### Case Study C:

C [redacted] with mild intellectual disability. C engages in violent and aggressive behaviour towards others and property, and obsessive behaviours. C's obsessive behaviours include a fascination with mail, phones, and cleaning. [redacted] obsessions have led to stealing postcards and mail, destroying phones if [redacted] is refused constant access to the phone, and agitation if [redacted] can't clean [redacted] clothes as soon as they have become dirty.

C was raised by [redacted] parents and resided in the family home with [redacted] parents and sister until [redacted]. C considered [redacted] relationship with [redacted] father as special and would become physically aggressive and abusive (hitting, kicking, punching) towards [redacted] mother and sister if [redacted] perceived they became too close to him.

[redacted] C's parents allowed C very limited access to the community during childhood and adolescent years.

C attended a special school [redacted]. During [redacted] school aged [redacted] years C was described as pleasant and compliant by teachers, displaying only minimal challenging behaviours. C would refuse to do tasks and activities, be passive aggressive in [redacted] responses, and engage in some stealing behaviours.

In [redacted] adolescent years C started to become increasingly more aggressive and abusive with more incidents of stealing between the [redacted].

In 1990 when C [redacted] decided to move out of the family home and [redacted] family supported [redacted] decision to become more independent.

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C resided there until (approximately 1990-1995) when another vacancy in a house with the same non-government agency became available. C lived with 11 other co-residents in the client residence.

C decided to live independently in the community with , who also has an intellectual disability, when was in approximately 1994 -1999 . During time living in an accommodation setting with very minimal drop-in support, C 's behaviours escalated into more challenging and dangerous behaviours. C would attempt to engage in sexual liaisons with any male with whom was familiar. In particular, C would "hang out" with a group of males in the city, some of whom were known to the police. This behaviour put C at risk of being a victim of violent assault . C would also accost males met at employment service. During this period, it is reported that C did not take anti-psychotic medications which had been prescribed for mood stabilisation.

C's stealing and obsessive behaviours intensified with C constantly stealing bins, mail, money, and items in shops. C would take neighbour's mail and throw it away, and take other people's bins from outside their property. The police responded to numerous complaints and spoke to C many times. Eventually C was charged with stealing, fined \$400 and ordered to do community service. This occurred more than once. From around 2000 to the present C has been charged approximately 6 times with stealing C has subsequently appeared before the Magistrate's Court on numerous occasions.

On a number of occasions in 2003, while residing with , C became abusive (kicking, punching, use of weapons) towards resulting in being taken to the emergency ward several times. That same year, after an abusive incident, police escorted C to the watch house where was detained for 4 hours, a domestic violence order was issued against C and was not permitted to return home. Against family's advice C's rescinded the DVO.

Later that year C was taken to a mental health unit as a result of uncontrollable aggressive behaviours, including threats of self harm and suicide. C's injuries (cuts) were attended to however C was calm when arriving at the hospital and was subsequently released from the MHU.

C received a lifestyle support package through DSQ in 2001 which afforded 4-6 hours of community access a day. A non-government agency also developed a positive behaviour support plan for C which included money management, community skills, domestic skills (washing, cooking), and social skills training. Funding for the staff to monitor this plan was ceased after a year and again continued in 2004 through an external consultant. A new behaviour support plan was developed by a DSQ behaviour support team in 2005. This team currently still provides support to C.

In 2004 continued to engage in challenging behaviours. Notably C would be verbally and physically aggressive towards support staff and destroy the phone when staff would not allow C to call and breach the DVO. C would tell to give all money, which did.

In September 2005 a domestic episode ensued C was again charged and issued with a DVO. This DVO is currently in place. C relocated to a non-government supported accommodation house with one other co-resident. Though a DVO had been issued C continued to make contact with . On occasions C would visit , invite other males to home, and flirt and attempt to



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went to bingo, lunch, shopping, and dinner with mother. D frequently accessed the community independently in his adulthood. D's mother died when D's father died prior to this.

D attended special school and during school years there were no reported issues or incidents of challenging behaviour. D was described as easy going and did not have a history of aggressive or challenging behaviour as a child, adolescent or even as an adult up until the

In 1998, D moved out of home and into a non-government semi-supported accommodation facility. Twenty-four hour support was provided, however residents were permitted to come and go as they pleased. D resided there for approximately 5 years.

In 2001 when D was hit by a car while riding bicycle. sustained several broken bones but no reported brain damage. Shortly after the accident began to display significant challenging behaviours. D engaged in uncontrollable aggression, hitting and punching others from behind (co-residents and staff), stealing co-residents' belongings, assaulting those who confronted and threatening to hit staff. D also assaulted two police officers. speech also deteriorated. used more gestures than words, and became harder to understand. This resulted in D becoming frustrated when people couldn't understand. D's social skills and mobility also decreased, resulting in increased incidents of challenging behaviour. As a result, community access was limited to 2-3 times a week under strict supervision.

In that same year (2001) heart condition worsened which resulted in heart surgery.

D relocated to a more secure accommodation facility with the same non-government agency. While residing there D was consistently aggressive towards a young female staff member which culminated in D indecently dealing with the young woman. As a result, D's support agency decided to allocate significant additional internal funds to support D in a one on one accommodation support arrangement.

In 2004 D's aggression towards co-residents and staff intensified and included punching, kicking, throwing small objects and threatening assault. D also consumed large amounts of food using tools to get into canned items. In one instance D consumed 4-6 litres of milk and 2 loaves of bread in one night.

D's obsession with unconstrained eating also resulted in police involvement. D began visiting the local bakery and convenience store to locate items to consume. On one occasion D took 2 dozen bottles of coke and 6-8 ice cream bars and walked out of the shop without paying. D became aggressive with those who tried to intervene, throwing objects at and threatening to assault shop owners. The police were called and attempted to discuss the issue with D, however threw rocks at and verbally abused the police officers. Despite a police warning D repeatedly engaged in stealing food items and destroying property which eventually led to further police action. D was charged with improperly dealing with shop property, being a public nuisance, and attempting to assault a police officer. D appeared at the Magistrate's Court and was issued a \$400 fine which parents paid. As a short term strategy, DSQ emergency funding was used to provide extra support to minimise D's obsessive visits to the shops in the afternoons. This was successful but was not a long term option.

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Also in 2004 while on a walk with a support worker D found a plank of wood and attempted to attack the staff member. D then broke into a house in the community. The police were called and escorted D to the watch house where was charged with attempted unlawful entry. D was due to appear before the Mental Health Court however broke ankle in a fall and the police dropped the charges.

After the fall D remained in a private hospital for three months while fractured ankle healed. D engaged in aggressive behaviours towards hospital staff, stealing food, chasing staff, roaming the corridors and harassing other patients. Urgent and critical funds sourced from DSQ were used to provide one on one support for D during stay in hospital. While still in hospital (June 2004) a CAT scan and other assessments were conducted over 6 weeks. Results indicated no signs of dementia however there was some neurological break down consistent with progressive Alzheimer's disease. D was admitted to the local mental health unit for two months because behaviours were too difficult to manage in a mainstream hospital.

In the same year (2004) the non-government agency providing accommodation and support services to D engaged an external consultant to review D's situation. The consultant recommended that D move to a more secure environment. A DSQ behaviour support team also worked with the external consultant to develop behaviour support strategies for D within residence. The non-government agency considered that an unsuccessful application to DSQ for recurrent funds made in 2004 would have assisted in more effectively maintaining D in a suitable support arrangement. However, in the absence of additional funds, the non government agency relinquished care of D to DSQ in late 2005 on the basis of insufficient funds, a lack of specialist staff skills, the lack of a suitable facility and incompatible clients.

Since coming into DSQ's care D has been supported in a number residences with a view to accessing an appropriate long term arrangement. In early June 2006 D relocated to current residence which is a DSQ accommodation support and respite service house with 24-hour support. The house is in a semi-rural setting where lives with three other co-residents with disabilities. It is not a secure facility with the front door remaining unlocked during the day; however the house is situated on acreage. The backyard gate is locked due to the absconding behaviours of one of D's co-residents. D is supported by a team of five support workers with one staff member providing support to all four residents at any one time.

D's current challenging behaviours include kicking, punching, throwing objects, excessive eating, stealing and threatening to assault others. current treatment includes anti-psychotic medications for mood stabilisation and anti-convulsant medications for epilepsy.

A stable routine of community access has not yet been established in D's new residence, however would currently go out into the community 1-2 times a week. Due to D's incontinence and increasing mobility difficulties (D uses a walking frame) accessing the community has become more difficult.

Whilst D's parents are deceased, D has weekly phone contact with brothers and spends some holidays with family. D's family are close and usually maintain regular contact with D.

### Case Study E:

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E was diagnosed with autism spectrum disorder and a suspected metabolic disorder. In the past there has been suggestion of a mental illness, however no formal diagnosis has been made of mental illness. E displays cyclical but prolonged episodes include kicking, punching, screaming, property destruction, self abuse, and the throwing and smearing of faeces.

E was raised by [redacted] mother and father together [redacted]. E displayed delayed milestones as a child and from an early age is reported to have displayed frequent oppositional behaviour, emotional outbursts and temper tantrums. Reports suggest that E's parents used a firm approach with E but there was no reported abuse.

E attended special school from [redacted] and continued attending until [redacted] 1986. Little is known of [redacted] school years other than on exit the school indicated that E's future was unclear and that there was "no clear path" forward. Throughout [redacted] school years and up to 1988 E lived at home. In 1988, records from a non-government day service indicate that E's behaviours included pacing, throwing water, touching others, temper tantrums and inappropriate masturbation.

In 1989, E's parents referred [redacted] to DSQ, indicating that they could no longer cope with [redacted] behaviour. From this period E was supported by a series of funded non-government service providers all of which have withdrawn service. Reports suggest these agencies have withdrawn services on all but one occasion not because of the challenges that E presents to service providers, but because of difficulties working positively with E's family, particularly their insistence that staff use restrictive practices to manage E's behaviour.

E has been supported by DSQ operated services since April 2001. Since assuming a service provision role DSQ has provided 24-hour accommodation support, 7 days a week. A team of 5 direct support workers have provided the majority of support with assistance from casual staff. Due to the nature of E's behaviour, it has proven difficult to identify staff willing to work with [redacted] and to retain staff.

E's behavioural pattern is cyclical in nature. Typically, 3 to 4 week periods free from challenging behaviour are followed by 3-4 weeks of challenging behaviour. During this time E displays prolonged episodes of behavioural outbursts that include punching, kicking, property destruction, screaming, self abuse and throwing and smearing of faeces. Assessments have been unable to explain these behavioural cycles.

E has injured a number of staff. Staff have suffered cuts, scratches, and bruises from punches and kicks.

On occasions the Police have been called by neighbours (due to the level of noise during extended episodes of challenging behaviour) or by ambulance officers to assist in restraining [redacted].

To date all attempts at modifying and reducing the occurrence of these challenging behaviours have been unsuccessful. A number of behaviour intervention plans have been written and various strategies implemented without noticeable impact on the frequency or intensity of the behaviour. For this reason more recent strategies have focussed on minimising the impact of E's behaviour. This approach includes removal of community access to reduce the likelihood of risk to the wider community.

DSQ reports support the experience of earlier service providers describing the difficulty in working with E's parents. E's family berate DSQ staff, have been obstructive in

pursuing appropriate medical assessments for E and frequently raise complaints within the department and with the media.

Around 2001 the Adult Guardian (AG) became involved when concerns were expressed by DSQ staff about inappropriate personal and health care decisions being made for E by E's parents. In 2004 the AG recommended an independent medical and psychiatric assessment be conducted. This led to the commissioning of a comprehensive health assessment for E by the Queensland Centre for Intellectual and Developmental Disability (QCIDD). The assessment occurred in early 2006. The final report is yet to be completed.

E currently resides alone in a Department of Housing owned unit which is staffed by two DSQ support workers for 8 hours each day and one support worker at other times. During periods of escalating behaviour, two staff are rostered on for longer periods to reduce the incidence of injuries to staff and to E. The living area is divided into two distinct areas. One area is very sparsely furnished with essential items fixed to floors and walls and a television set behind a Perspex screen. E is confined to this area when is in a period of challenging behaviour, due to destructive behaviour. When E is more settled has open access to a second area which is comfortably furnished.

E still enjoys a close relationship with all members of family including siblings. E's parents are still very active in life and visit often. spends every 2<sup>nd</sup> or 3<sup>rd</sup> weekend with them unless is engaging in very challenging behaviour. E has limited community networks, apart from one friend who visits briefly on occasions.

family have stated that behaviour is less intense and frequent when visiting the family home, however they have also acknowledged that, at times, they do use physical restraint.

E's likes singing, dancing, walking, crafts and working on scrapbook. also enjoys dressing up & going out, and going for coffee or a meal.

E may participate in community activities on a daily basis depending on behaviour. Currently when E engages in challenging behaviour is restricted to unit and refused access to the community. Reports suggest that it is unlikely that this level of restriction will be reduced in the short or medium term.

### Case Study F:

F with a mild intellectual disability, Borderline Personality Disorder, Depressive Disorder (not otherwise specified), and Type II Diabetes. F has an indigenous background (mother's side). F engages in aggression towards others, self harming, property destruction, lighting fires and stealing. These behaviours tend to be cyclical in nature and seem to occur every 2-3 days unless triggered earlier.

F's parents were separated when was young and F was raised by paternal aunt interstate from the. F also lived with grandparents for one year when. F's mother had no contact with after the separation and moved interstate. F does not talk about mother at all. F's father remained in contact though he was not very present in life. F attended a special school to year 10 level. During school aged years F engaged in challenging behaviours such as walking out of class, verbal abuse, physically attacking teachers and other students (putting them in a headlock), and stealing items.

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On one occasion F was banned from the school bus and taxi service for 10 weeks as a result of challenging behaviours. The school developed various strategies to assist F in coping with the classroom environment however after numerous incidents the school suggested that F leave and threatened to call the police in the event of another incident.

While living with aunt F told teachers was being abused. The family and F's aunt subsequently were investigated and cleared due to a lack of evidence.

In adolescent years F assaulted grandmother and aunt and engaged in constant displays of aggression towards others which included bullying individuals who could not defend themselves (smaller children, teacher aides), verbal abuse, self harming behaviours, damage to property and stealing from others.

In November 2003 relocated to Queensland to live with another paternal aunt as F's aunt was no longer able to provide care.

F became known to DSQ in March 2004 through intake processes and in April 2004 F received an Adult Lifestyle Support Package. Services were provided through two non-government agencies over several years until F refused support in April 2006.

(2004) claimed had been raped. Social workers and health care workers from an Indigenous support group and the hospital were engaged to provide counselling and investigate the allegations. F refused a medical examination and became aggressive and avoidant when pushed for details of the alleged incident. Counselling sessions were continued for months, however no outcome was reached.

In 2004 F was consistently aggressive towards aunt and grandmother. Consequently, F was moved out of aunt's (Qld) house and into a hostel. This placement was unsuccessful due to an altercation with another hostel resident, incidents of stealing, lighting fires and absconding. This resulted in police involvement. F then required emergency accommodation and was placed in a non-government charity organisation for young people for three months. While residing at this facility F absconded and stood in the middle of a highway. was escorted back to residence by police. F received 24-hour support while residing in this facility and reports indicate a reduction in challenging behaviour. In June of the same year the accommodation placement was deemed inappropriate and subsequently ceased.

F (June 2004) again relocated from the emergency accommodation facility to a supported accommodation house with a non-government agency. While residing there F's behaviours escalated into numerous critical incidents. Specifically, F hit a support worker and community member at the local shop, hit staff in the house and damaged vehicles, broke an ashtray and cut a staff member's wrist which required 5 stitches, cut own arm with a razor and locked support workers out of the house. F also attempted to stab another co-resident and was charged with attempted murder. F was held in custody in the watch house for five days and then transferred to a Brisbane correctional facility. F was incarcerated for approximately 4 months and released on bail in January 2005.

Upon release F resided in another non-government supported accommodation facility, funded through DSQ's Adult Lifestyle Support Program. In February 2005 again exhibited property damage, fire lighting, and physical aggression towards others, in one instance pinned a staff member to the wall and repeatedly hit them. F became increasingly obsessed with violent movies and

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music and identified with the Columbine Massacre. Support staff threatened to leave and refused to work with F.

In that same month (February 2005) F was admitted to a mental health unit (MHU) for 3 months. The behaviours of concern included self injurious behaviours, threats to others and self with a knife, and physical aggression.

In September 2005 F was offered a place with the Innovative Support and Housing (IS&H) Project and resided with two other clients with disabilities. Over a period of two months F displayed aggressive behaviours toward staff and clients and refused to adhere to the house rules and processes. During F's time at the IS&H program physically assaulted a staff member and was charged by police with 'assault with a weapon'. F faced the Magistrates Court for this offence on 3 July 2006.

2005 (September – December) F was admitted to a MHU several times for attempted suicide and self harming with sharps. stays at the MHU ranged from one day to a few hours. As mental health professionals had not assigned F a formal diagnosis they continued to release F shortly after admittance.

While in the MHU during one of the admittances F met current who has a diagnosis of paranoid schizophrenia. F moved in with new

Over 2005 and 2006, F has attended various psychiatrists, doctors and community services, however, quickly refused to participate and terminated attendance.

Currently F is living alone with . The house is owned by mother and they live rent free. F has complete freedom of movement. has the ability to access the community independently and participate in activities such as swimming, shopping and visiting friends with . However, reports show that F currently prefers to live a sedentary life staying home, doing no household chores, and engaging in activities such as smoking, drinking, and occasionally drawing or watching television. Before F refused support in April 2006 was receiving 18hrs per week of community access with a community based organisation.

F currently has a parole officer from the Department of Corrections and is required to appear at the police station each Friday.

There have been no reports of significant incidents since F has been living with . No suicide attempts, major self harming, or aggression has been reported. However, F recently (3-4 weeks ago) assaulted sister and grandmother over an incident while was living with but visiting family.

Whilst residing with , on a number of occasions F returned to the Innovative Support and Housing facility. However, became aggressive, physically and verbally assaulting staff and on one occasion stole a vehicle. F was not charged for the stealing offence.

F was previously on daily anti-psychotic medication and medication to be administered in response to behavioural outbursts. Since it is unknown whether F has ceased taking medications.

F maintains regular contact with family members via phone and visits. F is respectful of father and has a good relationship with . F's father has recently moved to

Queensland from Western Australia. F and father, and aunt maintain regular phone contact. also visits grandparents however contact has been reduced due to the risk of F causing harm to them.

### Case Study G:

G diagnosed with a moderate intellectual disability and autism spectrum disorder accompanied by significant sensory and communication impairment. G has also been assessed as having a personality disorder. G has a history of exhibiting complex challenging behaviour which include inappropriate sexual advances towards adults and children, aggressive and violent behaviour towards staff and members of the public, major property damage, the use of broken items as weapons, abusive and threatening verbal behaviour and inappropriate urination and bowel movements.

G was an overdue baby born “blue” after a long labour. G was raised by mother and father. G was hyperactive as a child and delayed in attaining the normal milestones of growth. mother reported that was not particularly impulsive as a child. G’s parents reportedly had a stressful relationship. G’s father reportedly often belittled mother which resulted in G having a negative attitude towards mother. G’s father was diagnosed with borderline personality disorder and depression. There have been allegations that father mentally and physically abused G. G did not develop a close relationship with either parent. G’s closest familial relationship formed with sister.

G’s mother and sister have reported that G was an ‘odd’ child. would not interact with other children and never had any friends. G found it very hard to socialise with other people and gradually became more aggressive as got older.

G attended special school from an early age. did not interact well with other children and preferred working in isolation. School reports indicate that minor aggressive outbursts occurred during the school years but there were no major incidents reported at school. G developed set routines when at school which enabled to feel secure. This strategy did help G achieve some success with learning. G was very opposed to change and needed to be constantly monitored and cued to finish tasks on hand.

G’s parents report that at the (1991) started to become more aggressive at home. ran away from home and hid in nearby cane fields after aggressive and destructive behaviour. On one occasion smashed every window in the house with rocks. At this time G did not self harm.

In April 1995 G was placed under a care and protection order through the Department of Families. This order was reportedly due to father making threats of physical violence to G, the family and . G was relocated from home into care. The scope and frequency of incidents during G’s time in care are not known. The care and protection order ceased in 1999. G’s father passed away that same year. G had little understanding of father’s death.

In May 2000 G was admitted to the local mental health unit. was diagnosed with moderate intellectual disability, autism spectrum disorder, epilepsy, psychosis and signs of obsessive compulsive disorder (OCD). was managed in the Intensive

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Care Unit after absconding from the open ward, assaulting wardsmen and kicking a glass panel off a sliding door. Reports indicate that G was secluded on a daily basis for acts of violence directed towards staff. Reportedly G urinated and defecated on the floor and furnishings. During stay received daily injections of anti-psychotic medication to control behaviour. On one occasion G severely bit a staff member. This led to G's admission to a medium secure unit in an inpatient mental health facility in June 2000 as a regulated patient on the direction of the Director of Mental Health.

During G's stay at the inpatient facility G's behaviour was described as very guarded and suspicious. became very aggravated and aggressive if, when asked questions of staff, they would not answer to satisfaction. Staff found it very difficult to build rapport with G. continuously requested the staff to have the door locked. At times G became fixated with particular patients and chased after them. On some occasions had to be managed in the Intensive Care Area of the Unit. G also displayed obsessive behaviour such as eating in room with the door locked and insisting that staff hold elbow in the toilet.

In October 2000 G was placed in the care of Disability Services Queensland (DSQ), initially on a temporary basis, after continued disagreement between DSQ and Queensland Health staff regarding primary diagnosis (intellectual disability and/or a mental illness) and the agency with primary responsibility for G's treatment and/or care. This arrangement became permanent as it was recognised that G's behaviour was becoming extremely complex and more aggressive. G was transferred to a DSQ villa-style accommodation support arrangement.

G assaulted staff on numerous occasions from this period. incurred major property damage which led to living environment becoming very bare. All walls were covered with thick plywood and glass panels were replaced with lexcen. All kitchen appliances were removed and the kitchen became dysfunctional as it was a target of destruction by G. G also engaged in major vehicle damage. This happened at times when the vehicle was moving, putting those in the vehicle and members of the public at risk. G was supported by 1 male Residential Care officer (RCO) for 24 hours a day during this time, but backup was sourced from an arrangement next door which had 2 male RCOs supporting a young man.

In 2004 the Adult Guardian was appointed G's guardian for accommodation decisions, health care, including mental health assessment and assistance, services and behaviour management programs. This same year after admission to the MHU, a psychiatrist refuted earlier diagnoses of psychosis and OCD. Instead the diagnosis was intellectual disability, autism spectrum disorder and a conduct disorder or anti-social personality disorder. It was recorded that G would not derive any further benefit from the mental health team.

During 2004 G continued to be supported in the villa arrangement. G's behaviour started to escalate once understood that there was only one staff person on shift. A major incident occurred in February 2005 after an extreme escalation of behaviour occurred. G broke a door off its hinges and attacked the single staff on shift who was seriously injured. This staff member has been unable so far to return to support worker duties. As a result of this incident G is now supported by 2 male residential care officers each shift for 24-hrs a day, 7 days a week.

In early 2005 a behaviour management plan was approved authorising the use of restricted medication in response to behavioural outbursts, physical restraint and

environmental containment. The physical restraint component requires two staff at all times. This plan is reviewed monthly by the Systems for Behaviour Support and Management (SBSM) committee.

A full service review of G's service is underway, overseen by a range of relevant DSQ staff and a representative from the Office of the Adult Guardian. G's medical practitioner receives the meeting minutes. G's medication is monitored by his general practitioner in consultation with a psychiatrist from the local community mental health service.

G currently resides in villa style accommodation operated by DSQ. It is a secure environment with purpose-built locked doors, lexcen windows, high timber fences with barrel tops and locked gates.

Two residential support officers provide direct support to G 24-hours a day, seven days a week. G also receives specialist therapy support including access to a psychologist. Consistent implementation of behavioural strategies over the last twelve months has resulted in positive outcomes for G. These positive outcomes have resulted in increased community access (walks in his local area 3-4 times a week), improved interaction with support workers, which include reading, writing, craft, games, safer access and improved interaction with visitors to the site and more intimate family visits.

G's mother and younger sister are only family contact. They visit G approximately 4-5 times a year.

The extended family will not make any contact with G. At present, G's social network is limited to mother, sister and support workers.

### Case Study H:

H with moderate to severe intellectual disability, autistic spectrum disorder and severely challenging behaviour. has significant difficulty receiving and interpreting verbal information and can react violently in situations where feels a loss of control. has intensive support requirements due to proneness to self harming behaviour, property damage and serious aggression towards others, including hitting and severe biting. H has no diagnosed mental illness; however, displays marked and persistent difficulties with social and personal judgements characteristic of some mental disorders and which manifest in unpredictable and harmful behaviour with no identifiable triggers.

Little is known of H's early family and or educational experiences, but admission to Basil Stafford Centre suggests behavioural challenges from an early age. H was admitted to Challinor Centre, a facility for adults with an intellectual disability due to "extreme aggression" towards staff and young clients at Basil Stafford and setting fire to nearby bushland. Over time at Challinor Centre, H was relocated to residential arrangements with increasing levels of supervision and security, due to aggression towards staff and other clients. In 1988, H was admitted to the Barrett Centre after violent behaviour towards staff at Challinor Centre and , admitted to Wolston Park Hospital even though was not diagnosed with a mental illness.

Throughout time in Challinor Centre and Wolston Park Hospital, H retained six weekly contact with parents who would travel some distance to visit. H was invariably pleased to see parents, well behaved on outings and immediately afterwards.

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H's extreme aggression continued throughout stay at Wolston Park and in 1996 was transferred to the Pappora Unit, a ward within Wolston Park Hospital for people with an intellectual and/or dual intellectual and psychiatric disability and severely challenging behaviour. Behaviour support plans developed at the time indicated the need for highly experienced and appropriately trained staff in the management of H's behaviour. For instance, plans suggested the need for more than one staff on shift at all times, that all staff be trained in passive self defence techniques and that consistent techniques for communication be used at all times to reduce the likelihood of behavioural outbursts.

In 1997, H was again moved to a more secure arrangement in the maximum security unit at the John Oxley Memorial Hospital (JOMH) after assaulting staff at Wolston Park. The Mental Health Court placed H on an involuntary treatment order in a medium security ward within JOMH where H remained for the next . H was commenced on a regime of psychotropic medication to reduce the frequency and intensity of H's aggressive behaviour. H was considered inappropriately placed within a mental health facility given that assessments continued to indicate that H had no diagnosable mental illness.

From this period, ongoing discussions ensued between Mental Health Services and Disability Services Queensland regarding a more appropriate accommodation arrangement. The goal of long term placement in an appropriately supported community environment close to H's parents remained the goal of parents and service providers.

In August 2002, DSQ allocated a project officer to work with staff from JOMH and the family to transition H to DSQ services; however, it was acknowledged that this process required considerable planning and an extended timeframe given H's long history of institutionalisation. Both departments assumed responsibility for developing an arrangement that maximised successful transition to the community while minimising the risk of harm to the wider community. In March 2003 the Mental Health Review Tribunal revoked H's involuntary treatment order because H had no diagnosable mental illness. H was transferred as a voluntary patient to the Park Centre for Mental Health (the Park) as an interim arrangement and DSQ was formally directed to continue to work with Queensland Health to develop a transition plan for H.

By mid 2003 H was receiving funding from Disability Services Queensland to facilitate community access while residing in the Park and discussions continued about an appropriate community placement. Later that year H was accepted on the waiting list for a place under the Intensive Support and Housing (IS&H) initiative being developed by DSQ. This DSQ initiative focussed on developing non-custodial and transitional accommodation and support options for people with complex and challenging behaviour, including the construction of purpose built residences. In early 2003 H was considered for relocation to an IS&H residence to be closer to H's parents, however, the intensity of H's ongoing support requirements could not be catered for by the non-government service provider at the facility.

H's mother died in early 2004. Through 2004 negotiations for H's transition to an alternative IS&H facility in Brisbane were protracted due to delays in the construction of the building. These negotiations were further complicated by H's strong tendency to damage and destroy property including ripping clothing, manchester and other bedding materials, removing cupboard doors and fittings and placing objects in the toilet. These behaviours necessitated further negotiations regarding building modifications required to cater for H's needs. In April 2005, H's DSQ-funded community access was stopped following an assault of a staff member in the community.

In August 2005 H appeared before the Mental Health Court on five charges of assault. Following this the Adult Guardian was appointed H's guardian for decisions relating to living and support arrangements. Given the high and the extreme potential for ongoing aggression towards co-tenants, H was considered for placement in one side of a south east Queensland IS&H facility, sectioned off from other co-residents. This arrangement was further delayed due to difficulties finding appropriately experienced and trained staff and in meeting the requirement of the Adult Guardian that, before leaving the Park, a contingency plan needed to be developed in the event that the IS&H arrangement proved unsuccessful. This proved difficult particularly because DSQ was unable to identify an alternative arrangement and the Queensland Health position was that H would not be readmitted to the Park at any time in the future.

H is currently accommodated as a voluntary patient (as decided by the Adult Guardian) in the Dual Diagnosis Unit at the Park. Whilst this is not a secure unit does spend large amounts of day secured in room on seclusion. Sometimes this is through personal choice; however, this seclusion is part of behaviour management plan. The staffing arrangement fluctuates between one to one only and one staff to four patients.

H continues to display frequent challenging behaviour which usually involves assaulting another client or carer on a weekly basis. Further, on what appears to be a 5-yearly cycle, H has engaged in episodes of assault comprising severe biting, one such incident in the past resulting in the severing of a victim's finger. H does not currently have any community access as the frequency of assaulting others presents a significant risk to the wider community. H's father, who is in his mid-80s, has continued to visit H on a six weekly basis until recently.

After significant assessment and consideration of existing options the Director-General DSQ has recently informed the Director General Queensland Health that DSQ will not be able to take over the care of H as he presents an unreasonable risk in the context of DSQ's currently available service options.

### Case Study J:

J who has a moderate intellectual disability and attention deficit disorder. displays extreme and persistent sexualised behaviour generally targeting young and vulnerable girls. has no diagnosed mental illness.

J has siblings, of whom have an intellectual disability and are clients of Disability Services Queensland (DSQ). J lived in the family home with mother when was placed in the care of the Department of Child Safety (DChS) at the request of family. mother relinquished care, stating that she could not manage aggressive and sexualised behaviour. Prior to this had experienced numerous separations from family both in short-term care and respite care. J's father has a history of violence and is currently incarcerated at a correctional centre for a violent offence against a member of the public.

J's family have been in the child protection system since 1991, with a total of 15 notifications recorded. The most recent notifications from 2002 – 2005, relate to J's sexual abuse of sister. J's mother displays a lack of insight into sexual offending and a limited capacity to recognise the risk poses to community. She has previously failed to protect her daughter from J.

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J demonstrates a significant attachment to mother and siblings. Although mother plays a significant role in life, it is the Department of Child Safety's assessment that the mother's inconsistency in her relationship with her contributes to levels of anxiety and confusion for J.

Between 2002 and 2005, J was charged with a number of offences including sexual assault against sister and a further five counts of sexually related offences against children.

J has had various placements while in foster care. In January 2003 breached the conditions of bail by absconding from various placements and on one occasion was found in the bedroom of a four year old girl. was placed in Brisbane Youth Detention Centre (BYDC) as no alternative secure accommodation could be found to contain J and protect the community.

In February 2003, J was released from Brisbane Youth Detention Centre (BYDC) and placed in a unit with a youth worker providing 24-hour support. In March 2003, J was placed with carers working for a not for profit organisation providing a range of programs to young people with disabilities in crisis. This placement broke down due to J exhibiting violence, non-compliance and truancy from school. also made an allegation of abuse against the carer.

J continued in and out of placements until October 2003 when was placed with carers from the same service in a different location. Again the placement broke down due to the difficult behaviours exhibited by J, primarily related to non-compliance. Later in 2003, was again placed with carers from the service and resided there for almost a year. The placement ended after J physically attacked the male carer.

From December to mid January 2004, J lived in various homes, all short-term placement options. In January 2005 was placed in accommodation provided by the DChS utilising a youth worker model.

In March 2005, re-offended and was charged with indecent treatment of a child under 12 years, sexual assault and deprivation of liberty. was refused bail and placed in BYDC. was remanded in custody between March and October 2005. Extensive assessment during this period ascertained that J was unfit to stand trial due to the degree of intellectual disability and lack of understanding of the court process.

From March 2005 to October 2005, J remained at BYDC, with the Mental Health Court stipulating it was the DChS's responsibility to develop an alternative to ensure that J could be released into the community. The department proposed a youth worker support model in a private rental situation following Queensland Health Child and Youth Forensic Outreach Service (CYFOS) recommendations. A DSQ-approved service provider was engaged to provide the support. J was released into the community on a forensic order on 11 October 2005 under the care of DChS and the service provider. The conditions of the forensic order required that J remain under the constant supervision and direction of youth workers (operating within a 2 to 1 model of support) and under regular psychiatric review. The forensic order also specified the supervised nature of the contact between J and family and peers.

In January 2006 J allegedly offended against young female neighbour, by climbing through her window before getting into her bed. was charged with 1 count of indecent dealing and 1 count of burglary. appeared at the Magistrates Court and

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was refused bail. was remanded in custody at Arthur Gorrie Correctional Centre. Again there was significant pressure on DChS to find a suitable community option.

In April 2006, DChS submitted a community-based support option to the court which was assessed and rejected by Queensland Health's CYFOS on the grounds that it was a co-location model (with three other youths), with only one youth worker on at night. Additionally, the physical layout of the home did not fit within the prescribed recommendations of the CYFOS assessment.

J has remained in the Mental Health Unit (MHU) at a local hospital since April 2006 which is a secure arrangement with 24-hour staffing.

At present DChS is funding 50 hours per week youth worker support through a non-government agency. Some of this support occurs in the hospital and some occurs in the community. CYFOS recommendations stipulate that any outings outside of the hospital must include two youth workers at all times. Consequently, this substantially reduces the number of hours of service available to J in a week. DChS is also considering respite options to allow J to be supported away from the hospital every second weekend.

The youth worker support hour are also used to allow J to receive private tuition within the MHU to meet educational needs. Educational input has recently commenced and includes private counselling sessions on grief and loss relating to J's current incarceration and life skills training. J will also receive counselling from Queensland Health staff while in the MHU on loss of freedom and developing a lifestyle without offending.

J has shown the capacity to respond to questions and comply with most directions given to and has learnt a number of effective behaviour self-management techniques. This suggests that has a number of strengths and abilities that may be developed to further improve behaviour.

A timetable has been developed between DChS, Queensland Health and J's family to ensure regular contact with J's mother and siblings. Outings with the family outside the hospital must be supervised by two youth workers. To date J's mother has been inconsistent in keeping to this timetable.

Once J reaches DSQ will assume the role previously undertaken by DChS. Consequently, DSQ is preparing a Young Adult Exiting the Care of the State submission requesting funding for similar supports to the current DChS arrangement. A secure mental health facility is the only legal option at present as DSQ does not currently have an accommodation option that meets the requirements of J's forensic order.

### Case Study K:

K diagnosed with XYY Syndrome which is associated with moderate intellectual disability. and due to condition is expected to continue to grow. K engages in a range of verbally and physically aggressive behaviours. These include setting fires, spitting, cursing, verbally and gesturally threatening others ("I will kill you/my mother"), hitting (downward clubbing of fists), pinching, biting, kicking, throwing and damaging property, threatening suicide or self harm ("I'm going to jump in front of a car"), tying things around body parts (, neck), inserting things into body parts (ears), head

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banging, and urinating or defecating in places other than the toilet or urinals. K does not have a diagnosable mental illness.

K was reared by [redacted] parents along with [redacted]. K's mother, father, brother, and sister were all diagnosed with learning disabilities. Records suggest that K may have been physically abused by [redacted] father as a boy. Reports also indicate that K was allegedly sexually abused while residing in one of [redacted] placements as an adolescent. K's parents are separated. [redacted] father has had difficulties with the law, recently being released from a correctional centre.

K began displaying challenging behaviour from the [redacted] attended special pre-school [redacted]. In pre-school K engaged in severe tantrums which were difficult for teachers to manage. School reports did however indicate that K was responsive to positive reinforcement and consistent management and was able to follow the classroom rules. K's development was delayed compared to [redacted] peers; however, some learning was achieved in these years.

In 1994, [redacted] parents admitted [redacted] to the children's ward at a hospital due to [redacted] increasingly difficult behaviours which had culminated in K starting a fire in [redacted] bedroom. K was assessed, returned home and K's parents were given strategies to manage K's behaviour. Allegedly, K's parents were advised to use the cupboard as a "time out" area when K was uncontrollable.

During the same year (1994) K attended a mainstream state school for approximately eight months. K was then transferred to a special school due to the school's difficulties in managing K's physical aggression towards students and teachers, destruction of property and [redacted] learning difficulties. From the age of [redacted] K's schooling required the development of behaviour support plans including a crisis intervention component to manage K in the school environment. K was assessed as requiring a high level of behaviour management and one on one support in the classroom. During this time while still residing in the family home, K received counselling and therapy, and [redacted] family received assistance with behaviour support at home.

In 1995 [redacted] the Child and Youth Mental Health Service felt that the behaviour management strategies being used by K's parents were not appropriate and subsequently K was placed in a shared family care arrangement with [redacted] maternal grandparents.

K resided with [redacted] grandparents for approximately one year until a care and protection order was issued in 1996 [redacted] due to the use of restrictive practices by grandparents. K was placed with a foster family. While in foster care K's behaviours were sporadic with 3 consecutive months of good behaviour followed by 4-6 weeks of very challenging behaviour. The foster family placement was discontinued due to difficulties in controlling K's aggressive and destructive behaviour.

In 1998 [redacted] was excluded from special school due to uncontrollable aggression towards other students and teachers. Reports suggest that no further formal schooling took place from this time; however, K may have subsequently been sporadically home-schooled for as little as one hour a day.

Later in 1998 K was relocated from the foster family to a children's home managed through a church organisation and resided there until March 1999 [redacted]. In March 1999 the children's home could no longer adequately cope with K's aggressive outbursts and [redacted] was placed in a non-government accommodation support facility. While residing there a DSQ psychologist, on behalf of the non-government agency,

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conducted an assessment and developed a lifestyle support plan aimed at addressing K's challenging behaviours. Records indicate that this plan was never adequately or appropriately implemented due to resistance from staff who objected to the positive nature of the plan, preferring the use of punishment and more punitive consequences. This placement ceased after 10 months due to the agency's inability to manage K's challenging behaviour.

In December 1999 K was relocated to the Basil Stafford Centre. In March and April of 1999 K's challenging behaviours resulted in 3 separate charges of assault and bodily harm on staff. All charges were later withdrawn.

Basil Stafford records for 2001 showed that the frequency of K's aggressive and destructive behaviours averaged at 14 incidents per month. Over the next [redacted] K's behaviours stabilised and remained consistent with the monthly average of around 5 incidents.

When K was [redacted] (2003) assaulted a residential support officer who later pressed charges. Police did not pursue the charges against K due to failed attempts to prosecute K in the past. In the same year while on a family visit K hit brother on the head with a closed fist which resulted in K's brother collapsing to the floor. Staff intervened and were assaulted by K. Staff then used restraint techniques to allow those present to exit the premises. The outburst continued for another 4 and a half hours.

In 2004 [redacted] relocated to a DSQ-owned residential facility supported by a non-government agency as Basil Stafford was deemed to be too restrictive and inappropriate. Reports indicate that this residence operated with locked doors and gates. [redacted] of that year K hit a co-resident and began throwing electrical appliances at [redacted] support worker. K then engaged in property damage, tipping over the washing machine and dryer. In another incident in the same month K dragged a co-resident by the hair, pinned her to the ground, repeatedly hit her on the head (3-4 times) with a closed fist and attempted to rip her shirt off. K then ran into the yard, threw rocks at a support worker, hitting the worker and causing a concussion. The police were called and were able to settle K.

Reports suggest that in 2004 [redacted] K's access to the community was gradually decreased which resulted in an increase in challenging behaviours. A risk assessment for travelling in the car was conducted with the recommendation that there be a physical barrier between K and the driver. Later that year K was charged with wilful damage. In the following year (2005) the frequency of K's challenging behaviour rose to an average of 12 per month.

In December 2005 while residing at the non-government supported accommodation house, plans were in place to develop a more suitable house for K when K deliberately started a fire which burnt the residence down. K was admitted to the mental health unit at a provincial mental health unit for assessment. K was not diagnosed with a mental illness and it was considered inappropriate to detain K in a mental health facility. K was charged with arson and has not yet appeared before the courts. K was relocated back to the Basil Stafford site at Wacol where [redacted] currently resides.

K engaged in increasingly challenging behaviours while residing at Basil Stafford. Records show 34 incidents in the first 10 weeks of [redacted] residency at Basil Stafford, four of which were critical incidents involving assaults to staff, lighting fires and damage to windows, doors, electrical outlets, plumbing fixtures and the sprinkler system. In

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February 2006 there was an incident at a dentist surgery which resulted in K being restrained by police.

In March 2006 an assessment was conducted by the Institute of Applied Behaviour Analysis (IABA) a widely respected organisation from California. The assessment aimed to assist K in securing appropriate services, develop independence, skills, and provide more long-term opportunities for community participation. Recommendations included a less restrictive living environment, increased community access, use of role plays, preferred activities, diversion strategies, more family contact, physical activities, staff training and accountability systems.

K currently resides by [redacted] in a refurbished villa on the Basil Stafford site at Wacol. K is provided with 24-hour support with two staff members on shift in the house at all times. K appeared before the Mental Health Court in June 2006 on longstanding wilful damages charges. [redacted] was deemed unfit to stand trial and a forensic order issued that K be detained as an involuntary patient in a mental health facility. It was further decided that the Basil Stafford villa be gazetted as an annexe to the Park (a Queensland Health operated mental health facility) as this was considered the most beneficial arrangement for K. Under the arrangement, K receives accommodation support services from DSQ and, as required under the forensic order, is visited twice daily by a psychiatrist and psychiatric nurse from the Park to ensure regular observations are taken.

The villa is a secure facility with K currently being confined to [redacted] residence at all times. Reports indicate that there is a locked door between staff and K for the majority of the time. K is sometimes contained in the backyard for periods of the day. Due to K's property damage and self injurious behaviours K's living environment is very sparse. All furniture is bolted to the floor and the sink taps have been removed.

K is considered as unsafe to support in the community within a standard community setting and to prevent injury to others and property [redacted] is currently not taken into the community. The restrictive environment and lack of community access are at odds with the recommendations of the IABA assessment which suggests that positive opportunities such as community access would assist in reducing K's dysfunctional behaviour. Future planning for K involves implementation of the IABA assessment recommendations within a purpose built house, currently planned for construction on a rural property.

K has had no recent contact with [redacted] father although [redacted] mother stays in touch as much as possible and visits [redacted] at Wacol. K's mother has indicated that she would like to live closer to the family to allow them to visit more frequently. K is reported to greatly miss [redacted] family which at times can be a trigger to the occurrence of challenging behaviour.

### Case Study L:

L [redacted] diagnosed with autism and moderate intellectual disability. L is verbal and fluent in two languages, English and French. L engages in physical aggression towards others (kicking, pushing, pulling people, pulling hair) and damage to [redacted] own and neighbour's property (usually glass windows or mirrors). L's behaviours appear to be cyclical in nature with challenging behaviour occurring every 8 to 12 weeks.

L's mother was 15 years of age when she had L. [redacted] was reared by [redacted] very young parents [redacted] L moved in with [redacted] grandparents as

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parents were unable to cope with raising a child. L's parents separated when [redacted] was approximately [redacted] and L's biological father had no contact with [redacted] in following childhood to adolescent years. L's mother later remarried.

L's first step-father was reportedly punitive in his discipline approaches as he had no understanding of L's disability. L's stepfather would often lock [redacted] in [redacted] room, restrain and hit L to the point where bruises appeared. L was also a witness to other domestic violence within [redacted] family. Reports also suggest that when L moved in with [redacted] grandparents L's grandfather was quite aggressive towards L when managing [redacted] behaviours. L's grandfather reportedly hit and slapped [redacted], restrained [redacted] by sitting on [redacted] and stomped on [redacted] feet.

L began exhibiting unusual behaviours [redacted]. As a toddler [redacted] was very quiet and aloof and displayed rocking and screaming behaviours. L defecated on the floor and would be non-compliant to requests made of [redacted], particularly those from stepfather. [redacted] L's behaviours further deteriorated and became increasingly challenging.

L attended a special autistic school [redacted] (1981-1987). L also received respite services for community outings on a weekly basis. L's behaviours at school included pushing, pulling people, pulling hair, and throwing things away. Family members report that L began pulling others' hair after a teacher had earlier pulled hair when [redacted] behaved inappropriately. Apart from the above behaviours L did not engage in any seriously challenging behaviour during [redacted] primary school years.

L lived with [redacted] grandparents [redacted] (1981-1992). In 1987 when L was [redacted] relocated with [redacted] grandparents.

When L was approximately [redacted] (1988) behaviours started to change. During this time [redacted] developed an interest in breaking windows. L broke through a glass window using [redacted] whole body which resulted in injuries to [redacted] body. While [redacted] never repeated this act [redacted] continued to break windows by throwing objects at them. L often broke [redacted] bedroom window, lights, and toilet. Family members restrained L to prevent [redacted] from causing further damage.

L attended a special school from [redacted] (1987-1991). During this time L's behaviours were much the same as previous years with pulling hair, pushing, pulling, and throwing objects. L's school appeared to manage [redacted] behaviours adequately. Whilst L was sometimes suspended for challenging behaviour, [redacted] would be permitted to return to school.

At the [redacted] (1991) the school referred L to a supported employment agency who they thought would better meet [redacted] needs. L's family was in support of this decision. L worked with a supported employment agency for approximately 1-2 years without incident. L was involved in cleaning and working in the kitchen of a hospital.

[redacted] (1992-1993) L caused extensive property damage to [redacted] grandparents' home including breaking windows, lights and the toilet. The police were called and escorted L to a hospital. This was the first instance of police or hospital contact regarding L's behaviours. L was then transferred to the John Oxley Memorial Hospital (JOMH) and resided there for just over four years. L returned to [redacted] grandparents' home for the weekends. L's grandparents suspected that [redacted] was subjected to physical and possibly sexual assault from other clients while residing at the JOMH and that this had a detrimental effect on L's behaviour. In particular, L's property damage became much more extensive and frequent. L would attempt to break any window in sight if given the opportunity.

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In 1994 while residing at the JOMH, L's behaviours continued to escalate producing increasingly negative outcomes for L. From approximately January to July of 1994 L was admitted to a mental health unit numerous times and on some occasions resided at the unit for relatively long admission periods.

L left the JOMH at around (1997) and moved into a non-government supported accommodation house. This residence was staffed by two different non-government community based agencies consecutively over two years and funded through DSQ as L had received a DSQ funding package in 1995. Reports suggest that there were no incidents for the first six months while living in this situation.

In approximately 1998 relocated to a Department of Housing house. L was initially supported by staff from a non-government organisation and then by DSQ staff . This is L's current residential situation.

(2000) assaulted a staff member and was escorted to a mental health unit for assessment. L remained there for two days after which mental health professionals concluded that L's issues were behavioural in nature and not the product of a mental illness.

In 2001 challenging behaviour led to extensive police contact either through attending aggressive incidents in L's home or in the community, or through escorting L to a mental health facility due to uncontrollable behaviours. From January to December there were eight separate incidents of challenging behaviour requiring police intervention, five of which resulted in L being admitted to a mental health unit staying from two days to two weeks. The incidents involved property destruction at home or the shopping centre, damage to vehicles and assault of others (hitting, biting, kicking, pulling hair, throwing objects) including L's grandfather, a doctor and support staff. In spite of the scope and frequency of the incidents, no charges were laid.

During February to December in the following year (2002) L engaged in eight recorded incidents of challenging behaviour. In February L assaulted grandfather while on a family visit and engaged in property damage. In June L punched grandfather in the face and broke windows in the house. The police were called though no charges were laid. In July while out shopping L assaulted support worker and a security guard. L was escorted to the local hospital and soon released. Upon release L immediately engaged in more assault and was admitted to a mental health unit where stayed overnight. In August while at the bowling alley L assaulted two of support workers and another person with a disability. L was taken to a hospital for sedation. In September L took an overdose of medication on two separate occasions and was admitted to the mental health unit for several days respectively. Reports suggest that these overdoses were not a suicide attempt but a result of L's inability to fully understand the purpose of medication. L reportedly wanted to get better after engaging in property damage and consequently ingested more tablets to compensate for behaviours. Also in the same month L knocked down a staff member with open hand and broke several windows. The police were called and L was detained in the watch house overnight. In December L engaged in property destruction of own house and of neighbour's house. The police were called, however no charges were laid as police were satisfied with DSQ's actions to compensate all parties for any damages.

After many incidents of assault and property damage L was eventually charged with offences in 2004 . In June 2004 L threw very large rocks through all

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the windows of a neighbour's house. One narrowly missed a young boy sitting at his computer. Destruction to the ceramic tiles, computer, windows, linen, scanner, and carpet resulted in thousands of dollars being required to be paid for the damage. The police were called and L was charged with wilful damage. Bail conditions stated that L must reside in [redacted] home at all times and in the care of a DSQ officer.

In November 2004 [redacted] L attempted to abscond from [redacted] residence. Three staff members intervened by attempting to physically restrain L and as a result [redacted] were assaulted. Police officers passing by the house offered assistance to staff and escorted L to the watch house where [redacted] was detained overnight. Police recommended that staff press charges to ensure appropriate services such as an admission to the JOMH could be obtained. Staff complied and L was issued with three separate charges of common assault, however admission to the JOMH did not eventuate. Instead the bail conditions previously set for the wilful damage charge were again enforced. Later in that same year (October, December) L continued to make appearances at the mental health unit for property damage and assault, staying for up to three days.

L has consistently engaged in aggressive behaviours towards others and property over the past six years. So far in 2006 [redacted] records show five incidents of challenging behaviour which have resulted in either charges being laid or admissions to a mental health unit. L punched a psychologist during one of their sessions and was escorted to the mental health unit. L also slapped [redacted] grandmother and destroyed the ceilings in [redacted] kitchen and bathroom on two separate occasions. In 2006 L was again charged with assault, however these charges were dismissed and no forensic order was issued.

In March 2006 L was taken to hospital for assessment and treatment as [redacted] lips had turned blue. While in the hospital L assaulted a female police officer by pulling out a sizeable clump of her hair. No charges were laid. Doctors could not find the cause of the discolouration; L's PRN medications were altered and [redacted] was discharged.

Currently L resides by [redacted] in a DSQ supported accommodation house. The residence is locked at all times with 24 hour support and one staff member to provide constant supervision and support. L's residence is sparse with limited furniture, bars on windows, and taps removed from the bathroom and kitchen. Originally L was locked in [redacted] premises to ensure [redacted] complied with [redacted] bail conditions. Records show that since the requirements have been removed L's doors have continued to be locked as the risk to the safety of the community is considered too high. L's residence contains a staff office which can be blocked off by a barred door. When L engages in challenging behaviour staff have reportedly retreated to the office and locked L's access. The office does not currently provide adequate vision of the rest of the house to allow staff to appropriately monitor L when [redacted] is upset and engaging in a critical incident. However, reports indicate that planning for the future is underway, including providing a less restrictive environment, increasing L's access to the community, and the possibility of introducing a co-resident.

L currently accesses the community approximately 12 hours a week and is supported by two staff members at all times in the community. When L is engaging in challenging behaviour [redacted] is restricted to [redacted] house.

L's mother and second stepfather visit [redacted] 1-2 times a week. L has frequent contact with [redacted] grandmother and grandfather. [redacted] also has an aunty and uncle who have quite regular contact with [redacted]. L's biological father and first stepfather have no contact with [redacted] whilst L's [redacted] have very limited contact with [redacted].

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Case Study M:

M who has been assessed as having a mild to moderate intellectual disability with a significant associated behavioural disorder and possible schizophrenia, although M has not been formally diagnosed with a mental illness. M has a history of engaging in challenging behaviours including aggression towards others (including mother), property damage and self harming behaviours. The majority of M's behaviours can be linked to desire to obtain cigarettes and/or alcohol, or as a result of the consumption of alcohol.

M comes from a large family . M's mother was the sole family carer since 1999 when her partner left the family. Reports suggest that there is a history of mental illness on the paternal side of M's family although the nature of the illnesses is not known. M is the only known family member with an intellectual disability. M's mother has displayed a longstanding commitment to welfare, however, in more recent times; the relationship with mother has been placed under increasing strain, due largely to M's increasingly aggressive behaviour. There is no suggestion of an abusive family background.

Little is known of M's school years or the period from leaving school up to the . On leaving home at this age M took up residence at a range of private hostels in the local area and began consuming increasing amounts of alcohol. During this time anecdotal reports suggest that M spent much of time drinking alcohol, wandering the streets and getting into altercations with various members of the community. In 1999 M was admitted to the local mental health inpatient facility on a voluntary basis after chased one of brothers down the street with a knife. was placed on anti-psychotic drugs to assist in managing violent outbursts of behaviour; however, received no diagnosis of a mental illness. was released to the care of mother and received no further mental health outpatient care due to the lack of a diagnosis.

From 1999 to 2000, while in mother's care, M's episodes of alcohol induced violence escalated and moved between home, hostel and voluntary admissions to the inpatient mental health facility.

In the period that followed, M's mother sought ongoing assistance from the outpatient mental health service, however, a lack of diagnosis precluded this avenue of support. In January 2003, after she became increasingly fearful of M's growing violence, M's mother was referred to Disability Services Queensland (DSQ). No formal services were sought; however, DSQ provided information and linking to non-government services in the local area.

Later in 2003 a formal assessment by DSQ of M's situation led to the provision of a family support package which provided access to respite, community access and day options. Meanwhile, M continued to move between home and hostels and continued to drink and engage in challenging behaviours. Emergency respite was utilised during this period and M was also trialled in supported accommodation outside the family home. This lasted eight days before returned home.

In mid 2004 M was arrested for creating a public nuisance and assaulting a police officer, was remanded in custody for several days and was admitted to the acute mental health unit from where was discharged 24 hours later. In December of that year was admitted to the local hospital for overdosing on prescription medication. was released a week later.

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In January 2005 M began to cancel community access activities funded through the family support package because objected to support worker encouraging not to drink alcohol. The following month M assaulted mother after she refused to provide with money for alcohol. During the incident, M smashed a number of windows and cut severely. The police were called; however, no charges were laid. M's mother, becoming increasingly frightened at violent outbursts indicated she was no longer willing for M to live at home and applied for and was granted a Domestic Violence Order, limiting M's contact with her.

At this point, DSQ provided Emergency and Crisis Funding which enabled M to take up residence with a non government disability service provider which was initially successful and behaviour was manageable. In May 2005, however, M left the residence unaccompanied purchased and consumed alcohol and went to mother's house. hit a taxi driver and threatened police with a knife before discarding the weapon. M was placed in custody before returning under bail conditions to different accommodation supported by the same disability support agency. This arrangement provided M with one to one support for twelve hours per day. During the following months M was breached for failing to comply with bail conditions. During this time resided at mother's house, a hostel with support and the local watch-house.

In January 2006 M again breached bail conditions, was arrested and remanded in custody at the Sir Arthur Gorrie Correctional Centre awaiting the outcome of a Mental Health Court hearing. The hearing in April 2006 found that M was unfit to stand trial due to incapacity to understand the charges and court proceedings. was placed on a limited treatment order and placed in a mental health inpatient setting for a period of 5 months from 18 April 2006 to 18 September 2006. Under the order M must remain in the facility for the prescribed term, be escorted by health officers when accessing the community and on discharge must abstain from alcohol and submit to random medical tests.

The unit is a high security unit for people on forensic orders. While residing at the unit M has own bedroom and can have personal possessions. Residents of the unit do not have community access, however, they are allowed family visits. It is unclear whether M's mother has visited at the facility since admission.

Suggestions have been made by the Adult Guardian that M needs considerable assistance and support to build a structure of daily living and to build relationships as even relationship with mother has become estranged. The involvement of DSQ in this support is considered essential.

The range of accommodation and support options that have been tried to date have proven to be unsustainable due to M's behaviour or as a result of leaving the accommodation to return to family home or to seek opportunities to purchase cigarettes an/or alcohol. The current voluntary and non-custodial nature of DSQ funded and provided services suggests the likelihood of a continuance of this behaviour if returned to these options and the need for post discharge support planning to identify more effective options. Planning is currently in place for immediate post-discharge living and support arrangements.

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**CHAPTER 3****The Response to Challenging Behaviours So Far (1989 – 2006)**

In “a brief historical context” in chapter 1 it was noted that in 1968 the places where those with intellectual disability were then housed came to be known as “training centres” and a decade later the transition to community living had commenced. Basil Stafford Centre (BSC) and Challinor Centre (CC) remained operative and in 1989 there were 134 persons accommodated at BSC and 246 at CC. A total of 196 were part of the developing Alternative Living Service (ALS) and 77 clients were registered as being accommodated at the Villas which had been constructed at BSC, Toowoomba, Maryborough and Rockhampton from 1977.<sup>1</sup> Also in 1989, the Intellectual Handicapped Branch, formerly an agency within the Health Department, came to be incorporated into the Department of Family Services and Aboriginal and Islander Affairs, as the Division of Intellectual Disability Services.

**The Joachim / Attwood Documents**

At that time Mr Ron Joachim (now Deputy President of the Guardian and Administrative Tribunal) was the Acting Executive Director of the Division of Intellectual Disability Services. On 14 April 1989 Mr Joachim, as Deputy Director, authored a report of a visit by him to the U.K. where he had visited several facilities in London, Bristol and Kent which provided services to “people with an intellectual handicap who have challenging behaviour”.<sup>2</sup> He there conferred also with leading practitioners who were working in the field.

His report, which he volunteered to me with other personal documentation in the course of the consultation, contains the earliest reference to “challenging behaviour” in the documents which are available. It is noted also, in passing, that the greater bulk of the published literature seems to date from about this time or a little earlier.

In March 1989 Mr Joachim convened “a small task group” “to develop strategies to manage challenging behaviour”. This occurred as a result of his U.K. experience in late 1988 and appears to be the first attempt within the relevant Queensland Government agencies to develop such “strategies”. The first task of the group was to conduct a survey in Queensland of those with “challenging behaviour”. This was most probably the first attempt in the State to survey the sector to attempt to ascertain the size of the cohort. It needs to be understood when considering this survey that in 1989 BSC and CC were still a well established part of the government disability sector and the great majority of the “registered clients” were at BSC and CC, in the ALS, at the Villas or with family. A small percentage lived in a hostel in church operated facilities or were cared for by the Endeavour Foundation. The NGO facilities and operations which are now such a feature of the sector was of much lesser significance in 1989.

The Report of the “small task group” notes that once the “survey form” was designed it “was distributed to the regions in May 1989 and regional staff completed a form for each client with a challenging behaviour “. By the end of July 1989 all of the completed forms were returned and the analysis of them began.

“A total of 769 forms were completed by staff of varying designations, but predominantly by residential and resource staff who have daily contact with their clients”.

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<sup>1</sup> Joachim: Survey of Challenging Behaviours March/July 1989.

<sup>2</sup> The Joachim Documents – Report on visits to personnel and facilities providing services for people with an intellectual handicap who have challenging behaviours: Joachim 14 April 1989.

It needs to be understood also that the Joachim group had to construct its own definition or categorisation of “challenging behaviour”. This was 6 years before the publication of the first edition of Emerson’s text in 1995 which contained his oft – quoted definition set out earlier in this Report. The survey reported that the percentage of the clients with challenging behaviour was the highest at BSC (70%) and CC (54%). Across the regions the percentage varied from 20% to 35% of registered clients.

Mr Joachim also made available papers written by Dr A.J. Attwood, Senior Clinical Psychologist in the Division dated April 1989 and May 1990.

In the first, “*An Alternative Approach to reducing Challenging Behaviour: A Model for the Community* (April 1989)”<sup>3</sup>, he proposed a new and “alternative” approach, one which had “a decentralised model with an intensive intervention team” rather than the historical approach, namely “a special residential unit” within “large government institutions”. The published literature to which he referred is dated 1981-1987.

Dr Atwood’s April 1989 Paper concludes:

**”A specialist intervention team with a small crisis admission assessment unit has considerable potential in supporting people with challenging behaviour in community based services”.**

This was written in the context of the proposals for deinstitutionalisation.

Dr Atwood’s second Paper (May 1990): *Psychiatry Clinic in Brisbane for People with an Intellectual Disability* argued for the establishment of a Psychiatric Clinic in Brisbane “specifically to help the intellectual disabled and using a multi-disciplinary team” as a “solution to the problems” of those persons with intellectual disability particularly those with behavioural problems.

Mr Joachim put the Attwood proposals in the second paper to the Division of Psychiatric Services, Department of Health and the then Deputy Director of that Division replied by letter dated 20 February 1991 advising that “this Division is not in a position to be able to contribute to the development of this proposal.” He cited “very limited resources” as one reason and continued: “but also due to the fact that we believe a single clinic would have only limited benefit”. Mr Joachim by letter dated 18 April 1991 responded and again argued persuasively for the facility and concluded:

**“I would be interested in your views about how you think we could go about improving co-operation, co-ordination and mutual understanding at a regional level”**

Obviously the perceived need for cooperation and coordination of treatment and for the support of persons with intellectual disability is of long standing. So too has the desired level of mutual understanding been absent or at best only fragmentary.

It seems that the Joachim/Attwood initiative (1989-1991) was short lived. The first legislation, DSA 1992, is brief and does not address the issue even peripherally.

The impetus in 1989-1991 given to the issue of challenging behaviour dissipated when Mr Joachim’s left Queensland for W.A. in June 1991. It is well to remember that intellectual disability was still covered by the Mental Health legislation at that time and

<sup>3</sup> Included in the Joachim Documents

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that legislation was probably seen to have the capacity to provide an adequate response to any situation of crisis.

### **1992 – 1997**

Meanwhile de-institutionalisation had continued although in the early 1990's the Challinor Centre and Basil Stafford Centre site had a combined population of about 350. In 1991/2 the Commonwealth Government instituted its Better Cities policy which was designed to create better urban environments and endorsed the de-institutionalisation of psychiatric hospitals and of the intellectual disability sector.

In 1993 Queensland applied for funding pursuant to this policy with its proposal for the closure of Challinor Centre. This application was successful and the decision was taken to close Challinor Centre. In 1994 the closure of Challinor Centre was announced and later in that year the closure of Basil Stafford Centre, at the time of the Stewart Inquiry/Report.

By the time of a change of government in early 1997 the population of Challinor had been reduced from 500 to about 170 when a new decision was taken to retain Challinor Centre but this decision was again reversed in 1998 with a further change of government. Whereupon Challinor was closed and the site was sold and later redeveloped by the University of Queensland.

Meanwhile, in the context of the movement towards de-institutionalisation a system of individual funding packages was instituted and the need to support persons with intellectual disability in the community was recognised. The individual funding packages were to provide the appropriate level of support. These packages survive to the present and are presently the subject of review. De-institutionalisation also led to the creation of the position of client service coordinator and the proposal for a Behaviour Support Model. Two Behaviour Support Teams were established, one on the North and the other on the South sides of Brisbane but which were used to service the whole of the State. Their role was to implement appropriate behaviour programs and to engage in the coaching and training of carers and families. Remnants of those teams still operate now but they have become for all practical purposes obsolete.

In the period 1991-98 the institutions were closing and their former residents sought and received housing from the Department of Housing which had developed Shared Housing arrangements.

As indicated elsewhere the enactment of the Mental Health Act 2000 excluded intellectual disability from its operation and the attitude of Mental Health hardened even more. It had been anticipated through the latter part of the 1990's that a new Mental Health Act was in the making and that intellectual disability was a likely exclusion from the definition of "mental illness". The year 2000 put the matter beyond doubt.

Accordingly after the Joachim initiative had foundered, the emphasis during the 1990's was elsewhere. Deinstitutionalisation had become the focus for policy development. In 1994/5 the CJC Stewart Inquiry was a disturbing distraction. In October 1996 the Systems for Behaviour Support and Management Resource Manual (SBSM) was published to staff by the Executive Director Division of Disability Services. It remains to this day the basic structure for behaviour management and support although it is now somewhat out dated and serious questions abound concerning its usefulness and effectiveness in the light of further development in the relevant expertise

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The issue of appropriate behaviour support during the 1990's was dealt with in a fragmentary way but also against the background of the process of deinstitutionalisation and the belief that, if needs be, the Mental Health legislation provided a legislative framework within which challenging behaviour could be managed. This was in spite of the fact that Mental Health personnel were becoming increasingly uneasy about intellectual disability being coupled with mental illness at least for statutory purposes.

Throughout this period there was no specific or focussed attempt made to address the issue of challenging behaviour. Challenging behaviour was a daily fact of life at Challinor and Basil Stafford Centre and the movement of those with behavioural concerns to the community transferred also the need to address the issue to the community.

Some of those who had care responsibilities for a part of the cohort in the institutions also moved, at times with the same people into the Alternative Living Service. Therefore to some extent – the people were the same people; the behaviour was the same, often the carers remained the same – only the location in which the behaviour was exhibited had changed – from the institution to the community.

The provision of individual funding packages and an imperfect system of behaviour support were the chosen responses.

Whilst the movement to the community had many benefits for many people, concerns about the management of challenging behaviour remained and in retrospect some behaviours were escalated for a number of reasons.

One of these was the grouping together in the one living environment of a number with challenging behaviour. Congregate care became a regular feature of the new community living models and in the course of the consultation I was made aware of how in individual cases behaviour concerns escalated on this account. The present day literature commonly rejects congregate care particularly for those in this cohort although one witnesses some limited circumstances where it has been appropriate and successful.

However I am persuaded that congregate living for the majority of those in the cohort is generally unacceptable and useless, indeed, counter productive. Hence the proposed model will specifically address the development of appropriate accommodation for members of the cohort.

But during the de-institutionalisation process, not only were the individual funding packages inadequate, behaviour support interventions were less than efficient and often the available housing facilities were inappropriate. All of this was no doubt the result of limited available funding to support processes which were not cost efficient.

DSQ it will be recalled came into being in December 1999.

There can be no doubt that many DSQ personnel continued to do their “imperfect best” in devising and implementing what were thought to be the preferable strategies to deal with the “challenging behaviour” issue. The published literature continued to increase discussion of the problem and potential solutions throughout the 1990's.

However, the lack of a positive solution – what Dr Attwood in May 1990 had called “an alternative approach” – failed to effectively displace the “historical approach”. There is no better evidence of this than the regrettable fact that by 1994 the treatment of persons

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with intellectual disability many of whom no doubt exhibited challenging behaviour became a public scandal and the subject of a damaging public inquiry and report.

Since 1994 and the 1992 legislation, the community living option has been at the forefront of service delivery by both DSQ and an expanded and funded NGO system. There is considerable scope for argumentative discussion about how well those services have been delivered and whether the “community living” option has been entirely successful. It is beyond question however that it is the preferred model and a return to the experiences of the past is simply not negotiable. That said, it has to be recognised that the processes of funding and service delivery for community based living were and remain less than perfect and in some cases open to strident criticism. The challenge to government and others to provide sufficient acceptable accommodation, to recruit and train adequate specialist and carer staff and to put into place a coordinated and positive process of care and behaviour support for this particular cohort remains to a disturbing extent, unanswered. The statutory caveat of “finite resources” (s8 DSA 2006) is invariably the justification, and this is well recognised, but even in 1990 Dr Attwood was quick not only to recognise it also, but to argue that his “alternative approach” was more cost effective. So too did Mr Joachim and his small task group. They were intent on supporting an alternative which was more cost efficient. It is submitted that the model proposed in this Report is designed to ensure maximum cost efficiency.

Little had been done systematically since the Joachim/Attwood period to successfully address the issue of challenging behaviour in a coordinated attempt at effective response. There has been much discussion, many meetings and a lot of paper writing but there is no evidence of any sustained and successful attempt to systematically respond to the problem.

There are no doubt individual cases which were stunningly successful but these were mainly on account of the individual efforts of family and well motivated carers.

Challenging behaviour was probably seen to be a lesser priority and able to be managed by an available process of crisis management. But an attempt at the proper solution to the issue remained at the forefront for many DSQ committed personnel.

### **1997 - 1998**

The issue of properly managing challenging behaviour took an interesting turn on 15 December 1997. On that date a special inter-departmental meeting was convened by Queensland Health “to examine the issue of the management of people with extremely antisocial behaviour”. As a result of the meeting a discussion paper was written in March 1998 and following a further meeting, the paper was amended and produced in May 1998. It is entitled: *Discussion Paper: Managing Individuals with Seriously Harmful Behaviours*. The document is described as follows:

**“This discussion paper has been prepared by the Department of Families Youth & Community Care (DFYCC) on behalf of the Interdepartmental Working Group comprising representatives of Queensland Health, Queensland Police Service, Department of Justice Queensland Corrective Services and DFYCC”.<sup>4</sup>**

The work of the interdepartmental group and its focus can best be described by referring to the text of the Discussion Paper itself.

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<sup>4</sup> Cover sheet op. cit.

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**“It should be noted, however, that this discussion paper focuses on the imperative need to respond to the seriously harmful behaviours, with the aetiology of the behaviour being a secondary consideration.**

**Often these individuals will have been referred for psychiatric treatment or assessment or their behaviours have resulted in the involvement of the Queensland Police Service.**

**The group comprises children and adults whose needs are extremely difficult to meet. Historically, they have always been a challenge for service providers, both in terms of obtaining and retaining suitable staff with the necessary expertise plus the willingness to work with the person and also the resources required.**

**Workers tend to feel that they do not have the requisite skills for responding to or helping these individuals, and confusion or erroneous assumptions exist in the community about which agency can or should assist the person.**

**The person demonstrating seriously harmful behaviours requires a service or support from a number of agencies. However, the person frequently does not meet a service’s eligibility criteria, due to their behaviour, age and/or disability or disorder.**

**Such individuals are often referred to “as falling through the cracks” of service provision, with a more concerted response only occurring when the person commits an offence. Given the high level of need of this group and the resource constraints of agencies, it is understandable that agencies rigorously “gate keep” according to service eligibility criteria. However such a situation promotes interagency conflict and poor client service.**

**Inadequacies in service responses are exacerbated in remote areas of the State and indigenous communities.**

**A significant group of people who “fall through the cracks” are adults with a “disorder” rather than a diagnosed mental illness or disability.**

**Conduct disorder is a diagnosis that can apply to children and adults; however it is only applied to adults where the criteria for antisocial personality disorder are not met.**

**Severe personality disorder is held to be generally not amenable to psychiatric treatment, although psychiatry may have a role in the management of severe behaviour disorder. There is no *involuntary* treatment that can be applied to a person with a personality or conduct disorder.**

**However, both children and adults with conduct/personality disorders do access services from community mental health service, dependent on the discretion of the Director.**

**It is considered essential that people with conduct/personality disorders, including people who also have a disability, are assessed and, where appropriate, receive specialised mental health services on the basis of individual need. This refers to range of therapeutic interventions, not**

**necessarily psychotherapy or treatment approaches used for mental illness.**

**The Disability Program, DFYCC, funds support services in the community for people with a psychiatric disability, which are also accessed by people who have conduct or personality disorders or people with a mild intellectual disability plus another disorder. These people can engage in very complex, disruptive/disturbed behaviour and require specialised responses which funded services are unable to provide.”<sup>5</sup>**

All of the characteristics of the problem as presented by the 2006 experience are presented in that passage of the Paper – the need for interdepartmental collaboration, the difficulty in service delivery, the need for specially equipped and trained staff, bureaucratic “gatekeeping”, the relationships between the intellectual disability issue and mental health services, the need for community based “therapeutic interventions” rather than the application of psychotherapy and treatment approaches used in the treatment of mental illness, but above all the central focus on “the imperative need to respond to the seriously harmful behaviours, with the aetiology of the behaviour being a secondary consideration”.

One of the outcomes of the interdepartmental dialogue was:-

**“A joint working party of the Disability Program and Mental Health Services is being formed to look at the problems associated with people with an intellectual disability being held in psychiatric hospitals and forensic facilities.”<sup>6</sup>**

That statement written in May 1998 has a familiar ring about it. A reading of the following chapters of this Report will show why.

So too will the “Response Options”: proposed in May 1998 resonate with what is written in Chapter 5.

**Two responses are provided which are designed as a service response for individuals in the target group.**

**Response Option 1 is a community-based individualised service response for the group of people not requiring a secure or contained environment.**

**Response Option 2 is proposed as a service response for the small sub-group who do require a secure or contained environment.<sup>7</sup>**

These response outcomes are obviously not alternatives and respond to a subdivision within the cohort – Option 1 for those “not requiring a secure or contained environment” and Option 2 “for the small sub-group” who, it was thought, do require secure containment. I hasten to add that almost 10 years later, the frank and apparently unequivocal emphasis on the need to contain and to provide a secure environment has undergone significant modification. No longer can containment in a secure environment be seriously considered and pursued as an end in itself. As this Report will demonstrate whether such a response warrants consideration can only be properly and validly considered in the context of a process of service delivery which places a much greater

<sup>5</sup> Para. 1.1 op. cit.

<sup>6</sup> Para. 1.2 op. cit.

<sup>7</sup> Para. 5.1 op. cit.

emphasis on the human rights of the person as the dominant consideration, which is based on an initial process of comprehensive assessment of the person to identify individual needs, which in turn will require multi disciplinary intervention in the most desirable accommodation setting and which will only permit of the use of a restrictive practice as part and parcel of a Positive Behaviour Support Plan designed specifically for the individual person to meet his/her needs.

Another interesting piece of evidence revealed by this 1997/8 initiative is that it was estimated “that 40 to 60 individuals known to DFYCC might fall within the target group at the present time or in the near future”. It was further estimated that about 40 persons “might fall within the target group’s larger sub-group and that possibly up to 15 individuals might fall within the sub-group also requiring secure accommodation or containment”. Those estimates are now of historical interest only.

There is one other important and relevant aspect of this Queensland Health (QH) sponsored initiative in 1997/8 which one should dwell on. Chapter 4 of this Paper is headed: *A Group Facility vs Individualised Approaches*. The focus of the Chapter is to address the relevant issue of the preferred service delivery and accommodation placement in “dealing with the needs of the people with an intellectual disability and challenging behaviour”. The Chapter concludes –

**In considering the advantages and disadvantages of a group Vs individualised approach a number of principles become apparent which should underpin any response. These are:**

- **For any individual, the provision of a community based service response which is as close to his or her usual living environment is preferable to containment in a secure facility.**
- **Any service, facility or community based, should be individualised and tailored to meet the person’s specific needs.**
- **Any service response, facility or community based, should not place undue hardship on the person or his or her carers.**
- **Any service facility or community based, should take account of the person’s cultural needs, be age appropriate and take account of the person’s legal status i.e. whether the person voluntarily or involuntarily participates in the service.**
- **The person has a right to have access to developmental programs and services.<sup>8</sup>**

This Report in dealing with the same issue quite independently recommends a very similar approach. Again this Discussion Paper only came to my knowledge relatively later in the consultation process. That paper in respect of this issue reflects the result of the research literature available then. The modern day literature confirms in essence the core elements of the preferred service response set out above. The work of Epstein et al in 2006<sup>9</sup> is quite explicit and reflects the evidence based experiences now regarded as essential in providing an effective service response to the cohort. It is disconcerting to note in 2006 that the result of the work done by that interdepartmental process in 1997/8 seems also to have been non-productive in all relevant aspects. I do not know what the ultimate fate of that collaborative attempt to deal with this problem was. What is readily apparent is that that work failed to influence at all policy development and service delivery models in the interim. All of the concerns reflected in the Discussion

<sup>8</sup> Ch. 4 op. cit.

<sup>9</sup> Presenting the Evidence: Accommodation and Support for people with Disability

Paper remain. The kind of service responses seen then as necessary in proper service delivery to the cohort are still evident even now. The Multi-Disciplinary Intervention and Support (MIS) Teams proposed by the Discussion Paper in 1997/8 may have provided the model for the IBST's developed years later and which, as pointed out in this Report, are presently struggling in an effort to service the relevant needs of persons across the State. One effective team only and another incomplete team constitute this present day critical resource.

One can be forgiven for wondering why this valuable work achieved little or nothing. Perhaps, the fact that DSQ was in the process of formation in December 1999 was a powerful distraction. Perhaps as justification for the obvious official lethargy, resort was had to the comfortable and regularly asserted mantra of "lack of resources". Whatever the reason, its clear that QH's motivation for convening this process in 1997 was, at least in part prompted by the following sentiments expressed in the opening paragraphs of the Paper under the heading "Background"-

**"The discussion paper from the meeting stated Queensland Health's position in regard to its involvement with this client group, and concluded that the provision of suitable placement and programs is not the primary responsibility of Queensland Health."**<sup>10</sup>

Shades of what Dr Stafford had written in the Annual Report in 1963-4!

### **2001- 2003 (The Ipswich Initiative)**

Surprisingly the next serious attempt at a coordinated solution appeared at a regional level and as a regional response rather than as an integrated systemic and departmentally sponsored project.

In the course of developing the targeted service response set out in Chapter 5 I had the opportunity of visiting "The Park" mental health service where I had a very cordial and fruitful meeting with Drs Steadman and White and other senior officers. In the course of the meeting reference was made by them to an earlier initiative in which "The Park" mental health services personnel had engaged with regional DSQ officers for the purpose of establishing and developing a pilot assessment service to address mutual concerns with the delivery of services to the target group and to respond to a "localised need for collaborative inter-agency services". This project was designed as a pilot assessment service for people with intellectual disability and serious harmful behaviours, with the collaborative involvement of both DSQ and Mental Health the key strategy. Its geographical focus was to be the South West Region of DSQ and its primary objective was the development of a partnership between The Park – Centre for Mental Health and DSQ Ipswich South West Queensland Region for this purpose.

Its other primary objective was to identify models of service for persons with intellectual disability and seriously harmful behaviours. The notion that there was a recognisable primary need for establishing an assessment service for the target group was seen to be of fundamental importance, as was the need for collaboration, at least, between Mental Health and DSQ in the provision of an acceptable service to meet the "high and complex" needs of this particular group.

In January 2001 a draft report was prepared by the Ipswich and Southwest Queensland Region DSQ: *Managing and Supporting Individuals with Extremely Complex and Dangerous Behaviour*.

<sup>10</sup> Ch 1. Background op. cit.

This Draft report had been written because of the perceived lack of effective response in the Region to properly dealing with those in the Region who fell within the cohort. A creative, imaginative and professionally designed model was the result. It was based on cross agency cooperation and collaboration. It attempted to address in a spirit of collaboration the particular concerns of each agency. It informally networked with all such agencies and other stakeholders, particularly family and other experienced care givers, and of course the individual persons with intellectual disability. For at least 2 years the cross agency group worked towards achieving a proactive model which would respond to a localised need for collaborative interagency services that would address some of the issues related to people with intellectual disability and serious harmful behaviours within the South West region of DSQ. It developed as a DSQ/Queensland Health proposal directly as a result of cooperation between DSQ officers in the region and the QH Mental Health Service at The Park. The group met regularly and advanced the proposal to the point at which it had constructed a proposal for a Pilot Assessment Service based on the available evidence and research into the best practice models for the target group. Although it involved DSQ/Mental Health cooperation (something wanting in the Joachim/Attwood period) it also failed.

My discussions with Dr Steadman and the others at “The Park” led to my receiving a copy of a Report entitled “Cessation of DSQ/QH Pilot Assessment Service Proposal Project, January 2004”, jointly authored by DSQ and The Park personnel.

The Cessation Report notes in May 2003 – “Process disrupted due to communication issues with DSQ”. The final event on 3 December 2003 was a meeting between senior DSQ officers in the region and senior officers in QH from The Park mental health service. The report notes – “Decision to cease proposal development due to different focus from senior management in DSQ”.

The Executive Summary of the Cessation report states:-

**The project ended following direction from DSQ. Reasons for cessation included:**

- **Lack of allocated resources and funding**
- **The DSQ business reform program meant that the project fell outside of the Department’s priority areas. The project was considered premature in the revised business context.**
- **The Innovative Support and Housing project is considered the major project for people with seriously harmful behaviours and intellectual disability.**
- **Piloting a service at The Park is in conflict with DSQ’s commitment to community based services.<sup>11</sup>**

One passage from the Report reads:

**“The difficult situations resulting for people with intellectual disability and seriously harmful behaviours still exist. This project attempted to develop a possible solution, however this did not eventuate. This group are still a high cost to both DSQ and Queensland Health. A rising trend is the cycling of people through the criminal justice system to mental health facilities, against the advice of mental health. This trend has currently resulted in around four to six clients that fit the target criteria being in The Park –**

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<sup>11</sup> Op. cit. page 3.

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**Centre for mental Health at any one time, at a cost of around \$750,000 per annum. With no other services available to address the needs of the target group, this trend will most likely continue. It is important to recognise that organisations will have to work together to provide viable and suitable services to people with complex needs, and that interdepartmental solutions remain a priority.”<sup>12</sup>**

The Joachim/Attwood initiative (1989/1991), the QH initiative (1997-8) and the Ipswich Regional initiative (2001/2003) had some common features the most integral of which was the need for a coordinated response based on interagency cooperation in the development of an holistic model of care and behavioural support which would address the individualised needs of the particular person. The model proposed by the Ipswich initiative also provided that the person’s individual needs must drive service responses including assessment and intervention.

There are two obvious lessons to be learned from the Ipswich experience.

Firstly, it is a sterile exercise to undertake unless there is a commitment to funding the proposed option(s). The Ipswich initiative was undertaken in the knowledge that there was no funding available either at regional or departmental level to support it. Those who initiated it were driven by a frustration based on a professional concern that “something needed to be done”. They had attempted a possible solution but failed.

Secondly, the fact that it was a regional proposal and not supported at departmental level was equally a cause of its downfall. There is a critical need for all stakeholders in the department, at whatever level, to “own” the key proposals advanced in this Report and where necessary to refine and ensure their effective implementation, for the benefit of those in the cohort.

The unproductive effort of governmental disability services over the past 30 years to effectively address this issue is now a matter of history. This is therefore a critical time for DSQ and this is a critical issue.

This Report will propose what is believed to be the right model for this time and into the foreseeable future and one must acknowledge the effort and commitment of those who sought to respond over the past 20 years and who have made a substantial contribution to this report.

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<sup>12</sup> Op. cit. para. 8 page 9.

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**CHAPTER 4****Day to Day Problems in Current Service Delivery**

There were several matters identified by Regional Managers, other agencies, NGO organisations and other stakeholders like Queensland Centre for Intellectual Disability Disorder (QCIDD) and those which are obvious and, which impact negatively on DSQ's and the sector's capacity to respond efficiently and positively to the demonstrable needs of the target group. I will not deal here specifically with the questionable service models in place and the obvious lack of facilities which are core problems. I will deal with those matters in that part of the Report which proposes the development of specific future options. My present intention is to identify the negatives. The positives will be proposed later and will provide for the preferred development of a new and proactive coordinated approach, the core feature of which will be the adoption of a flexible and individualised positive behaviour support methodology based on a comprehensive assessment of need and appropriate intervention and coordination supported by the provision of the necessary accommodation and other support options.

**1. The Inevitable Crisis**

It was hardly surprising to find that the case studies involving those with intellectual disability who exhibit seriously challenging behaviours, have a number of common features, the most dominant and overwhelming of which is the inevitable crisis, the keynote of which is the demand for an emergency response and the consequential need to try and manage the crisis in circumstances characterised by a limited capacity for appropriate accommodation, robust disputes between agencies as to where the responsibility lies in leading the response, ad hoc decision making even at the higher levels of government, an apparent inability to respond urgently with the aid of the required specialist disciplines and generally a lack of coordination of effort which often results in a so called "temporary" solution which, so readily, assumes an element of permanence. Meanwhile considerable energy has been consumed, tempers have become frayed, which aggravates even further the lack of capacity for coordination, maximum effort has been expended and the outcome, invariably an expensive and unsustainable one, has been much less than optimal. This is a common scenario and I saw one such case at relatively close quarters. It is wholly unsustainable and cannot be supported any longer.

All of this seems to be the inevitable and typical outcome because of the failure to have in place a dedicated process into which is inbuilt all of the necessary elements which are the essential parts of a disciplined and planned response. Such a response is the reverse of the process of crisis management which is a core feature of present service delivery.

Crisis management is often required in the case of unpredictable events and circumstances. But in this context one is not dealing with an unpredictable Act of God but with events which are entirely predictable, indeed, in some cases inevitable because the challenging and disturbed behaviour which often requires an emergency response is the known and predictable consequence of that persons intellectual disability. In short, crises should be and can be managed efficiently and productively with proper planning by having in place the means to provide an urgent and ready response which is the very antithesis of the ad hoc proposals and decision making which is a feature of current service delivery.

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There is therefore an urgent need to address this issue not only in association with the services available within other departments, other agencies and the private sector, but also by the provision of a suitable process which can respond to and service the urgent needs of the person who is the high profile centre piece of the crisis. The current mechanisms for confronting crisis have to be rejected entirely and are counter productive in achieving the ultimate objective of ensuring a quality life for that person. Therefore they have to be replaced with a planned and productive alternative which will.

The sources of the crisis are well known and easily identifiable. Senior DSQ officers know them well – the person with disturbed behaviour who cannot be effectively managed any longer by family or current carer; the young socially dysfunctional teenager, rising 18 who to the obvious relief of some in the Department of Child Safety, will soon become the responsibility of DSQ; the offender in contact with the Criminal Justice System which has no capacity, or only limited capacity to provide a suitable option for the offender with intellectual disability, in relation to bail at the Magistrates Court level or other decision making in the Mental Health Court, the insistence by QH Mental Health Services that a person with intellectual disability taken there, say, by police, does not have a diagnosable mental illness and cannot be placed in a mental health service.

These types of cases, some of which have at least one or more of the above features, not infrequently engage senior DSQ officers whose decision making is seriously constrained by inadequate or insufficient accommodation and service options and a lack of legislative support. The crisis is inevitably “solved” by an unacceptable and poor quality response which itself is inevitably problematic and counter productive for the person’s well being. Containment in one form or another, in an outdated or hastily renovated facility said to be supported by considerations of necessity of doubtful legal validity has been the usual response. Already limited resources are strained even further by the need to accommodate and “support” the person in question. Usually the person’s previous community based living option is no longer available or is considered to be inappropriate.

The unambiguous need for change has already been emphasised and the necessary changes are of a fundamental nature; they no doubt will make a significant impact on present structures; they have also to involve a change of culture and of practice. The proper implementation and management of those changes can only benefit the persons within DSQ’s and NGO’s area of responsibility.

## 2. A Collaborative Approach

A collaborative approach which will effectively and positively manage and address the individualised needs of the person who demonstrates disturbing and damaging behaviours, is to be contrasted with one which is fragmentary and uncoordinated, which is productive of disharmony and incapable in the final result of effectively addressing the special needs of the person.

These last mentioned features are readily identifiable in the way that services are presently delivered. That is not to say that in all cases systems failure is ever present. There are exceptions but the general rule is that challenging behaviour as a component of intellectual disability instantly provokes a negative mindset the focus of which is difficulty in service delivery, the “too hard basket”, lack of resources, the apparent need to devolve responsibility elsewhere, a lack of trained staff and inevitably, the idea of an unsustainably expensive solution.

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Yet clearly that need not be so. The literature and experience elsewhere amply demonstrate that.

The fact is that the person in the target group is a person who is or who may be a person of interest to DSQ or a funded NGO, other government agencies and community organisations like Autism Queensland, Acquired Brain Injury Association, Education Queensland, Department of Child Safety, Queensland Health, particularly the Director of Mental Health, Police, the Criminal Justice System especially the Magistrates Court and the Mental Health Court, Department of Justice and Attorney-General agencies such as the Adult Guardian, the Guardianship and Administration Tribunal, the Public Advocate and other Advocacy bodies, the Legal Aid office and the Corrective Services system. Each of course has its own area of interest. But the notion that sectional interests will not need to confront other sectional interests in this context is fanciful. The obvious focus of each is the same individual person. Obviously the challenge is to provide in service delivery terms or in any decision making which will affect the life of that person, an outcome which will benefit that person and assist that person to achieve maximum potential and/or development in a way which respects his/her inherent dignity and which complies in all relevant respect with universal human rights principles. The idea of working together collaboratively is obviously the desirable methodology.

There can be no retreat from that stance. If any relevant agency fails to measure up to the statutory yardstick provided by the Disability Services Act then an immediate reassessment is an urgent requirement. If any relevant agency so acts in a deliberate way that is relevantly non-responsive to the person and his/her needs, then correction is an urgent requirement. If any relevant agency fails deliberately to cooperate and to collaborate within its capacity to do so then at the highest level of the agency or organisation, direction is an urgent requirement and in this context lip service is a useless substitute.

A collaborative approach and, where necessary a whole of government approach is essential. The need for collaboration will be of the essence in constructing the desired service option.

Intellectual disability usually, though not invariably, begins in infancy. It will often be an added challenge for young parents who themselves will need support. Not only the child but also the parents will need appropriate support during the education process. The Department of Child Safety will not infrequently need to respond to young persons in the cohort at a young age on various grounds - physical or sexual abuse, a dysfunctional family or even a functional one which is, again for a variety of reasons, unable to cope with the legitimate demands of the disabled child, the consequence of marriage breakdown, the incidence of teenage development which may include homelessness, social dysfunction, alcohol and drug abuse. The Child Protection Order is a commonplace feature of a child's life in many instances. The experience of a child with intellectual disability and with serious behavioural problems, including challenging behaviours, is at the more troublesome end of this youthful cohort.

### 3. Infancy – early intervention

Whilst there are some identifiable funded programs provided by DSQ, DCS, Education Queensland and Autism Queensland for the support of the child with intellectual disability between infancy and adulthood, and in some cases beyond, there is a clear case to be made for the fact that certainly in the age group 14 – 17 there is a definite lack of suitable responses which specifically are designed to address the behavioural issues arising from the intellectual disability which often times is the product of Autism

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Spectrum Disorder. One respected and experienced Regional Manager in DSQ advanced the view that the apparent escalation in this potential cohort was “exponential”. The fact that DCS statutory obligations in respect of the child cease at age 18 and DSQ’s only commences then means that the ones involvement is necessarily terminal whereas the others is yet to begin. No doubt resource implications are influential in this context. But the plain fact is that the child’s attainment of adulthood at 18 should not provide justification for a fragmentary service response to the needs of that child/adult at a much earlier stage, which not infrequently results in the child losing contact with family and becoming socially dysfunctional.

There are promising signs that these concerns are being better recognised but much remains to be done. In December 2005 the CEO Sub-committee on Disability was formed. Earlier in 2004 as a consequence of the CMC Report in relation to child safety issues, a Child Safety Director was appointed in each of several department’s and together they form the Child Safety Directors Network. As a result of this initiative and the provision of funding it is proposed to form 6 Child Safety Behaviour Support Teams to work as part of an interagency model across the State. However this service is available only to those young people with disturbed behaviours because of mental health issues or intellectual disability who are in the care of the Department of Child Safety. Those who are not cannot access this service. The justification for this limitation should be revisited and reviewed. It may be based on a wrong assumption that the family will remain supportive and in tact.

There is one specific area of concern which emerged in the course of the consultation. It related to service delivery issues at the time when teenaged youths are transitioning toward a requirement for adult services from DSQ, particularly those who have been caught up in the justice system and may or may not have become the subject of a Mental Health Court forensic order.

The point can be best illustrated by a particular case study. A particular 16 year old male had come to the attention of the Department of Communities Youth Justice system and from that source had been provided with practical support. He lived at home; both parents worked; he had a significant intellectual disability and no diagnosable mental illness. The Youth Justice System supported him in the absence of his parents with recreational and educational activities. He had been charged with an indictable offence and was referred to the Mental Health Court where he was found to be unfit to plead on account of the intellectual disability. The Court decided not to make a forensic order which would have required his detention in an authorised mental health service – a wholly inappropriate option for a 16 year old with no mental illness. As a result of his appearance in the Mental Health Court and the finding of unfitness to plead the Youth Justice System no longer provided support. DSQ and Department of Child Safety after some weeks provided support. From 7 February 2006 the date of the Mental Health Court hearing to 1 May 2006 when “children at risk” funding commenced the young man had suffered a significant decrease in resources. Since the availability of current funding and support his behaviour has significantly improved but remains problematic.

At 18 he will become the responsibility of DSQ but since he is not subject to a Child Protection Order he will not be eligible for exiting the care of the State funding from DSQ.

The logic of this outcome is not easy to accept. This young person, and there are potentially many others, are subject to a very inconsistent and uneven set of criteria which determine his/her level of support. If he had been the subject of a Child Protection Order his support would have been significantly enhanced.

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There are a number of young offenders who have been found by the Mental Health Court to be not fit to plead and who may or may not be under a Child Protection Order. Whether they can meet the criteria for DSQ support through the Family Support package or be supported by the DSQ Interagency Child Safety Teams is also problematic.

For early intervention strategies in the case of young people to be effective in the longer term it must be consistent, relevant and ongoing and be responsive to the individual young persons needs.

In my view the several issues relating to the support of children and young adults with intellectual disability should be the special focus of inter-departmental consideration and an effective and targeted response developed.

#### 4. DSQ/Mental Health Services

DSQ's provision of services to the adult members of the target group frequently – almost invariably – gives rise to an interface with Mental Health services which is also problematic.

There are fundamental differences between mental illness and intellectual disability. One of these only is the fact that the condition and symptoms in the case of the former may be successfully treated. In the case of the latter the intellectual disability may be genetic and be present through ones entire life. The manifestations of each however, at least in a general sense and to the eye of the uninstructed observer may be of the same general kind. Each person may be a potential danger to him/herself or to those close to them or to persons in the community. The Mental Health Services Act 2000 provides a range of legislative provisions designed to ensure the safety and well being of the mentally ill person and of others. Disability Services legislation so far has no like provisions. This Report will recommend that the proper management and care of those with intellectual disability, who at times exhibit serious and challenging behaviours, requires an acceptable level of legislative intervention.

It needs to be emphasised however that whatever differences there are between mental illness and intellectual disability, those in the latter category will generally need to be supported over much longer periods given that some significant proportion of those with mental illness will have their illness successfully treated and are thus able to be managed more easily over the longer term.

A major problem between the two streams lies in initially deciding to which group the individual belongs. Mental illness or intellectual disability? But the categories are not mutually exclusive. Psychiatry recognises the need for a dual diagnosis in some cases. Whilst there are some concerns between Queensland Health and Disability Services Queensland in relation to dual diagnosis and some of these emerged in the course of consultation with Mental Health Services, a major issue of concern is a developed tension between the two agencies. Mental Health insists that its obligations extend only to its treatment of those with mental illness and that a mental health service has nothing to offer the person with only intellectual disability.

The real source of the tension is the insistence by the one agency that it will not assume responsibility for those in the other category nor should it have to. This is aggravated by DSQ's inability to properly house and manage some of the cohort and its lack of supportive legislation. At the same time Disability Services Queensland needs to access the Mental Health professional resource to clarify and better manage

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its own position and responsibilities. At times this is available. At other times it is not, often in those cases where DSQ requires for its own purposes a comprehensive assessment of its clients or potential clients so as to maximise the effectiveness of its management and support plans. One detects a significant lack of collaboration between the agencies at the level at which the interaction is most likely to occur – in the case of DSQ at regional manager level; in the case of Mental Health at psychiatrist or Mental Health middle management level, although it is clear that sometimes a personal and friendly relationship between individuals in each agency can assist the process. There is however a systemic problem.

One can even detect a disturbing lack of mutual trust not only in relation to the adequacies of some diagnoses but also a robust and defensive insistence on “gate keeping”. Needless to say this level of contention has to be counter-productive and results in the fact that the real loser is the person whose mental illness/intellectual disability requires that it be dealt with properly and who is entitled to expect that he/she should have the benefit of appropriate government services which will optimise proper care and support. Any unnecessary and avoidable conflict has to be removed and major issues resolved. In each case there is the inevitable resort to “finite resources”.

Some of the contention no doubt arises from the terms of the Mental Health Act 2000 and its definition of “mental illness” which excludes a person with an intellectual disability. The issue of diagnosis therefore often becomes the occasion for the “parting of the ways” between DSQ and Mental Health. This is often aggravated by those cases in which the ambiguous “dual diagnosis” is made and which necessarily presents Mental Health with significant difficulties. Below I will deal with the major problem which confronts the Mental Health Court in the making of forensic orders in respect of person with intellectual disability only, given that the Mental Health Court is established under the Mental Health Act and the Court’s jurisdiction to make forensic orders is limited by the Act which generally requires that the Court can order “detention” in certain cases only to a “mental health service”. Discussions at Baillie Henderson Hospital and at “The Park” mental health service and with other relevant stakeholders can leave one in no doubt that this is a wholly unsuitable outcome. It is neither acceptable for those with mental illness to be treated in a place where persons with intellectual disability are to be accommodated nor for the person with intellectual disability to be housed where the mentally ill are being treated.

The allied “limited community treatment order” which the Court can make in some circumstances only serves to aggravate the situation between the 2 agencies. The source of so much of this contention is the fact that DSQ has neither the capacity nor the facilities to house and support the person with intellectual disability nor the necessary legislative support for such a process.

These are some only of the issues which illustrate how tensions between these major players arise, escalate and become somewhat intractable. However, they also illustrate the fundamental importance of having in place a collaborative and cooperative working relationship between DSQ and Mental Health.

As will appear the need for valid assessment of the persons in the target group as part of any intervention strategy is in my view a critical issue. The literature is unequivocal in emphasising the importance of comprehensive assessment. The necessity for valid behavioural analysis as part of the assessment is of the essence, if effective behaviour support strategies are to be incorporated into the long term plans for managing and minimising the challenging behaviours. Behaviour analysis as part of the assessment process which is coupled with behaviour management planning is essential.

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The present fragmentary and at times ad hoc responses to behaviour management in particular cases are so frequently the product of a lack of comprehensive assessment or an inadequate assessment. So long as comprehensive assessment of the person and the identification of his/her needs, which can only occur through a collaborative process across disciplines and agencies, is absent then a proper and cost effective planning strategy cannot be validly proposed. In the course of the review one has seen some of the developed plans which are genuine attempts to professionally address the behavioural issues in a particular case but one is often left with the impression that they are basic and less than adequate and one wonders to what extent if at all, they are implemented. In some cases where the psychologist has been instrumental in the development of the plan, there is an expressed concern that its implementation at residential carer level is not pursued and this is aggravated by a failure at management level to insist on compliance. There is a reciprocal concern on the part of carers that appropriate support and consultation with the psychologist in the implementation of the plan is lacking or less than adequate. If these mutual concerns are to be accepted, one can only conclude there is the need for enhanced staff training and more effective management.

Behaviour, particularly learned behaviour, can arise on several accounts. But one cannot avoid the need to also ensure that any psychiatric disability, if not a mental illness, as well as the general health care needs of the person, are also fully assessed at the same time and as part of the same process which seeks to plan into the future for the implementation of a meaningful behaviour support strategy. This needs the involvement of specialist medical personnel working with those other relevant stakeholders so that the primary objectives of this complex service delivery can achieve the best outcome for the individual person the subject of the assessment. Best practice has not always been followed. Indeed one wonders how often it is. The kind of assessment process which is proposed as a necessary precondition in achieving best practice for the target group is not presently used. Perhaps a want of collaborative effort is partly to blame.

The fact is that those in the cohort have individual needs that have to be addressed if the proper development of the person is to be optimally supported. It was said earlier that these persons are not in terms of their personal characteristics, static and intransigent and once categorised are then able to be the subject of a common management plan. Rather each needs to be supported in a way which individualises their needs and provides an individual response. Flexibility is therefore an essential requirement which in turn requires a specialised and comprehensive assessment of the person and his/her needs. It is presently not available.

DSQ's provision of services to date, particularly to those with high needs has been fragmentary and too frequently the subject of risk management in circumstances of emergency. There is no effective protocol or practical plan for an efficient response. Many cases observed in the course of the review are marked by the need for an immediate DSQ response, often in cases in which DSQ has had no past, or sometimes only passing, involvement. The resolution of the emergency has however so frequently devolved to DSQ officers who are required in pressing circumstances to respond as the emergency requires – to provide or arrange accommodation instantly, having no or only fragmentary information about the person, which often puts the agency in tension which other agencies and with parents and others including other service providers who so often regard DSQ as the provider of last resort.

The pathways to DSQ by the target group are many and varied and the relevant persons within it are individuals of different personality and temperament with a wide variety of needs. The fact that they are grouped with the often perjorative tag as

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having “challenging behaviours” obscures the core problem, which is often only met by developing expensive and financially unsustainable solutions which do little or nothing to resolving the individual needs of the person.

The maintenance of the status quo is therefore indefensible. This Report will propose an effective intervention by developing a proactive strategy which not only responds efficiently in situations of emergency but also lays the foundation for the ongoing development of proper models for the future care, support and development of the individual person and which addresses the needs of the individual person. A collaborative process of assessment which involves various disciplines and agencies is a necessary feature of these proposals.

The need for a collaborative whole of government approach to intellectual disability is also well illustrated by the experience of those who are involved in supporting the needs of children with Autism Spectrum Disorder and their parents. Challenging behaviour is a feature of this disability. In too few cases is any attempt made to support and assist in the management of the very disturbing behaviours which occur in this group. As has been said challenging behaviour is not reserved to the adult with intellectual disability. It is a constant feature of the life of the child with ASD and if it is not properly addressed then and the disturbing behaviour continues into adulthood, it almost invariably becomes a responsibility for DSQ in due course.

Again in too few cases are the appropriate interventions occurring in the case of children. DSQ through its FECS program funds assistance to parents with children in the 1-5 age groups. However, there appears to be a major shortage in appropriate intervention from the time the autistic child’s formal education commences. A major special education provider is Autism Queensland (AQ) which provides specific education facilities over the primary/secondary school range for about 144 children each year at its schools at Brighton and Sunnybank Hills. This is insufficient by far and Education Queensland should in association with private providers of education services reassess the plans for education for those who are unable to cope effectively with mainstream systems. AQ provides a teacher class ratio of about 1:6 but cannot fund a system whereby each child with ASD can be adequately educated.

This has substantial implications for DSQ and the wider community. There is an identifiable and enlarging problem for DSQ and other service providers who provide appropriate care and support facilities for a younger cohort of persons with this disability and who exhibit seriously challenging behaviours. It has been observed that a good percentage of those who generate the most concern are young adults – some still in their teenage years. I was informed that many, particularly those whose lives had become socially dysfunctional and who border on homelessness, were easily seduced into drug and alcohol abuse and soon involved in the criminal justice system.

The provision of a more broadly based facility for the education of young ASD affected persons appears to be an essential requirement in the personal development of those young persons in the ASD cohort. AQ senior personnel with whom I consulted expressed grave concern at the presently inadequate facilities to address the many needs of these young persons. As the social problems associated with this group continue to escalate and they will, the future demands on government for the provisions of services will likewise escalate.

The kind of behaviours whereby they and others are at risk as a consequence of their disability cannot be underestimated. One must be firmly of the view that the demands upon DSQ will require an increased response into the future and as this Report asserts requires an increased level of commitment and organisational infrastructure which will

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effectively manage the cohort and provide to its younger members a more professionally based level of service and an increased capacity to enjoy a level of lifestyle consistent with their inherent and guaranteed human rights.

Reference has been made to aspects of the present interface between DSQ and the DCS. An additional and urgent assessment of the present role of Education Queensland in the provision of education services to an increasing brigade of young persons with disability by the kind defined in the Disability Services Act 2006 should be another priority.

#### 5. Accommodation

A major concern and one in respect of which there needs to be an urgent response is the inappropriate accommodation which is presently provided for a number within the cohort. This accommodation for the most part has had to be provided in an emergency or crisis situation. Not only is some of the accommodation prison like in character, it assumes all of the worst features of detention, which, as said elsewhere, is unlawful but which is said to be supported by legal theory of doubtful validity. It is a blight on DSQ's efforts at service delivery and in its care and support of those who fall into this group. It can easily distract one from the major efforts of DSQ in other areas in seeking to provide the proper accommodation responses.

One has to unequivocally reject any proposition that would seek to support its continuance. It is totally unacceptable, represents a gross infringement of the relevant person's human rights and is wholly inconsistent with the principles enshrined in the Disability Services Act. This Report will recommend below the total redevelopment of the Basil Stafford site as a first priority.

The present unacceptable accommodation regime at Basil Stafford Centre has to be terminated as soon as possible. This view is shared by DSQ personnel. Considerations of convenience should not be allowed to dilute the urgent necessity to provide urgently needed and acceptable housing for those who are said to need appropriate secure care to ensure the safety of themselves and others. The core problem is that the maintenance of such facilities reduces the capacity of the service provider to properly address the many issues involved in the future development of that person. The present situation effectively prevents one from executing statutory objectives and obligations. It is also offensive to the dignity of the human person.

The urgent provision of suitable living environments is therefore not negotiable. I will expand on this matter in a later part of the Report, which will address the question of suitable accommodation models.

The problems for DSQ which stem from the lack of any comprehensive and integrated assessment of the person and the consequential ad hoc decision making which is necessarily ill informed are compounded by a lack of appropriate accommodation and a shortage of specialist and properly equipped and trained staff.

#### 6. The Mental Health Needs of Persons with Intellectual Disability

The ambiguity which is buried in the so called "Dual Diagnosis" has given rise to significant weaknesses in the service responses to the needs of this client group. For many years, at least from May 1990 when Dr Attwood, Senior Clinical Psychologist authored his paper "Psychiatric Clinic in Brisbane for people with an Intellectual Disability" (included in the Joachim documents) and he argued in correspondence with the then Queensland Health Psychiatric Services for the establishment of such a clinic,

which was rejected, (see letter 20 February 1991 from Deputy Director of Psychiatric Services to Mr Joachim), the question of how best to service the mental health, general health and other needs of those with mental illness and intellectual disability remain largely unanswered.

The relevance of this issue for this Report is readily apparent from this extract from a report on Models of Service for Dual Diagnosis, August 202, written by the Developmental Disability Unit (now QCIDD) School of Population Health, UQ. Referring to the target group, the report states:-

**“.....adults with a dual diagnosis or a suspected dual diagnosis may have one or more of the following characteristics:**

- **A range of support needs ranging from low (mild intellectual disability) through to moderate levels of intellectual disability (higher support needs);**
- **Challenging behaviour and/or dangerous behaviour involvement or a history of involvement with the criminal justice system.”<sup>1</sup>**

At page 3 of the same document the target group is defined as follows:-

**“The target group includes adults with an intellectual disability who have a diagnosed mental illness (dual diagnosis) and those who require assessment because their behaviour suggests they may have a dual diagnosis.”<sup>2</sup>**

The document also identifies the “organisational conflicts” which have impeded an effective collaborative approach to those with intellectual disability and who have or may have a mental illness – the group who are often identified as liable to “fall through the cracks”

- **Inappropriate admissions to mental health units;**
- **Delays in returning to community based living options;**
- **Blocked beds and no throughput means mental health services are reticent to accept further referrals of adults with a dual diagnosis;**
- **Mental health services fear abandonment by disability service providers;**
- **Disputes and disagreements result in discontinuity and fragmentation of care or clients fall through the gaps and get lost in the system;**
- **Inadequate communication flows through and results in poor coordination between services;**
- **Eligibility barriers feature in disagreements due to poor “fit” into criteria for services;**
- **Lack of dual diagnosis service options;**
- **Mental health doesn’t know what disability service providers do and vice versa;**
- **One size fits all approach by service providers eg there is no acknowledgment that the mental health needs of adults with an intellectual disability require specialist skills;**
- **Service responses are always crisis response driven and there are rarely preventative or quality of life maintenance functions;**

<sup>1</sup> Op. cit. page 3.

<sup>2</sup> Op. cit. page 3.

- **Negative attitudes and sometimes fear projected towards working with people with an intellectual disability who have co-existing mental health problems;**
- **Minimal acknowledgment that people with an intellectual disability experience vulnerability to mental health problems;**
- **Poor dual diagnosis knowledge, skills and expertise with virtually no awareness of the growing evidence base in this field.<sup>3</sup>**

QCIDD in its Report of the Dual Diagnosis Project 2002, entitled “*Not on the Same Page*” explains the title of the report as follows:-

**The term “*not on the same page*” emerged during consultations undertaken by the Dual Diagnosis Project Team. The term was used to describe the relationship between stakeholders. It is an apt term that suggests all dual diagnosis stakeholders are not working together on the same agenda. Participants suggested that the agenda should be focused upon the mental health needs of the person with the intellectual disability, rather than the needs of the service providers.<sup>4</sup>**

QCIDD has since 2002 expressed its concerns that there is a shortage of professionals and clinicians in Australia who have the knowledge and skills to appropriately respond to the needs of adults with a dual diagnosis. The shortage of skills in DSQ which impacts on its capacity to effectively address the behavioural issues inherent in intellectual disability and cases of dual diagnosis is referred to elsewhere in this Report.

The problems associated with dual diagnosis cases cannot be ignored any longer. Dual Diagnosis was recognised as a matter of major concern by Joachim and Attwood some 15 years ago. The issue has been enlivened significantly by the QCIDD work and its publications since 2001 and there are sound and valid reasons for adopting the QCIDD recommendations including the urgent need for DSQ and non government service providers to work collaboratively with QH Mental Health Services and QCIDD in order to ensure that service delivery to those with Dual Diagnosis is effectively responsive to the needs of that client group.

There needs to be recognition of the fact that the major emphasis in this Report is closely allied to the recommendations in the QCIDD reports, authored by Professor Nicholas Lennox and Ms Niki Edwards both of whom have assisted me in the course of my consultations. There are at least 2 major aspects of this Report and the subject of its core recommendations which are intimately in tune with the thrust of the QCIDD work to the extent that it focuses on the sector’s past inability, incapacity or lack of will or one or more of these, to seriously address the challenging needs of persons with intellectual disability and co-morbidity mental illness.

Firstly, the lack of sufficient professional and specialist expertise in DSQ has minimised its ability to provide a comprehensive and targeted response to that client group which exhibits disturbed, dangerous or otherwise challenging behaviours. This lack of sufficient expert professionalism can only be properly addressed through what this Report in Chapter 5 calls The Centre for Best Practice in Positive Behaviour Support to be led by a high profile practitioner of national/international reputation who can lead and influence the total sector in the provision of expert specialised service in response to the unmet needs of so much individual persons with intellectual disability.

<sup>3</sup> Op. cit. page 9.

<sup>4</sup> Op. cit. page iii.

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Obviously the work of the Centre and that of QCIDD are complementary to each other and in the course of collaboration not only inter se but with all of the other relevant disciplines and agencies can seriously inform service delivery so as to make excellence achievable.

Secondly, as the QCIDD report emphasises, there is a need for ensuring comprehensive assessment of the person if his/her needs are to be properly addressed and responded to. So too does this Report. The need for multi disciplinary assessment is fundamental to the provision of the preferred service response. The additional needs for development of a positive behaviour support plan, effective intervention in the support of that individual person and effective coordination of services and plan management at community level are key elements of this Report's recommendations.

When one in 2006 reads the reports of QCIDD's work in 2001/2002 (Not on the Same Page; Sand in Society's Machine and Lessons from the Labyrinth: Lennox and Edwards) one cannot but question: what has been the impact of that work? Is it reflected in 2006 service models for the proper support of persons with intellectual disability? Sadly one has to report that little or nothing has happened. An absence of any apparent systemic response clearly suggests that the brilliant energy and creative thinking inherent in the QCIDD work has lost its momentum and has failed to displace the inexpert and crisis driven culture which in respect of this Dual Diagnosis client group at present seems almost immovable.

This Report will strongly recommend that DSQ through its Centre for Best Practice regard the QCIDD recommendations in respect of Dual Diagnosis cases as a matter of priority. The issue when revisited and its ongoing relevance in Mental Health Court decision making will also be confirmed.

## 7. Staffing Issues

A satisfactory approach to the proper care and support for those persons with intellectual disability who are the focus of this Report is simply not possible and will remain incomplete and inadequate so long as the sector does not have access to specialist and care staff who are properly trained and well resourced.

Firstly one has to focus on the issue of specialist staff. Here I am mainly concerned with the allied health professional disciplines relevant to those persons with intellectual disability – psychology, speech pathology, occupational therapy and social work. In the course of the review it became apparent that the availability of suitable professionals, in particular psychologists, is a systemic problem. At the same time, it is in my view impossible to provide a service of excellence unless the service is adequately resourced with psychological expertise. The availability of an integral and comprehensive assessment approach and intervention is not possible nor is the necessary ongoing procedures for assessment, monitoring and review of the individual person possible if appropriately trained and skilled psychologists are not available.

Advertisements in the State, inter-State and overseas are regular features of DSQ attempts to recruit staff, particularly psychology staff. Success in this respect is frequently hampered by the need for DSQ to compete with other recruiters not only in the private sector but also with other government agencies. This Report will seek to address this issue as part of its presentation of a fully integrated and coordinated scheme for adequately and properly resourcing DSQ's capacity to successfully establish a service of excellence to persons with intellectual disability whose high and

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complex needs have to be addressed for a variety of reasons, not the least of which is the best interests of the person and of the community and its several interests groups.

Any problem of this dimension needs a proactive and innovative solution or else the provision of a proper service is really not possible. Plainly for the status quo to remain is not an option. Nor do piecemeal attempts at solution suffice. The problem of recruiting properly trained psychologists is a necessary part of the solution and it is addressed below. It requires a vigorous and planned response as part of an holistic strategy which will have permanence rather than be subject to frequent change or a process of trial and error. This report will propose such a response. The issue of having available the required pool of specialist staff support has to be a part of that response.

In the course of the review a meeting with DSQ regional psychologists revealed, and it has been confirmed, that behavioural analysis, an integral feature in properly dealing with challenging behaviour, is not taught at undergraduate level in University Schools of Psychology. Intellectual disability is seen as having a relatively low priority. There are opportunities provided at post-graduate level for this part of the learning. I was informed in this meeting that one person's first contact with behaviour analysis was after commencing employment with DSQ and in the course of a DSQ sponsored in house training program. Therefore if undergraduate university based education does not provide an integral part of the training of one who will work in intellectual disability then DSQ has a serious problem which has to be addressed. DSQ should therefore become influential in ensuring that this professional resource which is essential to its service delivery in respect of persons with intellectual disability is available.

There is an urgent need for DSQ to comprehensively assess its present capacity to provide adequately equipped allied health professionals for the care and support of those in the cohort. This does not involve only ensuring their proper professional education in addressing high and complex needs but the whole issue of adequate professional development. Intellectual disability is core business for the sector. Maximising the professional skills of its professional staff is therefore a fundamental requirement. So too with its other specialist staff.

RCO staff are at the forefront of service delivery to those with whom this Report is concerned. It was commonplace to be told that staff turnover is high, casual employment a feature of the system, that it was not always a safe workplace, that specialist staff did not adequately support RCO staff and by specialist staff that RCO's rejected specialist advice on the basis that "they" knew best. There were several references in the course of conversation to the fact that the abuses of the institutional system had been reborn in the newer environment of community living, in short, that the undesirable "culture" of the past had not been eliminated.

All of this has to be seen as a serious concern. One cannot verify on the basis of hard evidence the truth or otherwise of some of these serious assertions. On the other hand one can not reject them as false. The mere fact that they are made is sufficient to support the need to intensively review the critical issue of adequate staff recruitment policies and ongoing professional development and training, not only of specialist staff but also of RCO staff. The need to have RCO carers and other carers involved in the processes of assessment and planned intervention which this report endorses is a critical matter in my view. Therefore not only is their capacity to assist the relevant functions to be respected, their ongoing and day by day involvement must be duly recognised and enhanced at least by ensuring proper training and development.

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This is not only a staffing issue; it is also an example of the need for a more collaborative effort referred to above.

DSQ has recently reviewed its Accommodation Support and Respite Services (AS&RS). This service has had, since 2004, its own Directorate. In providing this substantial service I have been able to meet and observe many of the RCO staff in the course of their daily work with a substantial variety of persons with intellectual disability including those who fall clearly in the cohort. One cannot but have the greatest respect and admiration for those many employees who are committed to making a professional and hard working effort to provide a quality service to those for whom they care. Not a few of them have been the victims of assault and other unacceptable behaviour in their workplace.

The need for quality well trained RCO staff is therefore obvious. If the workplace is to be regarded as unsafe or problematic many will leave. Finding suitable replacements is a serious problem not only for AS&RS but for the several NGOs who also seek to recruit suitable staff.

Therefore whilst proper training of staff is a basic requirement the development of a service of professionalism in the work they do on a daily basis is essential. The impression one gets from a review of the system is that in this respect there is an element of inconsistency and whilst a basic formal qualification is set, the process of quality in-service training and professional development should have a higher priority.

RCO staff have so much to offer the integrated assessment process. Their experience with the person and their ongoing attempts in the workplace to observe relevant events in the daily life of the person are fundamental to the validity of the assessment process and so the RCO personnel should not be regarded as being of relatively inferior status. Rather they should be regarded as having a core role in not only the formation of the individual care and behavioural support plans but in monitoring them and in the review process.

The AS&RS review was timely and DSQ's proposals for its implementation are endorsed. It is also relevant in this context.

#### 8. Innovative Support and Housing

One matter of immediate concern is the Innovative Support and Housing Project which presently is represented by 2 accommodation facilities at Morayfield and Wacol and a recently completed facility in Townsville. A visit to each of the Morayfield and Wacol laces confirms them to be accommodation facilities of thoughtful design, a tasteful décor, quality appointments and generally attractive living environments. The congregate nature of the accommodation however is a matter of concern. This is a matter which requires review.

A review of the project reveals an original planning intention that the facilities were to be transitional in character only and were to occupy a specialist niche in a continuum of care for specially selected individual clients. The facilities were said to have been designed for that express purpose.

The fact that DSQ is often driven by crisis management and ad hoc decision making is no better illustrated than by the experience so far of the 2 "innovative" houses at Wacol and Morayfield during the past year. Each has now been occupied for about that period. The period of transition which the houses were designed to provide is now or should be complete for its occupants. However, with the exception of one or two

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persons, an initial assessment can leave one in no doubt that their present operation is less than innovative and the fact that each operates at a sub optimal level is a direct consequence of the fact that an emergency demand for accommodation could only be met by accommodating persons there who do not meet the criteria for access to the houses. The availability of specialist staff is also less than optimal

Although the concept was valid to some extent it has failed largely because of a failure to provide appropriate professional behaviour support and because of the need in an emergency situation to accommodate persons whom the criteria for admission would ideally exclude.

All of this occurred because the particular concept was developed ad hoc rather than as part of an integrated and coordinated continuum of services of which the Innovative Housing and Support Model was to be a part. One must add that the concept is generally acceptable and consistent with the implementation of an holistic and integrated continuum for care and therefore should be retained. In the approach which is recommended in this Report it can remain an integral part and ought be retained but further developed. But in that context there has to be a rigid inherence to the access criteria defined for these facilities and thought given to the development of smaller facilities.

It needs to be said also that there has not yet been completed a quality evaluation of this project. One can safely speculate that when completed an evaluation will be less than favourable.

On 31 October 2003 DSQ completed preparation of a document relating to the Innovative Support and Housing Models Pilot, as the project was then known, and part of the document headed "Summary Overview" and the related architectural drawings were submitted for expert comment to Emerson (Emerson Education Research and Training Consultancy, UK), a noted expert and respected author. His reply is dated 11 December 2003; also to Jayne Clapton (School of Human Services, Griffith University) whose reply is dated 30 November 2003; and to Stancliffe and McVilly (University of Sydney Centre for Development Disability Studies) whose reply is dated 5 December 2003.

The preliminary assessments made by these respected professionals in response to the DSQ documentation, individually and collectively are significantly less than positive. Each should be compulsory reading for those whose obligation it is to advise on any further development of the project. Each reply speaks for itself and raises more questions of substance than answers. A few extracts from each will suffice to emphasise their concerns:

**"Congregate services are (1) more costly and (2) provide poorer outcomes in terms of increased reliance on psychoactive medication and physical restraint for the control of challenging behaviour, increased risk of injury by co-tenants, increased risk of deterioration in mental health and challenging behaviour, more restricted access to day activities."**  
(Emerson)<sup>5</sup>

**"Ensuring access to sufficient support from staff skilled in both psychological (behaviour) and bio-medical approaches to treatment will be critical to the success of this venture."** (Emerson)<sup>6</sup>

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<sup>5</sup> Letter Emerson Education Research & Training Consultancy to DSQ page 2 11/12/03.

<sup>6</sup> Letter Emerson Education Research & Training Consultancy to DSQ page 2 para. 5 11/12/03.

**“I consider the uneven nature of strategy development in this area to be highly problematic given the aims of this specific project.” (Emerson)<sup>7</sup>**

**“(The service philosophy) which embraces the Developmental Model and the Principle of Least Restrictive Alternative ..... are confusing in the document. I would also question the reliance on these approaches which are both functionalist.” (Clapton)<sup>8</sup>**

**“the transitional nature of the service appropriately emphasises its role as a specialist resource in support of a wider service delivery system. To maximise this capacity and to prevent the service developing as simply an accommodation option of last resort, strict adherence to entry and exit criteria will be essential.” (Stancliffe & McVilly)<sup>9</sup>**

One cannot read each of the assessments in detail without concluding that the very concerns variously expressed by experts came to be realised. Ad hoc responses, and this project was of that type, will fail or will provide a less than desirable response when driven by irrelevant and extraneous imperatives. This is one such case.

That is why this Report attempts to address this issue holistically and not piecemeal. The proper responses to be effective, have to be driven by professional and expert knowledge and advice of what is required not by uninformed decision making based on what “seemed to be a good idea” at the time.

#### 9. Mental Health Court Concerns

Persons with intellectual disability, who do not have a mental illness, frequently come into contact with the Criminal Justice System. In many cases Police are called to an incident involving probable criminality in the conduct of such a person but choose to take no further action for a variety of reasons. These are usually persons living in the community, at home, in a boarding house or in supported accommodation. Not infrequently these are persons who are known to DSQ or who come into contact with DSQ, usually at Regional office level and usually in circumstances of emergency or crisis of the kind to which reference has already been made.

Here I wish to deal specifically with that not insignificant section of the cohort who are brought by Police into the Criminal Justice System and who as a result frequently come to the Mental Health Court and before the Mental Health Review Tribunal. In the course of the Review I was able to have helpful discussions with Justice Holmes of the Supreme Court who, before her recent appointment to the Court of Appeal, presided in the Mental Health Court and I received a detailed and helpful submission from Mr Barry Thomas who presides at the Mental Health Review Tribunal. In his submission Mr Thomas writes:

**The Tribunal comes into contact with intellectual disabled individuals exhibiting the more severe end of the spectrum of challenging behaviour, including sex offending (rape, unlawful carnal knowledge, indecent treatment of children) as well as non-sex-related criminal offences (stealing, unlawful use of a motor vehicle, unlawful entry to premises). Some challenging behaviours may also be related to psychiatric co-**

<sup>7</sup> Letter Emerson Education Research & Training Consultancy to DSQ page 3 11/12/03.

<sup>8</sup> Jane Clapton PhD to DSQ 30/11/03 page 2/3.

<sup>9</sup> Stancliffe & McVilly University of Sydney CDDS 5/12/03 page 2.

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**morbidity (for example, obsessive personality traits, Korsakoff's dementia, sexual fetishism) and dual diagnosis (schizophrenia, bipolar disorder). There is a need to consider services for individuals with psychiatric co-morbidity separately to those individuals with challenging behaviours associated with intellectual disability alone. My comments relate more specifically to people with intellectual disability in the absence of any psychiatric co-morbidity.<sup>10</sup>**

Intellectual disability was expressly excluded from the definition of mental illness in S12 of the Mental Health Act 2000, a situation specifically different from that contained in S5(2) the Mental Health Act 1974. However Mr Thomas in his submission goes on:-

**Yet, in the absence of any other appropriate scheme, an interface continues to be created by the insanity defence in S27 of the Criminal Code that encompasses loss of capacities by both mental illness and natural mental infirmity. This is carried through into the forensic provisions of the MHA 2000 both in relation to the role of the Mental Health Court in determining unsoundness of mind and fitness for trial, and the tribunal in determining unacceptable risk. In S204 of the MHA 2000, the risk considered by the tribunal must be attributable to either the person's mental illness or intellectual disability.**

**The referral of an intellectually disabled person into the mental health system via the Mental Health Court upon a finding of unsoundness of mind or permanent unfitness for trial (if the Court elects to make a Forensic Order) brings with it all the inherent problems of inappropriate living arrangements and service delivery, departmental conflict over roles and responsibilities, and poor outcomes for the individual including vulnerability, institutionalisation, stigma and skills atrophy.<sup>11</sup>**

The making of a Forensic Order by the Mental Health Court is intended to provide a management structure within the mental health system to manage risk throughout the individual's mental health treatment and rehabilitation until the Mental Health Review Tribunal (The Tribunal) is satisfied that the person no longer represents an unacceptable risk to the community. Therefore conflict necessarily arises where the person before the Court is a person with intellectual disability but who has no mental illness, yet because the Court has jurisdiction in respect of persons with only an intellectual disability, who are found to be of unsound mind or to have a natural mental infirmity for the purposes of Section 27 of the Criminal Code or who are found to be unfit for trial because of the intellectual disability, the Court on making a forensic order is limited to ordering that that person with intellectual disability be contained in a mental health service. Alternatively the making of a limited community treatment order presents difficulties for the mental health service.

Mr Thomas continues:

**Both the Court and the tribunal are confronted with the issue that placement of a person with intellectual disability in a psychiatric facility is inappropriate. Yet both are charged with a responsibility to ensure that there is not an unacceptable risk, and in order to manage risk, there is often no suitable alternative than detention in a psychiatric facility.<sup>12</sup>**

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<sup>10</sup> MHRT Submission page 2 19 May 2006.

<sup>11</sup> MHRT Submission page 2 19 May 2006.

<sup>12</sup> MHRT Submission page 3 19 May 2006.

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Justice Holmes has repeatedly expressed her concern. In a particular case in 2005 the Court was concerned with a person with intellectual disability who had no mental illness but who on account of the intellectual disability was of unsound mind at the time the offences were committed. He was also found to be permanently unfit for trial. He had been charged with repeated offences of indecent treatment and indecent dealing with children.

Justice Holmes said:-

**The largest problem has been whether a forensic order ought to be made in this case. It is the problem commonly encountered by this Court that a forensic order is an inappropriate mechanism for supervision of somebody charged with offences such as these. It is really an order designed to manage somebody with a medical problem not the behavioural problems that might be associated with retardation. Unfortunately, the Act allows of no other mechanism. It seems to me it is a case in which supervision is needed. It has been suggested that the matter be adjourned to obtain further information from Disability Services Queensland. I think that is unlikely to be a productive course and it is better, I think, to proceed with an order at this stage.**

In another case in 2005 the Court was concerned with another male person just turned 17, who was found to be permanently unfit for trial on account of an intellectual disability. He had no mental illness. He was charged with sexual offences in respect of young girls. Her Honour noted that he was subject to a Child Protection Order but would turn 18 shortly and that then "DSQ would take over its role" in respect of the person concerned.

Her Honour said:

**[18] This case exemplifies a two-fold problem which the court encounters in cases of persons suffering from intellectual disability such as to render them either of unsound mind or permanently unfit for trial, without accompanying mental illness. The Mental Health Act 2000 makes the forensic order under s288 the mechanism for management of persons in respect of whom findings of unsoundness or unfitness are made, but it entails detention in an authorised mental health service for treatment or care, with provision for limited community treatment where appropriate. The obvious difficulty is that a mental health service can offer little by way of treatment of a person who has no mental illness and can provide little by way of supervision to such a person in the community. But the Act provides no means of supervision specifically adapted to the circumstances of intellectually disabled persons who present a risk of re-offending. To compound the problem, the carers provided by either the Department of Child Safety or Disability Services Queensland have, it seems, no clear statutory power to restrain such an individual when he or she seems likely to abscond or re-offend.**

**[19] The second difficulty is an associated, practical one: the absence of existing, structured living arrangements for persons in this position. This case throws that problem into sharp relief, with the alternatives given to the court in August of CMM remaining in a youth detention centre or being placed in a motel with a social worker. It is difficult to see how either alternative could meet the obligations of the Chief Executive of the Department of Child Safety as CMM's guardian. There has never been**

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**any dispute about CMM's condition. All parties – his legal representative, the Director of Public Prosecutions and the Director of Mental Health – have been in agreement since this matter was before the court in May as to his permanent unfitness for trial. He has however spent almost five months since then, and seven months in all, in a youth detention centre for want of any alternative placement. The accommodation and care arrangement now provided has assured funding only for a period of three months. It is, of course, a matter for those with expertise in this area but the case does seem to illustrate a need for permanent, specialised residential facilities and clear legislative guidelines for the management of persons in CMM's position rather than ad hoc funding packages.**

Her Honour made a forensic order with limited community treatment in accordance with a Behaviour Support/Management Plan which was constructed by the Department of Child Safety for the purposes of the case. He will soon become the responsibility of DSQ. DSQ senior officials are aware of the case. It is common ground that persons with intellectual disability should not be encompassed by the provisions of the Mental Health Act for the involuntary treatment of the mentally ill.

Mr Thomas notes:-

**From the Tribunal's perspective, it would make sense for DSQ to be the lead agency in coordinating responses to people with intellectual disability, with clearly defined links to other relevant agencies. A current problem is the lack of a formalised process for bringing key players to the negotiating table to actively problem-solve and find effective and timely solutions for intellectual disability individuals with challenging behaviours. A legislative scheme needs to provide for roles and responsibilities of relevant agencies, and provide a head of power to intervene when services are not being provided.**

**The Mental Health Court is an effective and appropriate jurisdiction for dealing with severely intellectual disability offenders who are entitled to a psychiatric defence under the Criminal Code. An advance on the previous scheme has been the availability to the Court not to make a forensic order in cases where there is a finding of unsoundness of mind or permanent unfitness for trial, and the risk is not unacceptable. However, where there is a high degree of risk of harm to the person or others, a forensic order is required, and the Court has no alternative than to order detention of the person in an authorised mental health service. Consideration needs to be given to providing a wider range of options to the Court that is suitable alternative to psychiatric care alone.**

The criminal offending of course may cover a range of criminality. Some serious, some less serious. The disturbing fact is that as the Court notes, there is no provision, not only by way of a suitable legislative scheme, but also there is no provision made for suitable facilities or opportunities for community based care for those who are persons with intellectual disability only and in respect of whom the Mental Health Court may wish to make a forensic order. The making of a limited community treatment order may be appropriate in some cases but to date DSQ does not appear to be able to respond to the requirements of the Court in cases where the relevant person is a person with intellectual disability only.

In my view the present situation is unsustainable and a positive and proactive strategy is an urgent requirement not only to be able to respond to the requirements of the Mental Health Court but also to be able to proactively intervene in the future care and

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support of the person whose needs are obviously “high and complex” who may be a young adult, just turned 18, and who is entitled to the benefit of the principles and service delivery which DSQ is mandated to assist in providing.

There is in my view a potential capacity for DSQ to be able to respond appropriately to the specific needs of the person before the Court. It will be a part of the comprehensive and integrated approach which is identified in detail in the Report.

#### 10. Bail – Magistrates Court

A similar problem exists for the Magistrates Court which is the first point of contact with the Criminal Justice system if the person with intellectual disability is charged by police with an indictable offence. The immediate concern of the Court will often be whether to grant bail to the alleged offender. The Court is presently concerned about its traditional processes in the case of those who suffer some measure of social disadvantage, including those persons with an intellectual disability. Provision is being made for establishing a Special Circumstances List. However, the issue of whether to grant bail, which is subject to legislatively defined criteria, which have to be considered, is frequently a difficult one for the Magistrate in the case of a person with intellectual disability. It is generally agreed that to remand a person with intellectual disability in custody, which means detention in prison, is unsatisfactory just as the Mental Health Court finds it unacceptable to order such a person's detention in a mental health service facility.

The Chief Magistrate, Judge Irwin has referred me to a recent case of concern in the Magistrates court at Rockhampton which illustrates the point. A child (born ) appeared in May 2006 charged with entering a dwelling house, stealing a bottle of shampoo, assault of a police officer, setting fire to a lawn, animal cruelty and a breach of duty of care to an animal. When he appeared in Court the Magistrate was told that:

- He was also before the District court, but that those proceedings had been adjourned pending a decision of the Mental Health Court;
- His parents were reluctant to have him at home, because of their fearfulness of his sometime violent behaviour;
- He had an IQ of 50;
- He was mute, and unable to be engaged by his solicitor and the Department of Communities officer in a meaningful way;
- There was no facility in Rockhampton providing the level of supervision that he required; and
- He did not fit the profile of a person who could be admitted to the Barrett centre in Brisbane.

As a consequence the magistrate considered that she had no alternative other than to remand him in custody. He was admitted to the Brisbane Detention Centre.

When the matter was next mentioned before the magistrate she was advised that:

- He had settled well in the Detention centre;
- He was again verbal, and able to converse with the department of communities officer; and
- An appointment had been arranged with a psychiatrist.

The magistrate was asked to again remand him in custody until after the psychiatrist had provided a report.

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She did so because there was still no other place available for him in Rockhampton, and no non-criminal facility available for his residence pending the determination of his status by the MHC.

Judge Irwin in his letter to me comments:

**“This example again demonstrates the need for children and adults with intellectual disability which do not qualify them for admission to the mental health system to have available to them, some form of supervised detention in a facility which is not a facility administered by the Department of Communities or Corrective services. This will ensure that their vulnerabilities are not exploited by others who are detained in the facilities administered by those Departments.”**

In the event that suitable accommodation facilities and appropriate legislation is available and a Magistrate would regard such a facility as a suitable bail option, the Court’s difficult judicial decision making is assisted and the person needs are more likely to be addressed.

This is not intended to qualify in any way the point made earlier that DSQ should not be in the business of providing for the criminal justice system an alternative corrections facility or scheme. Such a suggestion has to be unequivocally rejected. The granting of bail by a magistrate can be made subject to conditions. An appropriate condition in the case of an alleged offender with intellectual disability could be that he/she reside at suitable DSQ accommodation pending trial or reference to the Mental Health Court.

Furthermore once the person is in the care of DSQ the opportunity is available to address the issues relevant to any challenging behaviour which he / she has demonstrated and which brought the person into contact with Police. If the basic problem is assessed and the person’s individualised needs are addressed by the implementation of a valid behaviour support plan, the person in question can be provided with a more stable and acceptable lifestyle, a matter which the courts would in the normal course regard positively and would be more inclined to place the offender in the community with appropriate support rather than commit the person to be detained in the much less acceptable environment of a prison pending trial and/or hearing.

Support for the Mental Health Court, the Mental Health Review Tribunal and the Criminal Justice system generally is a realistic and valuable outcome provided the proper system of care and management is available.

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**CHAPTER 5****A Targeted Service Response for Adults with Intellectual Disability and Severe Challenging Behaviour**

The documentation referred to in Chapter 3 came to light rather late in the process of consultation by which time the key elements of my targeted service response for the cohort had begun to form. I am encouraged by the fact that there was a significant level of coincidence between the content of the Joachim documents, the Queensland Health initiative and the Ipswich proposal, on the one hand, and the key elements of the developing response on the other.

***Based on the evidence of best practice, the published research literature and the consultation with experienced persons in the intellectual disability sector both persons within DSQ and respected persons outside of the Department and overseas, I state my strong view that a targeted service response for the proper care and support of the persons within the cohort must reflect unambiguously the following operational principles which must be regarded as being of basic and fundamental importance:***

- ***An individualised and flexible approach which provides for and specifically addresses the person's specific needs and the circumstances of the individual case is the unequivocal key element in the proper care and support for the person with intellectual disability and challenging behaviour;***
- ***A co-ordinated and cooperative working relationship between DSQ and QH to the extent that a comprehensive multi-disciplinary assessment of the individual person requires both general health and psychiatric assessments.***
- ***A comprehensive multi-disciplinary assessment process in respect of the particular person with a view to the development of an individualised positive behaviour support plan for that person.***
- ***An ongoing effective interaction between the assessment process and the intervention process within the community which will require co-ordination and individualised plan management at regional level so as to ensure the effective maintenance and integrity of the total process in the best interests of the individual person;***
- ***This process of assessment, intervention and coordination and individual plan management will operate collaboratively across the whole sector and will be available to and accessible by both DSQ and NGO service providers;***
- ***The incorporation of the above into a Queensland Centre for Best Practice in Positive Behaviour Support under the leadership and management of a high profile and highly regarded practitioner supported by a suitably qualified Reference Group. The Leader should have an academic appointment;***

- ***The Centre for Best Practice will develop as a Centre of Excellence in ensuring the proper care and support of persons with intellectual disability and challenging behaviour. It will also develop as a valuable research facility and itself become a valued research resource. Its role will include community development and education. Its functions are set out more fully in this Report;***
- ***The immediate establishment of suitable accommodation to enable an immediate and effective response in those cases which require emergency management;***
- ***The urgent and planned development of a range of accommodation options which respond to the need for secure care, transitional accommodation arrangements and community living for the target group;***
- ***The recruitment and development of suitably qualified allied health and other support staff specifically for persons with intellectual disability and challenging behaviour and ensuring their ongoing training and professional development;***
- ***The incorporation of the Centre into and as a distinct specialist segment within DSQ;***
- ***A legislative framework which will ensure that the use of any restrictive practice in the case of a person with intellectual disability and challenging behaviour is independently approved and properly regulated and which will provide adequate legislative support as required.***

What is proposed necessarily involves a rejection of the present day's fragmented, crisis driven and entrenched practices for those with challenging behaviours and which do little or nothing to properly address the needs of the individual person. Present systems, both in terms of proper service delivery and financial expenditure, are not sustainable. Present service delivery has largely failed to provide acceptable outcomes.

***What is proposed involves a fundamental process of reform, renewal and regeneration of the DSQ and disability sector's response, which will provide an efficient, cost effective and financially sustainable outcome for the proper care and support of persons with intellectual disability and challenging behaviour across Queensland. Its adoption and development by DSQ will have the capacity to place DSQ and the Queensland sector in a position of leadership, both nationally and internationally, in ensuring the proper support and care for such persons.***

Below I will develop each component of the integrated proposal in turn but this should not be seen to detract from the unity and integrity of the whole proposal.

1. An Individualised and Flexible Approach

Emerson wrote<sup>1</sup>:

**“Perhaps the single most significant development in behavioural practice in relation to intellectual disabilities during the 1980s was the re-emergence of a functional approach to analysis and intervention (Axelrod, 1987; Carr, Robinson & Palumbo, 1990a; Mace & Roberts, 1993; Mace, Lalli & Lalli, 1991; Mace, Lalli & Shea, 1992). This approach is based on a belief that the selection or design of approaches to intervention should reflect knowledge of the cause and maintaining factors underlying the persons challenging behaviour.**

and at page 69:

**”Certain approaches to intervention, including much of the emerging technology of positive behavioural support (Carr et al., 1999a; Koegel, Koegel & Dunlap, 1996a), are dependent for their success on accurate knowledge about the factors which maintain an individual’s challenging behaviour.”**

In *Presenting the Evidence: Accommodation and Support for People with Disability*, Belinda Epstein, Frisch Trudy van Dam and Lesley Chenoweth (February 2006) wrote<sup>2</sup>:

**“Positive Behaviour Support (PBS) has been internationally accepted as the proactive and effective way of supporting individuals who display challenging behaviour (Dunlap et al: 2000). Its goals are to improve both the behaviour and the quality of life of individuals.**

**PBS delivers a sustainable and comprehensive system for supporting individuals through the integration of:**

- **The principles of applied behaviour analysis (providing a framework for identifying the function of behaviours and the basis for educative methods);**
- **With the principles of inclusion (an understanding that the opportunity for people to live a valued lifestyle contributes significantly to addressing difficult behaviours);**
- **And person centred values (“The guiding hypothesis is that if an individual’s needs are met, then quality of life will improve, and problem behaviour will be eliminated altogether” (Carr et al., 2002)).’**

and at page 44:

<sup>1</sup> Emerson: *challenging Behaviour*: Cambridge 2<sup>nd</sup> Ed. 2001 page 68.

<sup>2</sup> Epstein et al: *Presenting the Evidence: Accommodation and Support for People with Disability* Feb. 2006 page 43.

- **Government and service policy must prohibit practices known to produce poor outcomes for people with challenging behaviour including:**
  - **Reactive strategies without a comprehensive positive behaviour support program and significant preventative strategy;**
  - **The indiscriminate use of psychotropic medication and physical restraint;**
  - **Housing options that group people with challenging behaviour together;**
  - **Placing people in unstimulating environments that provide little opportunity for control and choice, and in environments that segregate people from the community.**
- **People with challenging behaviour must be accommodated in small scale living environments.**
- **Positive Behaviour Support must be recognised and implemented as a proactive and effective way to support people who display challenging behaviour. This will involve:**
  - **Highly individualised and comprehensive person centred planning processes;**
  - **Service systems that actively support and encourage the rearrangement of environments to meet individual needs;**
  - **Service systems that value and support the involvement and collaboration of families, advocates, friends and staff;**
  - **Changes to existing agency and staff practice including:**
    - **Significant staff development, support and supervision;**
    - **Support for service management to change systems.**

In its submission made in the course of this project the Queensland Centre for Intellectual Developmental Disability (QCIDD)<sup>3</sup> advanced an “Intervention Model” of service provision for adults who exhibit challenging behaviour” which is based on assessment which takes an “holistic view of the person”.

These views, which have as their focus the need for a person – centred approach, are entirely consistent with the paper presented by Dr Michael Kendrick for Disability Queensland and the Queensland Department of Housing, March 11, 2002. In his paper: *Housing and Support for people with “Challenging Behaviour”*; *Some guidance* he said:

**People with behaviour problems are not all the same – the causes for the behaviour difficulties are diverse and should be understood in this heterogeneous way. Treating them as a homogenous group already suggests that you are going to have trouble. Similarly, prescribing that the remedies are going to be the same for each person suggests a stereotyping of people that is unlikely to hold up in practice.**

**What does work is carefully creating flexible individualised supports targeted on a person-by-person basis; not a single remedy but multiple remedies, one person at a time. The solutions should be “person centred” or “person-derived” and arise as precisely as possible from the needs and identity of each person. These remedies should not stem from**

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<sup>3</sup> QCIDD Submission: Chapter 4.

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**a common programmatic template that says a person with a certain label always needs such and such. Such a rigid formula is a deception despite the allure contained in its false sense of concreteness. The only long-term surety will rest in properly understanding the person and what they most deeply need and providing this as best as one can.<sup>4</sup>**

The view that successful outcomes will only emerge for those with challenging behaviours, if the chosen interventions address the unmet needs of this particular person is now too widely accepted by respected persons with the relevant experience and expertise to not require acceptance. It has to be recognised as the keystone in any service option developed for those in the cohort. The tag “challenging behaviour”, when attached to a person, had in the past put that person into a class for whom “a common programmatic template” of service delivery was seen to be necessary. That is now known to be a recipe for failure and inevitably a failed outcome.

That is why the development of any service options for this cohort must, unequivocally, have at its major premise the proposition that the approach must be “person centred” or individualised and sufficiently flexible to meet the specific needs of the person.

Kendrick and the others would require the application of this fundamental principle to every element of the positive behaviour support plan developed to meet the individual needs of the particular person.

Why this person demonstrates this behaviour is the primary question. The relationship of the behaviour to the “unmet needs” of the person requires a rigid application of the principles of applied behavioural analysis and this presupposes the availability of an assessment strategy which will not only successfully identify the precursor(s) to the behaviour but also support the appropriate interventions. Related issues, such as the limited capacity of some in the cohort to communicate will also require appropriate analysis. But the emphasis must unmistakably be individualised planning.

Just as the approach must be person-centred so too must there be a comprehensive assessment of the individual.

## 2. Assessment – an obligatory requirement

Any targeted service response by way of positive behavioural support for those with challenging behaviours must have as its initiating core function the assessment of the individual person. The objective of the service response in respect of this cohort is the development of the individual and the enhancement of that individual person’s opportunity to establish a quality life (Section 2 of the DSA 2006). Pursuit of that objective necessarily requires a proactive ongoing professionally driven strategy not one which is merely reactive and which addresses only attempts to manage the disturbed behaviour and its negative consequences. It has to be one which seeks to identify the sources or reasons for the behaviours and then devises the appropriate interventions. It is not likely to be a short term solution or “quick fix”. It will, on the contrary, be a much longer term intervention requiring the co-ordination of services in association with the person, his/her carers and/or parents/guardian including an ongoing process of adjustment of strategies and re-assessments as required, all of which will need to be disciplined and integrated and of course relevant to the lifestyle of this person who is at its centre.

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<sup>4</sup> See Kendrick: Edited Presentation for Disability Services Queensland and Housing Queensland march 11 202 Brisbane.

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I have indicated that a crisis driven reactive process which does nothing to address the causes of the behaviour cannot have any successful impact on the development of the person or enhance that person's opportunity to establish a quality life. That is the very antithesis of what the DSA 2006 envisages. It is also inconsistent with the objectives which service delivery to persons with intellectual disability are meant to achieve. Therefore past practices have to be discarded and a new approach adopted, one which is based on best practice of the kind now reflected in the literature which will require a new beginning.

**A soundly based assessment of the individual by a committed professionally driven multi-disciplinary team in association with the person and his/her carers, and the formulation of a soundly based positive behaviour support plan is the centrepiece of the reform strategy.**

I am of the view that this process should be seen as operating not only in the same context as that which at present gives rise to the need for an emergency or urgent response but on a much wider basis and which captures all of these whose needs require this service paradigm and which is available to them across the State.

The familiar crisis situation which now provokes mainly a reactive response can and should be responded to by an immediate resort to a comprehensive assessment process for that person which focuses on the causes or antecedents of the behaviour, which in turn provoked the crisis. The consequential development of a positive behaviour support plan for that person, followed by an intervention strategy in accordance with that plan, then becomes the productive proactive strategy for the person in place of the present non-productive reactive attempts at crisis management.

In particular cases it may be that that assessment will take time and will need to extend over a longer period which may require the person's immediate access to accommodation to which the assessment team can also have ready access. At the same time that accommodation will be available for the person who is the subject of the crisis/emergency and who will probably have been denied further access to his/her prior accommodation arrangements. In this way the immediate need for comprehensive assessment can, in those cases, be coupled with the immediate need for suitable emergency accommodation for the person and both needs are thus able to be more efficiently satisfied at the same time.

An emergency situation however, is only one of the several pathways which are likely to lead the person with challenging behaviour to DSQ. A living arrangement which has become unviable or a concern on the part of AS&RS or an NGO in respect of escalating behaviours in the life of an individual will frequently give rise to the need for assessment of the person so that a valid and planned, rather than an ad hoc response or intervention, can, as a matter of course, be implemented.

It is expected that for the most part assessment can be and should be undertaken in the community and in the context of the person's current living arrangements. He/she may live with family or be supported in accommodation by AS&RS or an NGO. The comprehensive assessment process which I propose should be accessible across the whole of the disability sector. Not only will this satisfy a present need of some significance it will also ensure equity in service delivery. It is in my view incumbent on DSQ to provide this urgently needed assessment service. Complemented by an efficient intervention process and coupled with effective co-ordination at regional level

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of the assessment/intervention dichotomy, this will enhance exponentially the quality of service in Queensland to persons with intellectual disability and challenging behaviour.

It is an integral feature of this proposal for comprehensive assessment that it be undertaken by an interagency multi-disciplinary team. Psychiatry must be represented on the Assessment Team – psychiatrist, psychiatric registrar or psychiatric nurse – preferably with experience of persons with intellectual disability. Other allied health professionals are also necessary part of it – psychology, speech pathology, occupational therapy and social work as required.

Since the assessment process must necessarily lead to the development of a positive behaviour support plan for the particular person the person, his/her parents/guardian must be an essential part of the process. So too should those carers who have had close involvement with the person at community level and who know and are known to the particular person. Functional analysis of the behaviour and the formulation of the appropriate plan which will provide the basis for intervention in the course of everyday living for the person, are key criteria for the desirable and preferred service option decided upon for the person. The plan determined for the person may include a requirement for the use of restrictive practices. These need to be detailed in the plan. It is therefore essential that the assessment process be decentralised. There is obviously a strong case for positioning the Leader of the Centre (a matter discussed below) and the core administrative infrastructure in the South East corner. I will submit that it be conveniently located in the city but separate from any DSQ office accommodation or facility. Personnel engaged for the Assessment Team in the South East corner will need to be peripatetic but must have the capacity to respond urgently as the occasion demands. So long as the composition of the team is determined in terms of its necessary disciplines, the personnel may vary from time to time. This however should not be permitted to dilute the quality of the proposal and must be consistent which means that the professional development and training of the necessary personnel, who will engage in assessment and behaviour support planning, is integral. The South East Queensland assessment team should operate out of a facility located at the Basil Stafford site in close proximity to the emergency accommodation.

In regional and rural areas the model has to be replicated. The further development of the proposal will best assist in identifying the preferred location of these other assessment panels. However the key elements of the proposal must be retained and confirmed in the face of the need to serve other persons in other regional and rural areas of the State. Equity requires a common unified and coordinated process across Queensland.

It is essential that for this to be maintained there is the need for cross government agency interaction and collaboration. Whilst there is the obvious need for cooperation between mental health and intellectual disability services, the assessment and intervention process which I propose may require that the general health of the person with challenging behaviour may also need to be thoroughly investigated. It is envisaged that not only will government mental health services need to respond; so too will the public hospital services need to be available to those with intellectual disability and challenging behaviour whose general health may prove to be a relevant factor in the assessment of the particular person. If the health requirements of a particular person are serviced by a general practitioner, the assessment and intervention teams will need to liaise closely with him/her.

The submission made by QCIDD emphasises the relationship between challenging behaviour and both general and mental health. Adults with intellectual disability are at

a higher risk of developing a mental and physical health problem than the general population and therefore both mental and physical health assessments and services, must be accessible and be of high standard.

The QCIDD submission states the need for persons in the cohort to have access to hospital day-patient services because of the likelihood of their having undiagnosed health conditions and the consequential need for them to have access to the range of tests which hospital services traditionally offer. The limitations to which persons with severe intellectual disability are subject will often obscure some critical health issues which may be relevant to challenging behaviour in that person.

Comprehensive assessment requires that that be properly addressed.

The QCIDD submission notes:-

**“Access to this dedicated service for adults with intellectual disability needs to be established in public hospitals throughout Queensland. Access to these investigations or service should not be able to be blocked by clinicians at the hospital:**

3. Effective Intervention – Positive Behaviour Support (PBS)

The evidence based literature and research and the submissions made in the course of an extensive consultation overwhelmingly support the proposition that the traditional responses to dealing with challenging behaviour in the past have failed in Queensland. Not only does this refer to such matters as the negative impact of “congregate care” and “group housing”, it includes references to the use of practices which, in one form or another are seen to be coercive and/or punitive. Even in those cases where an attempt has been made to document “behaviour support/management programs”, these often consist only of reactive management strategies such as, “if he/she does this, do this or say that”.

Belinda Epstein, Trudy van Dam and Lesley Chenoweth (February 2006) state:-

**Contrary to the popular belief that such services have the specialist expertise to address challenging behaviour, Robertson et al., (2005) found that very few specialist services for people who display challenging behaviour had documented intervention programs that consisted of more than reactive management strategies.<sup>5</sup>**

and again:-

**There is considerable evidence that service systems continue to respond to individuals who display challenging behaviour using traditional punitive approaches (Carr et al: 2002, Felce & Emerson: 2001, Horner et al: 1990, Robertson et al: 2005, Scott & Meyer: 1999, Mansell et al, 2004). Staff lack the skills required, resulting in heavy use of psychotropic medication and physical restraint (Emerson: 2000) and poor implementation of behaviour support plans (Stanclife, Hayden & Lakin: 1999). The outcomes for people with disability are not positive.<sup>6</sup>**

<sup>5</sup> Presenting the Evidence: Accommodation and Support for people with Disability page 46.

<sup>6</sup> Op. cit. page 46.

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Epstein et al are firm in their view that although there is significant evidence as to the efficacy of Positive Behaviour Support (PBS) as being the proactive and effective approach to support individuals who display challenging behaviour, modern day research indicates that most services continue to use inadequate behaviour strategies.

The role of the presently developed Intensive Behaviour Support Teams (IBST) will be of critical importance in delivering across the State an effective intervention process consequential upon assessment and the development of the Positive Behaviour Support Plan for each individual. The IBST concept however will require considerable further development.

The concept was adopted firstly in March 2002 so as to increase DSQ's capacity to better meet the complex needs of adults with challenging behaviours. At present there is one IBST team based in Brisbane but which attempts to operate on a Statewide basis. Another is based at Ipswich but its Team is incomplete. Present planning provides for the development of other teams in Brisbane, North Coast, South Coast and Central and Northern Queensland in 2006/7. Interim Operating Guidelines were developed as recently as September 2005.

Recruitment of suitably equipped allied health professionals has so far proved to be difficult, an issue to be discussed further in this Chapter.

It must be emphasised that the problems which presently infect service delivery to this cohort can never be positively addressed without the required professional skills such as are required for an effective IBST. It must therefore be given a significant priority. The formation of the required number of IBST's, to be renamed Positive Behaviour Support Teams (PBSTs) regionally located should begin as soon as possible. Their recruitment and professional training is an urgent requirement. DSQ has had an ongoing professional relationship with the Institute for Applied Behaviour Analysis, Greenville South Carolina USA and has discussed this issue with Mr John Marshall Director of Professional Training Services. Dr Gary LaVigna is also well known to DSQ. The Institute which has an international reputation is well equipped to effectively resource DSQ professional services and it is understood that this issue is presently the subject of discussion with the Institute. There are no doubt other such professional bodies servicing the sector internationally.

Those at the Institute are well versed in and experienced in the requirements of positive behaviour support strategies of the kind recommended as an integral feature of the service response in this Report and its capacity to deliver education and training services and to monitor and maintain service standards on a wide geographical basis is well developed.

The resourcing and professional development of DSQ's IBST's in Queensland is an important and developing priority in constructing a successful and effective service response. It needs to be addressed urgently.

The PBST, if properly constructed and resourced, will prove to be an effective and readily available resource which can be accessed by all parts of the sector in any part of the State. NGO funded services and carers as well as those caring for a person at home should have access to the PBST. It was a matter of concern to learn that few, if any, NGO funded services employed a psychologist and in the event that such expertise was needed it was purchased. However there must be a query concerning whether some of the purchased expertise is experienced enough in dealing with intellectual disability and behavioural issues.

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The need for NGOs and indeed all parts of the sector to have ready access to psychological expertise is not negotiable and calls for an immediate review. Either the funding available to the NGO sector to enable NGOs to employ a psychologist should be reviewed or alternatively DSQ should take such steps as necessary to itself resource the whole sector by having available across the State adequately and properly trained psychological expertise to which the intellectual disability sector across the State can have access as required.

The present capacity for effective intervention is limited and accordingly its impact is limited. But the basic resource required has already been recognised and its development commenced. It must be significantly expanded in the short term. One predicts that the capacity to recruit the required professional expertise may be an obstacle but should be pursued aggressively.

An effective ongoing strategic intervention based on the further development of PBSTs and a system of positive behaviour support can significantly build on the present IBST experience.

Epstein et al (at page 48) develop the PBS strategy in the following passage:

**PBS was developed in the late 1980s in response to the ineffectiveness of traditional approaches. It has become accepted as a proactive and effective way of supporting individuals who display challenging behaviour (Dunlap et al: 2000).**

**The goals of PBS are to improve both the behaviour and the quality of life of individuals who display challenging behaviour. It emphasizes collaborative, assessment-based approaches which integrate behavioural science and a person centered values framework. PBS emphasizes community participation, system and environmental modifications and social relationships. The approach hypothesises that if an individual's needs are met, then quality of life will improve, and problem behaviour will be eliminated altogether (Carr et al: 2002, Dunlap et al: 2000).**

**PBS builds on the principles of applied behaviour analysis and integrates this with principles from the inclusion movement and person centered values (Carr et al: 2002) to deliver integrated, sustainable, and comprehensive systems for supporting individuals. The importance of the incorporation of these three areas in obtaining sustainable behaviour outcomes is:**

- 1. an understanding that the opportunity for people with a disability to live a valued lifestyle, with the same rhythms, roles, responsibilities and respect as others in the community, contribute significantly to addressing difficult behaviours (Carr et al., 2002);**
- 2. the principles of applied behaviour analysis offer a framework and techniques that contribute significantly to identifying the function of behaviours and provide the basis of educative methods. Whilst the limitations in the traditional implementation of applied behaviour analysis are recognised, the significant contribution that it has made is recognised and built on (Carr et al: 2002; Dunlap et al: 2000);**
- 3. the person centred planning framework provides systems and principles for addressing individual needs in a comprehensive**

manner. “The guiding hypothesis is that if an individual’s needs are met, then quality of life will improve, and problem behaviour will be eliminated altogether”. (Carr et al: 2002).

**The goals of PBS are to improve both the behaviour and the quality of life of individuals who display challenging behaviour. It emphasises collaborative, assessment-based approaches which integrate behavioural science and a person centered values framework.<sup>7</sup>**

These are the principles on which effective intervention has to be based. One has no hesitation in embracing them and in advising that an effective intervention strategy across the State must adopt and implement them in efficiently ensuring the delivery of the correct intervention strategy. The adoption of this approach is based on the level of consistency between the principles enunciated in the literature and the express legislative intent expressed in the *Disability Services Act 2006* in requiring the implementation of the following “Service Delivery Principles”:-

**21 Focus on the development of the individual services should be designed and implemented so that their focus is on developing the individual and on enhancing the individual’s opportunity to establish a quality life.**

**22 Participation in planning and operation of services**

**(1) Services should be designed and implemented so that people with a disability are encouraged, and able, to participate continually in the planning and operation of the services they receive.**

**(2) Services provided to people with a disability should provide opportunities for consultation in relation to the development of major policy changes.**

**23 Focus on a lifestyle the same as other people and appropriate for age. Services should be designed and implemented to ensure that the conditions of everyday life of people with a disability are—**

**(a) the same as, or as close as possible to, the conditions of everyday life valued by the general community; and**

**(b) appropriate to their chronological age.**

**24 Coordination and integration of services with general services.**

**Services should be designed and implemented as part of local coordinated service systems and integrated with services generally available to members of the community.**

**25 Services to be tailored to meet individual needs and goals**

**(1) Services should be tailored to meet the individual needs and goals of people with a disability.**

**(2) To be responsive to the needs and goals of people with a disability, innovation and flexibility are encouraged when designing services.**

Following upon sound and valid assessment, the focus for that individual necessarily turns to intervention and, having identified the person’s needs and the source of the behaviour, the objective then is to ensure that that person has the necessary support

<sup>7</sup> Op. cit. page 48.

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to modify or at best to eliminate the behaviour. This intervention also must be disciplined ongoing and relevant.

It is fundamental that the designed interventions for the individual person must be based on and be intimately related to the community environment in which the person lives. Accordingly his/her carers and family must figure in the planning and implementation of the intervention strategy. Furthermore those responsible for the day to day care and support of this person must be developed and skilled in a way which will ensure the right support for this person. This will involve programmed changes to the way in which routines, supports, staff approaches, resources and environment are structured. Staff training and performance needs to be matched to the support needs of the resident.

A collaborative approach and one which involves environmental modification as required are just two of the matters which need to be considered.

I acknowledge the significant contribution to this report by Epstein, van Dam and Chenoweth whose contribution to the literature identified above has provided the basis for my acceptance and definition of the required intervention.

Set out here are the key features of Positive Behaviour Support as identified by these authors:-

**Highly individualised and comprehensive person centered planning processes which focus on overall health and well being. These processes are in “sharp contrast to the traditional program centred planning, in which individuals with disabilities are provided with those pre-existing services that a particular agency or institution has available. In person centered planning, the specific needs and goals of the individual drive the creation of new service matrices that are carefully tailored to address the unique characteristics of the individual” (Carr et al: 2002).**

**Empowerment of the person using the service by actively working towards choice, problem solving and self determination. “People with disabilities are often told what they can do, with whom they can do it, and where, when and how they can do it. In contrast, enhancing the process of self determination involves changing systems and redesigning environments with a view to minimizing external (often coercive) influences and making the person with disabilities the primary casual agent in his or her life” (Carr et al: 2002).**

**Active support and encouragement for the rearrangements of environments to meet individual needs.**

**High value placed on, and support for the involvement and collaboration of families, advocates, friends and staff.**

**Genuine commitment of resources and time to develop the skills of all staff in all aspects of service support but most importantly educative supports, person centred approaches and PBS.**

**Knowledge and commitment of key decision makers to PBS to enable the necessary reallocation of resources and systemic, environmental and programmatic changes that may be necessary.**

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**Integrated community-based residential support. Felce & Emerson (2001) report on studies which have repeatedly confirmed that the move from institutional to community based services result in significant increases in adaptive behaviours.<sup>8</sup>**

The need to address the function of the challenging behaviour is accepted by expert contributors as fundamental in attempting to deal with it successfully. It is acknowledged that a person acts or behaves in a certain way for a specific reason. In the Joachim survey (1989) it was noted that 70% of the then BSC population exhibited challenging behaviour. Environmental considerations affect behaviour. The institutional environment has long been acknowledged as a precursor for challenging behaviour. That is why the creation of the right environment in the course of community living is of fundamental importance.

In the consultation with one efficient service provider it was noted that some clients whose reputation for challenging behaviour had caused concern but who, once removed from the institution and re-settled in accordance with positive behaviour support principles, are now actively enjoying a beneficial lifestyle in the community. I also had the benefit of discussions with Mrs Ann Greer a professional consultant in Townsville whose wide experience and professional skill and knowledge in this area is well known.

The QCIDD submission is entirely consistent with and reflects best practice as exposed by the literature and the consultation. It is also consistent with the successful interventions reported by certain NGO service providers.

Indeed in the course of the consultation I became aware of one very high profile case – a young man with severe intellectual disability whose behaviour was most disturbing and a concern to many. The future involvement of a particular NGO and its proposal to adopt a strategy of positive behaviour support mechanisms involving experienced and well trained staff will, so it is expected, return the person to the community where a positive lifestyle can be offered.

These principles and the successful outcomes based on them involve a targeted intervention aimed at this individual and his/her behaviour. The idea that a prior programmed intervention can work – the notion that “one size fits all” – is doomed to fail.

The need to develop and appropriately resource in each DSQ region the appropriate intervention strategy is likewise a key recommendation.

#### 4. Co-ordination – Assessment / Intervention

A targeted service response to this difficult cohort, which is based on a comprehensive assessment and an individualised flexible intervention strategy, requires efficient and effective coordination and individual plan management at regional level if it is to produce the best outcomes.

As this Report will submit below, there will need to be developed a centralised structure headed by a high profile Leader and supported by a Reference Group which will have final responsibility for overseeing and monitoring service delivery to ensure that effective assessment and intervention occurs across the State in all regions and

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<sup>8</sup> Op. cit. pages 50-51.

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which is accessible to all sections of the disability sector. Whilst the Centre will not have the immediate responsibility for service delivery its major focus in this respect will be to monitor the standard of positive behaviour support to the presently enlarging cohort of persons with intellectual disability and challenging behaviour.

Service delivery both in terms of assessment and intervention will be a regional responsibility. A key to the successful operation of the proposed service response is the need to effectively coordinate at regional level these twin processes of assessment and intervention. This requires the appointment at regional level of at least one person in each region whose sole responsibility it will be to ensure that both assessment and the required intervention in each individual case is available, operates effectively and that any emerging problems are addressed as a matter of urgency and efficiently. He/she occupies a key “trouble shooter” role and reports directly to the Leader of the Centre. The core role involves effective individual plan management.

It is beyond doubt that in the day to day execution of this targeted process of service delivery to the client group that practical problems will arise – the availability of key personnel at short notice, the need to fill a key role urgently, overseeing the interventions process to ensure that it operates in accordance with the designed plan, ensuring consistency, maintaining to the greatest extent possible an acceptable environment for each person, ensuring that consistency in staff practices is maintained, engaging in staff development and training in the proper application of positive behaviour support principles, dealing with accommodation issues and the like. All of these issues will require a ready response.

This will be an onerous role as well as a key one. It is recognised that in the larger more populous regions more than one person may be required in the role. The persons(s) will themselves have to be well qualified in terms of relevant expertise, have commitment to ensuring successful outcomes for those with intellectual disability, be good case managers and be able to effectively network to ensure the proper functioning at an optimal level of this specific service delivery strategy to this cohort. The person’s job classification will need to be at a relatively high AO or PO level. He/she will be a Best Practice Broker.

Here, as elsewhere in this section, the primary focus for an effective and efficient process of coordination of services and case management is to ensure an integral response and the well being and best interests of the individual person, recognising that that person’s needs are peculiar to that person and that the service response at community level in respect of that person is not only in accordance with the assessment process and the designed intervention strategy, but also that it operates successfully to ensure the well being of that person. Improving that person’s quality of life and that that persons everyday life is “the same as, or as close as possible to, the conditions of everyday life valued by the general community” (Section 23, DSA 2006) is like the other elements of the proposal the objective of the regional coordinator or case manager.

##### 5. A Centre of Excellence

This Report has emphasised the critical role which behavioural issues pose for the proper care and support of persons with intellectual disability. It is the behaviour of individual persons which is invariably the focus of the planned responses and the dialogue which the planning generates. The literature and its attendant research is about the behaviour and how best practice would deal with it. In that context there are many relevant issues. How does one determine its cause or the underlying reason for it? What professional expertise is needed for that purpose? And what are the most

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effective processes available? Since it is the particular behaviour of a particular person which requires a response, what are the particular fact circumstances of this person which require investigation? How does this behaviour impact on others? Other persons with disability? Other members of the family? Or carers? How is the home/workplace best managed and subject to what conditions? Are members of the community safe from it? And if not what measures are to be employed in the interest of safety for others? What are the preferable accommodation options that best address behavioural problems? How does the behaviour impact on the life of the person? Can he/she be given access to the community? And what is the impact on the person's capacity to live in a community?

All of these are only some of the pertinent questions and they are asked only because it is the behaviour of the person which is the central or focal point of interest. The intellectual or cognitive disability may be the immutable fact of life in that person but it is the variable behaviour of that person which becomes the focus for professional interest and the driver of the management and support strategies. As one psychologist said in a meeting: "At DSQ psychology is behaviour".

This investigation and report is not so much about intellectual disability, it is about behaviour, the behaviour of a particular person, and how is it best addressed in the best interests of the person and how are its damaging consequences of it best dealt with, diminished and hopefully eliminated. This Report in this Chapter has so far dealt with the process of assessment; intervention and consideration of professional effort to best coordinate, manage and address the behavioural issues. At present government departments and other agencies commit enormous expenditure in human and financial terms to best cope with it.

Behaviour is therefore the core issue, the most difficult in management terms and the single phenomenon which has spawned the bulk of the literature, the establishment of discreet professional bodies and disciplines, even Institutes of relevant learning. Across the broad spectrum of DSQ infrastructure it is behaviour which is one of the main sources of effort and financial commitment. But always in the context of the individual person and that person's needs and the relationship of the behaviour to the unmet needs of that person whether it be that person's need to communicate and a variety of other needs.

Justification, therefore, for a focussed response is not hard to find.

I am of the strong view that the importance and the nature and extent of the problem of challenging behaviour in intellectual and cognitive disability requires a systemic and dedicated response and treatment which has the capacity to systematically respond to the whole matrix of issues to which challenging behaviour gives rise in the lives of the relevant individual persons. I therefore recommend the development within DSQ of a Centre of Excellence to be called **The Centre for Best Practice in Positive Behaviour Support**.

Its core objective in respect of the cohort of clients across Queensland whether serviced by DSQ or the NGO sector, is to entrench firmly and unambiguously in service delivery the human rights and service delivery principles stated expressly in the Disability Services Act 2006. It must as a Centre of Excellence occupy a position of leadership, both nationally and internationally, in achieving successfully and with distinction the desired outcome for persons with intellectual disability and challenging behaviour which will enable them to be respected "for their human worth and dignity as individuals" and to "realise their individual capacities for physical, social, emotional, cultural, religious and intellectual development".

Whilst the Centre will not have direct responsibility for service delivery – that will occur as a feature of regional office management – it will be the driver of best practice, the overseer of service delivery to ensure that it is ethical, effectively responsive to individual needs and intent only on successful outcomes and that service delivery is professionally and appropriately resourced.

This and its other functions are reflected in this statement of functions set out here.

**These are the functions of the Centre which, for convenience, is called The Queensland Centre for Best Practice in Positive Behaviour Support –**

- **to advise on, develop and ensure the maintenance across Queensland of consistent and best practice service options for all persons with intellectual disability and challenging behaviour which expressly apply the human rights and service delivery principles expressed in the *Disability Services Act 2006*.**
- **to facilitate the establishment, maintenance and ongoing review of a system of Positive Behaviour Support for persons with intellectual disability and challenging behaviour, which is based on comprehensive assessment and targeted individualised intervention in the community and the plan management and coordination of those services.**
- **to continually monitor and review the quality of service delivery across Queensland to persons with intellectual disability and challenging behaviour.**
- **to liaise with and develop a positive working relationship with the relevant professional bodies engaged in the delivery of services to persons with intellectual disability and behavioural issues, such as, the College of Psychiatrists, the College of General Practitioners, the Australian Psychological Society and other like bodies such as QCIDD.**
- **to develop and maintain the required early intervention strategies in respect of young children with intellectual disability and challenging behaviours and to ensure and maintain as a permanent ongoing feature of service delivery a continuum of care and positive behaviour support for this client group through increasing maturity and teenage years and young adulthood and for that purpose to coordinate government, non-government, relevant community agencies and professional bodies in responding to the individual needs of young persons in this group.**
- **to develop as a professional research resource to the disability sector in Queensland and to government and for that purpose to develop a research facility which will monitor best practice nationally and internationally and ensure that the details and all relevant data in respect of the Queensland experience is collected and retained.**
- **to do what is necessary to ensure that suitably educated and skilled professionally developed expertise is available to efficiently service the individual needs of person with intellectual disability and challenging behaviour in Queensland and for that purpose to liaise with and develop**

**a professional working relationship with (a particular tertiary academic institution).**

- **to develop and provide the relevant professional development and expert training for those who will work in the disability sector specifically as day to day professionals, carers and support personnel for those persons in Queensland with intellectual disability and challenging behaviour.**
- **to liaise with all relevant government departments and agencies, NGO service providers and disability peak bodies in the community with a view to establishing a whole of government and sector response and the effective collaboration and cooperation of all bodies concerned in any respect with the well being and development of those in Queensland with intellectual disability and challenging behaviour.**
- **to develop as a valued community resource which can provide professional advice to any person, agency or government department which is concerned with the needs of any person in Queensland with intellectual disability and challenging behaviour.**
- **to provide a system of information sharing with and advice to the community generally and ensure that the community is better informed in relation to issues concerning persons with intellectual disability and challenging behaviours.**

The Centre has been designed to provide a systemic, specialised and focussed response to challenging behaviour whether that behaviour is sourced to intellectual or cognitive disability, Autism Spectrum Disorder, Acquired Brain Injury or physical disability, all of which are included in the definition of “disability” in the *Disability Services Act 2006*.

**This proposal has been constructed in response to the perceived need to lift this multi-faceted and troublesome issue out of its vague and presently ill defined regional/departmental location into a specialised area of interest requiring a special focus and a specialised response.**

#### 6. The Leader of the Centre

This is a high profile position requiring the appointment of a person with experience and a national/international reputation in this area of professional expertise and the capacity to oversee an effective and consistent service response to a geographically diverse group across Queensland. He/she will need to display those personal characteristics which facilitate effective liaison and the establishment of collaborative and coordinated relationships with government and other agencies. Early intervention strategies in the case of the young autistic child as well as the appropriate interventions in the case of the intellectual disabled adult or the young or aged victim of acquired brain injury will be comprehended as matters of interest to the Centre and its Leader.

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Special reference is made here to the need for a research facility. DSQ currently is at a serious disadvantage in providing an effective service response if for no other reason that it has no disciplined and focussed research facility. At the outset of this project there was no sure or accurate information available as to the present size of the cohort. I have attempted a more accurate estimate by consultation with the regions but this remains an imperfect exercise and little better than several estimations from within the Department.

But more importantly, issues related to this cohort have since the 1980's, become increasingly the subject of research and the source for the published literature. It is idle to suggest that the research and work in this area requiring special expertise has reached its zenith, or that the experience and information bottle is now full to overflowing. Service delivery in the area is volatile; attaining excellence remains an ongoing objective. Therefore DSQ in this and in other areas of disability expertise needs the capacity not only to remain abreast of international research at all times but also itself to be able to contribute to the literature by making known its own experience in attempting best practice. Not only can DSQ learn from the experience of others, so too can others learn from the DSQ experience particularly if the latter is founded on practical, innovative and professionally driven strategies which strive for excellence in supporting persons with serious intellectual disability and challenging behaviours across a State as geographically extensive as Queensland.

Such a research facility will, most importantly, have the capacity to better and more professionally resource in terms of expertise, the service delivery arm across Queensland which is engaged in service delivery to those with disability and challenging behaviour.

The necessary engagement of the Leader of the Centre with other agencies or relevant bodies supports the need for the Leader and the Centre to be supported by a Reference Group which would be relevantly inclusive. The Leader would be best placed to identify its personnel and its core role would be advisory. Because of the insistence of the *Disability Services Act 2006* upon the maintenance of human rights and service delivery principles, the advocacy lobby should be suitably represented.

The Leader should have a University appointment on terms to be agreed between DSQ and the chosen tertiary academic institution. There is sound reason for this. One is aware of the professional association between QCIDD and the University of Queensland and of the fact that both DSQ and QH provide funding. Both QCIDD and QH have provided valuable assistance and support to this project, perhaps for different reasons and with a different focus. QCIDD, for instance, now functions within the UQ Faculty of Medicine which emphasises the relationship between intellectual disability and both general and specialist medicine. That is an enormously valuable connection for the community of persons with intellectual disability and substantially enhances the status, influence and effectiveness of QCIDD in relation to its area of responsibility and interest.

The Centre proposed in this Report has a significantly different focus. In academic terms its focus is primarily of relevance to the behavioural and social science disciplines and the intellectual disability sector draws heavily upon the expertise which those disciplines have and offer to the community, including the intellectual disability community. DSQ is a significant employer of its graduates.

In the course of this Review it was a matter of concern to identify some perceived shortcomings in academic learning at undergraduate level and the quality of learned psychology for the intellectual disability sector. Behavioural analysis, for instance, is a

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key component of the practice of psychology in intellectual disability. However it is said to hold a significantly lower priority in undergraduate learning. Several DSQ psychologists expressed their concern. One DSQ psychologist said “when I came to DSQ I had to learn behavioural analysis”. This is not intended, in any sense, as a criticism of the relevant university educator. What it does imply is a lack of liaison and interaction between DSQ, a major employer of graduates and a major service provider and the financial resource for the wider intellectual disability sector, on the one hand and the relevant university faculties and schools, on the other. That, it is submitted, can only be to the disadvantage of each.

Therefore in framing a deliberate and targeted response to the critical issues touching persons with intellectual disability and challenging behaviour one necessarily has to examine the capacity of the DSQ specialist resource to effectively support its cohort. Furthermore I have become aware that across the sector relevantly qualified and experienced psychologists are difficult to engage. DSQ currently is attempting to fill positions in its Intensive Behaviour Support Teams (IBST) without success and this severely limits its capacity to provide a professional service. Few NGO’s employ psychologists and seek to purchase the relevant services at times, only with difficulty.

I am of the firm view that the Leader of the Centre, such as is proposed here, will need to seriously consider this issue if DSQ is to effectively optimise the quality and effectiveness of its service to this cohort in accordance with the service delivery option detailed in this report. Therefore an effective liaison with the relevant University Faculty or School becomes an essential requirement. There are mutual benefits not only for DSQ but for the University and the quality and expertise of its graduates, if the Leader of the Centre has a University Appointment.

I perceive that in the course of a working relationship with the tertiary institution DSQ can influence course curriculum and can provide work experience or placements for undergraduate and PhD students. Not only is their educational experience broadened so too are career opportunities and professional interests enhanced. For DSQ it is provided with the opportunity to recruit better qualified and more graduates with a developed interest in working with persons with intellectual disability. The same advantages can be made referable to other disciplines – speech pathology, occupational therapy and social work.

These are the considerations which support the appointed leader of the Centre having a University appointment. That such an appointment will enhance the profile of the Leader and of the Centre is beyond question.

Not only will the ongoing professional development and expertise of specialist staff be a major responsibility of the Centre, so too will the training and professional development of those who are the immediate carers of the individual person, be they family or DSQ/NGO employed RCO’s. A minimum level of formal education is now required for employment as a residential care officer. But the skills level and experience across the sector is variable.

Generally, the turnover of RCO staff is high. For whatever reason employment in the intellectual disability sector is not always attractive. Casual employment is a common feature. On the other hand there are many, and I have met some of them, who are highly committed, dedicated and extremely competent employees who value working with persons with intellectual disability.

That part of the cohort with challenging behaviour presents to those employed in the sector its own problems and difficulties. It is axiomatic that one have a safe workplace.

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With this particular cohort experience demonstrates that this has not always been so. An unsafe workplace is a disadvantage for any employer. It becomes unattractive for the employee who will want to separate from it. Also if the delivery of personal services in employment in this context acquires a reputation for lack of workplace safety, persons will refrain from entering it.

It is therefore essential that the issue of professionally developing the RCO workforce be comprehensively addressed at the same time as the relevant workplace health and safety issues are.

The quality of the workforce must be maintained at a high level. There is an immense power imbalance between the carer and the vulnerable person with intellectual disability. This is why the quality of the workforce has to be a matter of eternal vigilance. Care staff have to be recognised for the quality of their care and their role in the support of the persons with intellectual disability. They occupy a key role. Their ongoing training and professional development is essential. Their involvement as required in the development of positive behaviour support strategies is also essential. The effective implementation of a positive behaviour support plan requires significant input from the immediate carer. That carer must work closely with the intervention team and individual specialists. He/she is not merely a provider of basic services; the carer has to be an expert observer with the capacity to analyse and report. The validity of the observations in the individual cases will determine the quality and effectiveness of the intervention strategy. The whole assessment / intervention / coordination and plan management strategies will be diminished if the immediate carer is not properly equipped or trained to perform his/her role.

Therefore staff recruitment and selection for employment with the particular cohort is a matter of special importance. Because of the special requirements of such employment special care is necessary to ensure the proper selection of staff. Those selected to work with this particular client group need to have specific qualifications and the key criteria for selection must be drawn with care. As indicated above, ongoing training and professional development will be a core issue.

Therefore the Centre will need to facilitate the specialisation of the appropriate staff selected and ensure that the staffing function is employed consistent with the requirements of an effective positive behaviour support strategy for each individual. So too will the Centre need to research the preferred terms of employment for those selected for employment. Whether a 12 hour shift is appropriate for a person in this environment is one such question to be properly considered. Other terms of employment in this more specialist area will also demand attention.

All of these issues are best addressed and understood by those who have specialised responsibility for overseeing the development of those persons with intellectual disability whose lifestyle is so seriously disadvantaged by challenging behaviours.

Finally I wish to emphasise the role which the Centre must have in ensuring a collaborative response across the whole of government to the problems inherent in intellectual disability when attended with challenging behaviour. As has been said the matrix of behavioural issues is not formed only in adulthood. Nor do they develop only from the one source. In an increasing number of cases, some of which were seen at close quarters, the behaviours developed in infancy in cases of Autism Spectrum Disorder (ASD). Some of the parents with whom I consulted related the whole continuum of disturbed behaviour and lifestyle from an early age through childhood, through teenage years and young adulthood into mature adulthood. In the course of this life journey the person had had contact with the education system, perhaps with

the Department of Child Safety during teenage years, many with the juvenile justice system, more lately with DSQ, perhaps the Mental Health Court and police, some with the corrections system. In many cases the persons disturbing behaviours had continued unabated from childhood to adulthood, sometimes with temporary relief but for others not unusually with escalation. By adulthood some parents had suffered “burn out” as the result of years of stressful parenthood. DSQ not infrequently has become the substitute carer.

The need for early intervention (early, in terms of life years), is obvious. The literature emphasises it; those with years of practical experience in the sector advocate for it. Early intervention obviously implies ongoing intervention. It is a striking anomaly that DSQ can rightly boast of the success of its early intervention processes in the case of children up to the age of 5 years who have intellectual disability and provide funding in “packages” to support the family but may have no further involvement with the child or its parent until the child now a young adult at 18 years of age, requires intervention, not infrequently crisis intervention. By that time the child has been through the education process, may or may not have become the subject of a Child Protection Order or a person of interest to the Department of Child Safety and moved towards adulthood by which time the intellectual disability and challenging behaviour has ravaged the life of that person who as a result has become dysfunctional. DSQ is not uncommonly been left “to pick up the pieces” on that person’s eighteenth birthday.

**A continuum of care and support from the first stage of early childhood through the years of formal education to those of increasing maturity and adulthood has to be made the key feature of service delivery to those with intellectual disability who are likely to manifest the behaviours which prove so troublesome for the person, their family and the wider community.**

This will necessarily require a renewed system of collaboration across the relevant government agencies and other relevant community agencies and can best be initiated managed and maintained by DSQ and its specialised Centre for Best Practice. With such an achievement the core effort of DSQ will no longer be essentially reactive but essentially proactive. It will no longer be forced into positions of typically having to react or respond to emergency situations but will assume a leadership role in proactively addressing the relevant issues across government and the disability sector and hence achieve for the wider intellectual disability sector the human rights and service delivery outcomes which the Disability Services Act 2006 legislation espouses as its mandated objectives.

**This is possible only by the adoption of a new strategy, a major change of direction and an effective, more collaborative and integrated mode of addressing these issues. The real challenge is to devise the most efficient and acceptable means of achieving the desired transition.**

**A Centre of Excellence professionally led, properly resourced and managed is the most effective way of addressing all the issues across the whole of government and across the whole of the disability sector.**

To date fragmentation of effort has proved a failure.

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Coupled with a process of community education, the negativity which infests the public mind in relation to persons with intellectual disability, particularly if it exhibits challenging behaviour, can be minimised in the best interests of the State and its citizens.

### 7. Facilities and Accommodation

Any historical review of accommodation models for persons with intellectual disability in Queensland, indeed in any part of the western world, has as its core feature the well recognisable paradigm of transition from institutional living to community living.

Challinor Centre (CC) which housed in the 1980's as many as 470 adults and children<sup>9</sup> in an institutional setting was in 1998 finally closed. Basil Stafford Centre (BSC) in 1994 had accommodated 140/150 adults and children and is now closed although a few male adults remain housed in some of the villas. The relocation of persons from CC and BSC into the community in the course of the development of the Alternative Living Service (ALS) and more recently the Accommodation Support and Respite Service (AS&RS) has since the early to mid 1990's seen a major transition to community living.

This transition particularly since the *Disability Services Act* 1992, also saw the escalation of government funded non-Government organisations which have delivered accommodation and related services to persons with intellectual disability particularly those who were in receipt of a variety of DSQ funding packages.

In respect of clients living in the community, the Department of Housing has for some years acquired or developed housing stock which has become the subject of residential tenancies for those persons with intellectual disability whose placement in the community has been facilitated by DSQ and NGO organisations. At the same time newly built accommodation has been developed by DSQ at Loganlea and Brackenridge in Brisbane. This accommodation consists of well appointed group homes in a gated community managed by a unit manager and RCO staff as part of the DSQ AS&RS. A variety of other new facilities of the group housing type have also been developed.

There is no doubt that accommodation settings for people with intellectual disability have been shown to have significant impact on those persons who demonstrate challenging behaviour for better or for worse. It was interesting in the course of the consultation to become aware of a persistent and strongly held viewpoint that, the housing at Loganlea and Brackenridge was now viewed negatively and regarded as less likely to produce the best outcomes for persons with behavioural issues. The basis for this view was that to provide group housing was to replicate an institutional-like environment on a smaller scale and that the negative features of the latter were to be found also in the former. It is argued that those with challenging behaviour should not live with others with similar behaviours in large groups but in more discreet settings.

There is much in the literature to support this view. In a review of some Australian studies involving deinstitutionalisation; Young, Ashman, Sigafoos and Grevell quoted reviews which demonstrated that generally individuals who moved from institutions to dispersed community based supports show:

- improvement in quality and standard of life;

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<sup>9</sup> Young et al: A Preliminary Report on the closure of Challinor Centre: Journal of Intellectual and Disability Development June 2000 Vol. 25 Issue 2.

- increased adaptive behaviour;
- increased autonomy in self-care, domestic, community, leisure and choice making skills;
- increased amount and quality of interaction with staff, family and friends.<sup>10</sup>

In June 2000 the same authors in *A Preliminary Report on the Closure of Challinor Centre (NI)* examined preliminary data from 32 persons who were relocated from Challinor to small community-based group homes.

**“Assessments of adaptive behaviour, life circumstances, choice-making, and direct observations of activities were conducted approximately 6 months prior to the relocation and then again after 1, 6, and 12 months of community living. Standardized assessments indicated no significant changes in adaptive behaviour. However, there were significant increases in life circumstances and choice-making, and direct observations revealed more appropriate behaviour and less undirected and challenging behaviour following relocation to the community. These results suggest the relocation has enabled a more active and normalised lifestyle. However, community-based services may need to incorporate more effective active treatment programs if adaptive behaviour gains are to occur.”**

Evidence provided to us by NGO's, which have continued to provide accommodation and other services to former Challinor/BSC clients who had extremely challenging behaviour, confirms that supported small group housing and appropriate services can effectively assist in minimising challenging behaviour.

Kendrick (op. cit.) provides this warning:

**“Building centred” solutions do not work for people with “behaviour problems”. Here, I mean instances where a building, centre or group home is first established (usually with a staffing model attached) then have this followed by a process to go find people to fill the available openings. One should never start with a building or staffing model. On the contrary, one should always start with the person and what they need before consideration is given to what model is likely to best address that persons specific needs. It is evident that so-called “specialised behaviour units” will invariably become “poor behaviour sharing ghettos”. They will inevitably be too custodial, standardised and rigid to effectively respond to people and the broad range differences in their needs.**

**Pre-cast service models are essentially the reification of assumptions about what people need into largely invariant patterns into which the people must fit or be fitted. This conforming of the person to the model deprives the person from pursuing a strategy of address of their needs in which the key assumptions guiding service design arise from their unique identity. There are additional common dysfunctions in such models such as stigmatisation, an over-reliance on very expensive 24/7 staffing models, incapacity to alter support levels to respond to individual**

<sup>10</sup> Epstein et al (2006) op. cit. page 47.

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**needs, loss of the capacity to use other housing and lifestyle options and so forth.<sup>11</sup>**

The dominant service model that has emerged in the UK since the move to community living has been congregate provision. A comparison of costs and quality of two community-based residential settings providing supports to people with learning disability and challenging behaviour was undertaken by Robertson et al<sup>12</sup> between October 1999 and June 2002. One service response was provided in small houses in which all or the majority of residents were in the cohort (congregate care) and the other in small houses in which only one or a minority of people had challenging behaviour. The study found that there were few advantages associated with congregate care despite significantly higher costs (from higher staffing ratios) and better quality internal working practices. The researchers concluded that their findings reinforced the approach that care should be taken to avoid congregating together people with challenging behaviour.

**Mansell et al noted:**

**“If people with intellectual disabilities have the right not to live with others who show challenging behaviour then this right must be extended to all people with intellectual disability including people with challenging behaviour themselves. Thus, the ethical issue is one of whether it is appropriate for anyone to live and work in close proximity to someone with seriously challenging behaviours. Congregating together people with challenging behaviour does not provide a solution to this problem. Service providers have, of course, a duty of care to ensure that all those receiving services are protected from harm. This duty ensures that all those receiving services are protected from harm. This duty draws attention to the importance of giving careful consideration to the risks presented to others by an individual’s behaviour. This applies whether the ‘other’ display challenging behaviour themselves or not.”<sup>13</sup>**

More recent research by Mansell and Beadle-Brown<sup>14</sup> examined three studies looking at the impact of grouping people with learning disabilities and challenging behaviour in residential care. They found that all three studies showed that grouping together residents with severely challenging behaviour produces worse outcomes than supporting residents in homes where there is a mix of resident needs. They further concluded that any greater expertise that staff within these settings have or develop is not readily detectable in their care practices. However, they do raise the fact that the people living within these environments did not necessarily choose to live there and may well have chosen, had been given the opportunity, not to reside with another resident with severely challenging behaviour. Note also the earlier reference to Emerson’s concerns in respect of the Innovative Support and Housing Model.

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<sup>11</sup> Kendrick: Edited Presentation For Disability Services Queensland and the Queensland Department of Housing Brisbane March 11 2002.

<sup>12</sup> Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D., Meek, A., Carr, D., Lowe, K., Knapp, M., & Hallam, A. Quality and costs of community-based residential supports for people with learning disabilities and challenging behaviour. (2002).

<sup>13</sup> Mansell J, McGill P and Emerson E (2001)

<sup>14</sup> Mansell, J. & Beadle-Brown, J. Grouping People with Learning Disabilities and Challenging Behaviour in Residential Care. *Tizard Learning Disability Review*; April 2004; 9, 2 Career and Technical Education page 4.

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In my view considerable care needs to be taken in appropriately accommodating persons with intellectual disability and challenging behaviour. The primary focus has to be the needs of the individual person and the circumstances of accommodation in which that persons behaviour can best be addressed. This means that a number of options have to be available or provided which will facilitate the most effective response. The subject is ripe for ongoing research.

The consistent view expressed was that it was futile to provide housing consisting of 4 or more bedrooms for the accommodation of persons with intellectual disability and challenging behaviour. This form of congregate care with its consequential loss of privacy had the capacity to promote excessive interaction between persons in a stimulating environment which was counter productive. One can confidently exclude such an accommodation model for this cohort as undesirable. That is not to say that each person should be accommodated alone. Perhaps some might. It was noted in the course of the inspection of facilities that in one case two male persons who have exhibited seriously challenging behaviour were able to live together harmoniously in a home to their mutual benefit.

The general view is that three should be regarded as the maximum number who should be accommodated together and then only if the other supports were such as to ensure an acceptable accommodation setting in the best interests of all. There is much to be said for reconsidering housing design issues and moving away from traditional designs with a greater emphasis on designing a model which is expressly responsive to the specific needs of persons in the cohort. Essential characteristics are to ensure personal space and the capacity for privacy and the modification of excessive stimulus. Architectural design work will need to be influenced by the research to date. As mentioned earlier the issue requires detailed research – a matter which will occupy a key role in the development and ongoing influence of the Centre for Best Practice. The relevance of assessment of the individual and his/her needs in this context cannot be over emphasised.

In the next section I will deal with the various accommodation demands which are pertinent in the context of this Report.

Before doing that, it needs to be emphasised that there is an immediate need to reassess the value and relevance of the accommodation options presently available and to project a capital works development program which is relevant and responsive to the needs of persons with disability and challenging behaviour.

Current arrangements, whereby the Department of housing acquires the homes and becomes the landlord of the person with intellectual disability who becomes the tenant who is placed in a particular home by DSQ, is probably a response to Section 29 of the *Disability Services Act 2006* which requires that services should be designed and implemented to ensure that no single service provider exercises control over all or most aspects of the life of a person with a disability.

The purpose of section 29 is well understood and is designed for the protection of the particular person.

Many persons with intellectual disability are housed in Department of Housing accommodation as tenants of the Department. Support services for those persons may be provided in the course of service provision by AS&RS, the service delivery arm of DSQ or by anyone of a number of NGOs. Each service provider assumes the responsibility of locating tenants in particular houses which necessarily involves matching individuals to ensure compatibility and acceptable lifestyles. Each tenancy

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created as a result of this process which is subject to the Residential tenancies Act is with Department of Housing.

One is not convinced that these accommodation arrangements are effective in producing the desired outcomes nor that they are necessarily dictated by the terms of Section 29 of the *Disability Services Act* 2006. The proper accommodation of persons with intellectual disability and challenging behaviour is, as has been noted, the subject of research and there are some conclusions drawn which are extremely relevant to this client group both in respect of housing types and what constitute acceptable co-tenancies. These issues need to be further examined particularly in light of the presently available research. One thing is certain and that is that the choice of the right accommodation setting for a particular person has to be preceded by proper assessment of that persons needs and the accommodation option chosen has to be responsive to those needs.

#### 8. Accommodation – Present and Urgent Response

Accommodation matters which at present require an urgent response from DSQ are:

- the need for emergency or crisis accommodation;
- cases which may require some form of secure care;
- the need for an effective transition and
- suitably designed accommodation to maximise service delivery on the community.

Finally in this context I need to address the practice of so called “community access”.

#### 9. The Need for Emergency / Crisis Accommodation

At least into the foreseeable future there is an urgent need to ensure the provision of suitable acceptable accommodation for dealing with an emergency/crisis situation. This accommodation should be conveniently located so as to readily make available a comprehensive assessment of the individual whose behaviour is the cause of the crisis. It is frequently the case that the nature of the crisis means that the accommodation available to the person immediately before its onset whether with family, an NGO or with AS&RS is no longer available and the need for alternative accommodation becomes an immediate need.

The need for a considered and immediate response to that person’s total needs is required. Hence the need for a comprehensive and specialised assessment of the person and his/her behaviour and the relevant circumstances. That assessment has to be available at short notice and may have to be ongoing as required. The importance of an immediate capacity for assessment of the person in such circumstances cannot be overestimated. The more immediate need is to ensure the person have somewhere to live.

It is vital that the assessment identify the most desirable intervention as soon as practicable so that that person can, as soon and as effectively as possible, return to live in the community. How long this will or should take is best determined by the assessment and intervention process which focuses on the person’s short term and ongoing needs. Suitable accommodation for the immediate future of that person will inevitably be one of the short term dominant needs.

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In this context, given the nature and extent of its functions, the location of the Centre needs to be determined. The location of the office of the Centre for Best Practice is a sensitive issue. It should not be located at the BSC redeveloped site, for historical and emotional reasons. Nor should it be located in any DSQ departmental office or facility because of the need for the Centre, the flagship of a process of reform and renewal, to be seen to be separate from the department because of its specialised function and focus and, in particular, because of its function to monitor and review DSQ service delivery to the cohort. It should therefore be located in a nearby city office precinct with appropriate facilities, staff and infrastructure.

The location of emergency accommodation however is a different issue. The provision of crisis accommodation must necessarily be closely linked to the DSQ assessment process and to DSQ's capacity to urgently assess that person whose needs have prompted the requirement for an urgent DSQ response. That response will almost invariably require psychiatric input which can best be provided by The Park mental health service specialists in association with other DSQ specialists. There is an obvious and necessary link between the provision of emergency accommodation and an urgent assessment process. The DSQ crisis accommodation should therefore be conveniently linked to the DSQ assessment process. Accordingly a needs designed assessment facility should be located at or geographically close to the emergency accommodation. Both it and the emergency accommodation should be located at a redeveloped Basil Stafford site.

The quantum and size of the emergency accommodation is an important preliminary question. The facility must have the ongoing capacity to function effectively as an emergency response to an accommodation crisis. On the other hand it must be such as to ensure its cost effectiveness. There will be times when some of its capacity will be vacant or partly vacant. It has to be like that to be able to effectively respond in a crisis. At the same time those who live there will need the accommodation for varying periods depending upon the exigencies of the assessment process. It must be functional and therefore must be the subject to strict entry/exit protocols.

The maximum stay should be 4 months. Any assessment however comprehensive or difficult should be able to be completed within that time. Under no circumstances should it be used as a longer term or transitional facility. The relationship between its capacity to respond in an emergency and the need for assessment is not negotiable. A vacancy(s) is an essential feature of its function.

In my view a facility with a maximum of 6 specially designed individual units should suffice.

#### 10. The Question of Secure Care

The literature supports the generally accepted view that some of those with intellectual disability and serious challenging behaviours are a specialist or high risk group because of the risk which their behaviour presents to themselves and to others. Some of these persons will find their way to the criminal justice system; others may not. In this section I will also address the impact of Mental Health and other Court decision making and its relevance to this issue of appropriate facilities and accommodation.

However before addressing this and related issues it needs to be emphasised that in no sense should the proposals in this section of the report be understood as providing an alternative system of corrections for people with intellectual disability.

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Existing legislative and other provisions of the criminal justice system already provide a well developed process for judicially dealing with issues such as fitness to plead, unsoundness of mind and diminished criminal responsibility in the case of persons with intellectual disability.

The jurisdiction of the Mental Health Court is specifically designed to provide a specialist judicial forum within which such issues are determined.

The mere fact that a person with intellectual disability engages in conduct, which is criminal, does not support the establishment of a special or different judicial environment on that account alone. The existing mechanism is designed for those cases where, on account of intellectual disability and that person is charged with an indictable offence, some fundamental issues like fitness to plead and criminal responsibility have to be tried. But once that issue is tried and determined, if the result is that that person should be processed in respect of his/her alleged criminal liability in the usual way then that process should not be interfered with even if that person is subject to some form of intellectual disability. And further if found guilty and sentenced to imprisonment, the statute law in Queensland requires that his/her detention in prison is the responsibility of the Department of Corrective Services. There is no sound basis in law or logic for disturbing that position.

Hayes in her presentation to the 11<sup>th</sup> International Association for the Scientific Study of Intellectual Disabilities, World Congress 2000 Seattle Washington stated that NSW research established that persons with intellectual disability were over-represented in the custodial corrections system. That in itself does not support the establishment of a "separate" correctional system for those with intellectual disability who are sentenced to imprisonment. What it does is to impose on those with correctional responsibilities an onerous obligation to contain and humanely facilitate the lifestyles of those in prison who have intellectual disability. In considering and best executing that process those with the relevant responsibilities should have access to DSQ and its specialist knowledge such that the proposed Centre can develop but in the absence of a major disturbance to the existing judicial/correctional processes, there can be no sound basis for a separate and discreet correctional facility controlled by DSQ.

Where change is required, and urgently so, is in respect of the Mental Health Court's jurisdiction to make appropriate orders in respect of persons with intellectual disability only who are found by the Court to be not fit to plead or who were of unsound mind at the time of the offence and not therefore responsible criminally. The making of a forensic order by the Court in those cases is often the only appropriate order. Just as the detention of such persons in a corrections facility is wholly inappropriate so too is detention under the Mental Health Act in a mental health service. All of the evidence and experience both before and since the enactment of the MHA 2000 confirms that.

In respect of the need to accommodate and support those with intellectual disability who have been found not fit to plead or who on account of their disability are found not to be criminally liable, but in respect of whom the Court desires to make a forensic order requiring "detention" or a "limited treatment order", there is an immediate and urgent need for DSQ to respond and to have the capacity to properly accommodate and support those persons subject to the conditions determined by the Mental Health Court and subject to review by the Mental Health Tribunal.

There are persons who are already subject to forensic orders for detention who have only intellectual disability and not a mental illness. There are others who are subject to limited community treatment orders. The accommodation options which need to be considered will have to take account of all such matters.

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Apart from this section of the client group there are already at Basil Stafford Centre or in the community persons for whom secure care or some form thereof is and will be required in ensuring their own safety and that of the community.

I am of the view that the required accommodation arrangements can best be provided in the course of the redevelopment of the Basil Stafford site by proceeding as soon as practicable with the already designed Purpose Designed Housing or “Places of Safety” Project. There are in place plans for 10 purpose built units and this should immediately be duplicated. This will provide 20 units of secure care. Because of the terms of the usual Mental Health Court Order there should be an immediate consideration of enhanced design options for this kind of facility. The extent of the security required in particular cases will vary and alternative designs should be considered. Some will require more; some less. The least restrictive alternative for the individual will be the determining criteria. The question of preferred design and its relevance to the assessment of individual needs is referred to below.

Furthermore some immediate planning will be required to ensure the preferable staffing model for this “Secure care” facility which will present in appearance and appointments as close as possible to the present design. The features of the accommodation and its capacity to provide an effective and structured environment should be consistent with the fact that the expectations of the Mental Health Court and of the Mental Health Review Tribunal will have to be respected.

I wish to emphasise that this part of the cohort should not be excluded from the operation of the assessment/intervention process which will be the central focus of the renewed development at the BSC site. Indeed there are compelling reasons to make absolutely certain the inclusion of those in that process.

Whether subject to a forensic order or not, these persons can be regarded as the most difficult section of the total cohort and accordingly have the greater need for comprehensive assessment and intervention. They cannot under any circumstances be disregarded as unworthy of detailed consideration. They are as entitled as any other persons with intellectual disability to have the benefit of the human rights and service delivery principles applied to them. It would be inequitable and discriminatory to exclude them. Special circumstances such as a forensic order will apply to some of them and this must be respected. The ultimate objective however must remain the same. Even though considered the fit subject for detention or more secure forms of care, their further personal development must remain the main focus. This is so even though the assumption may have to be made that their status may be that of long stay residents and that they may never be capable of ultimate development to the point of being suited for community living. Only time will tell and that judgement should be made much later – not now.

I consider that this segment of the cohort will represent a small minority of the whole and that in part they will be subject to regular review by the MHRT. The maintenance of an acceptable accommodation provision and their ongoing involvement in positive behaviour support strategies with DSQ personnel will inevitably prove to be a process of immense worth not only to the individual person but also to the Tribunal in the ongoing review of forensic orders.

The issue of those requiring secure care is referred to further in section 12 of this Chapter. There are two other related matters which have to be considered in this context.

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Firstly consultation with the Chief Magistrate, Judge Irwin, confirms the concerns of some Magistrates whose court is the first contact for some with intellectual disability only who have been charged with an indictable offence. The initial question following arrest is always that of bail. One of the relevant criteria in this regard is whether releasing an offender on bail to the community would constitute an unacceptable risk to the community. If that risk is such that bail has to be refused the only present option for the Magistrate is to remand the person in custody which means in practice containment in the prison system at least pending a decision as to whether the matter will be referred to the Mental Health Court pursuant to section 256 of the MHA by one or others of the persons referred to in section 257. In the case of a person with serious intellectual disability and disturbed behaviour prison is an unacceptable option. Because of Court delays access to the Mental Health Court may take time.

Therefore the availability of a suitable facility for such persons is an urgent need and gives to the Magistrate an alternative option. In such circumstances the result can be achieved that that person once suitably placed pursuant to the Magistrates order can then become the subject of assessment and his/her needs more readily determined. Otherwise the person will be detained in prison without adequate support for an indefinite period. The preferable option is to allow DSQ to access that person for assessment and appropriate intervention in a suitable facility and environment. Such an outcome not only assists the life of the person with intellectual disability it also assists the proper operation of the criminal justice system in respect of that person.

The second matter to which reference should be made in this context is that there is no provision made in the current legislative schemes for those with intellectual disability only who are brought before the Magistrates Court and who are charged with committing simple offences. Their capacity to plead and issues relating to their criminal responsibility are as real as they are in cases of the offender who is alleged to have committed an indictable offence. There is a widely held view that in the case of simple offences alleged offenders with intellectual disability only are easily persuaded to plead guilty to have the matter dealt with quickly and that the magistrates may be ready accomplices for want of a better alternative. The fact remains however that such offenders are often repeat offenders and a sentencing magistrate may consider the need to order imprisonment in a particular case. There is no available alternative since the Mental Health Court is concerned only with those who commit indictable offences.

This is a matter of no specific concern to this project. It is however a matter that should be referred for further consideration by the Minister for Justice and Attorney-General and the Minister for Health.

### 11. Transitional Housing

The need for some form of transitional accommodation and support for this cohort has already been recognised by DSQ. It has, perhaps inaccurately, been said that the establishment of the so called Innovative Support & Housing project was DSQ's primary initiative in responding to the problems involved in the management of challenging behaviour and intellectual disability. On the contrary it was provided as a form of transition only for the cohort into the community. Issues relating to the Innovative Support Housing Model are addressed in Chapter 3 section 7.

I visited the Housing projects at Morayfield and Wacol, both of which fell victim to the need to provide crisis accommodation. At each facility the admission of one person in an emergency who failed to comply with admission criteria had such an impact on each facility and its culture as to ensure a disruptive environment which was for all concerned counter productive.

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In the result the outcome in respect of each facility has been anything but innovative. There is a certain sameness in respect of each which present as no different from other disruptive housing facilities of which I have been made aware or have seen. The need for ongoing therapeutic intervention in respect of an individual plan is essential and the desired service option must ensure that this is available. At present it is problematic.

That is not to say that the project has no merit. On the contrary it has considerable merit provided admission criteria are properly drawn and strictly complied with. There are several features of the accommodation planning which are admirable such as the provision for individual privacy in a comfortable setting, if the person wishes to withdraw from stimulating interaction which is often a negative feature of housing where people are grouped. At the same time I question the size of these facilities (2 or 3 persons may be preferable) and recommend a total reassessment of their operation

The concept should be retained and further developed as part of the ongoing decision making in establishing the appropriate accommodation. The idea of transitional facilities is consistent with what I propose. Assessment will determine the preferable ongoing living environment for the cohort, and the best outcomes for individuals will inevitably make use of transitional accommodation as part of the intervention strategies designed to facilitate positive behavioural support for the appropriate persons. The present initiative can readily be incorporated into the proposal for specialist accommodation which is an integral part of this Report. Ongoing review will best determine the process of required development for a suitable transition in housing terms to successful community living. Not only should reference be made again to the November/December 2003 documents of Emerson et al referred to in Chapter 4 but also an evaluation of the project so far will be a learning experience for any further development.

## 12. Community Living and Community Access

I submit that there is the need to continue to review the development of suitable accommodation for community living. The review of AS&RS is one component only of the need for ongoing reassessment of how best to accommodate and support in the community those who have exhibited challenging behaviour but in respect of whom effective assessment and intervention has made possible their capacity to live a meaningful lifestyle in the community. That review does not address the form of accommodation required to best deal with behaviours but is more relevant to staffing and management issues. It is however a matter of great importance, Positive Behaviour Support can only be effective if provided by people with the required skills in an acceptable community living environment.

The progress in the development of the person which assessment and community intervention can better initiate needs to be maintained and consolidated and the prospects of this can be optimised by ensuring that the relevant persons are suitably housed and supported in the community. It is entirely counterproductive to initiate the process only to see it fail by not providing suitable accommodation or a desirable environment. This involves not only acceptable and purpose designed housing but also the provision of productive access to community facilities, the establishment of desirable tenancy arrangements and whatever else is required to normalise the lifestyle of those who will profitably enjoy life in the community in spite of an enduring intellectual disability.

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A lengthy teleconference with Professor Eric Emerson, Professor of Disability and Health Research at Lancaster University U.K. noted author and prolific contributor to the literature, strongly confirms the view that to accommodate persons with intellectual disability and challenging behaviours together can only produce negative outcomes for each individual. A much preferred option is generally to accommodate the one with challenging behaviours with others without such behaviours but only after a comprehensive assessment of the needs of that individual have been determined and a studious and well considered decision is made as to the most desirable environment in which to accommodate the person. And again the number of those who may choose to live together must be kept to a minimum. It is hardly necessary to add that multidisciplinary expert support and quality direct carers must be available to support the person in that environment. Again the emphasis has to be on providing the correct matrix of environmental supports for that person. Considerable care is also essential in seeking to ensure compatibility of individual persons.

Again one has to return to the fundamental requirement, namely, assessment which is of fundamental importance also in this context. The assessment of individual needs comprehends also the individual need for the right accommodation environment. Kendrick, it will be recalled has rejected the “template” approach whereby individuals are “fitted in” to predetermined designs. So too does Emerson. The design has to be responsive to the needs of the person. So too must be the entire environmental arrangements within which the person will live and will have his/her behavioural concerns addressed. Assessment is again a basic and necessary precondition.

This does not necessarily mean that each person will live alone in his/her specifically designed home. That would be financially irresponsible. What it does mean is that assessment must necessarily precede the choice of placement. It follows that the accommodation, its location, design, appointments and facilities will need to be responsive to the needs of the various individuals. For instance, one form of behaviour which is very disruptive is the constant screaming by the person. It is logical that other persons who live with or nearby that person should be protected from the excesses of such behaviour by appropriate sound proofing. More experience with assessment will greatly influence the more acceptable accommodation designs over time.

I must however express some immediate concerns about the Purpose Designed Housing Project referred to above. For what “purpose” has it been designed? Is that “purpose” necessarily coincident with the individual needs of each person who will live there? One suspects that it may have all of the characteristics of Kendrick’s “common programmatic template” with a fixed and pre-determined purpose into which individuals will need to “fit”. If that is so then before further development it needs to be reconsidered. I am of the view and strongly recommend that there be an immediate identification of those persons who may be seen to require “secure care” and of those with severe behaviours and for whom this housing may have been originally designed and that there be an immediate and comprehensive assessment of each of those persons not only to better design the positive behaviour support plans which will address their behavioural issues but also the kind of housing and other environmental requirements within which that person’s needs can best be addressed. I refer to the most difficult segment of this cohort.

Priority should be given to this before the accommodation is itself considered for redesign and built and this is an urgent requirement. There is sufficient multi disciplinary expertise available now which can be marshalled and resourced to undertake these assessments now. In that event the accommodation design process can be much better informed and will be more likely to ensure a more effective response to the needs of those persons who will live in the “to be built”

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accommodation. Consultation by the designers with the assessment team is likely to produce better individual outcomes and better informed design rather than satisfy the urge to design for a “purpose” the content of which must necessarily be vague and ill-defined. As indicated about this process can be an integral feature of the redevelopment of the Basil Stafford site.

This altered approach to the provision of community housing for the cohort throughout the state should be reflected in a Capital Works Development Program which will have a more specific and well defined focus. The needs of those whose needs are “more complex” are different from those of others with intellectual disability. This will determine the nature and extent of their accommodation needs. Those with architectural expertise will therefore need to be better informed and advised by the disability sector. As the process of assessment becomes more integral in the process of service delivery to the cohort, better housing outcomes are more likely to become available as an important part of the whole range of disability services to this client group.

It is necessary for the sake of completeness to draw attention to the fact that at Baillie Henderson hospital there are accommodated about 30/35 persons who have intellectual disability but who are not mentally ill. Some of these may have challenging behaviours. Many of this group are now quite elderly and have lived at Baillie Henderson for many years. Family members have supported this and it seems still do. A serious question arises as to whether they should continue to be supported as part of a mental health service.

This question raises several issues; the well being of this group and how best they can be supported and cared for; the wishes of family in the light of their long standing association with Baillie Henderson; whether some may be better cared for in a nursing home type environment because of issues relating to their general health.

In my view these persons should be considered in the course of a collaborative dialogue between DSQ and Queensland Health. It may be that a suitable facility managed by DSQ or an NGO service provider of the nursing home type should be provided or suitable arrangements made by DSQ/QH whereby they are cared for at Baillie Henderson by DSQ or NGO personnel. There are no doubt other options. It is a fit subject for inter departmental action. The solution to the issue must necessarily be based on what in the circumstances represents the best interests of the client group.

Finally I turn to the question of “community access”, a term frequently used in the course of the consultation. It is specifically defined in section 12 (d) as a “disability service”. Its obvious meaning and intent is that persons with intellectual disability should not be quarantined from the community but should have the capacity to go into it, to use its facilities, to make use of what it has to offer and to engage with other people in the community as and when desired. Community access is the antithesis of a process of seclusion whereby people with intellectual disability are seen to occupy an inferior status vis a vis the community and that the opportunity to access the community is not a right but a privilege offered to the person with intellectual disability only as a reward in the same way as exclusion from access to the community may be used as a punishment or sanction.

The term “community access” as used in Disability Services Act 2006 is not itself specifically defined nor should it have to be. It should be given its ordinary everyday meaning. It is best understood in the context of the human rights principle that people with an intellectual disability have the same human rights as other members of the

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society and should be empowered to exercise those rights (section 19(1) of the *Disability Services Act* 2006). It should also be understood in the context of the service delivery principle expressed in section 28 of the Act which provides that services should be designed and implemented to promote the inclusion of people with an intellectual disability “in the life of the community”.

These statutory imperatives envisaged that disability services such as “community access” have to be “designed” before being “implemented”. The design of the “community access” service therefore must be meaningful so as to ensure that the community access designed for a person with intellectual disability will achieve the objectives mandated by legislation. These objectives are not likely to be achieved by taking the person on the weekly bus to a shopping centre in a group with other persons with intellectual disability as some form of relief from the persistent daily diet of television in a group house. Active support and meaningful access to the community are essential features of such a disability service.

Community access means visiting friends, going shopping, visiting interesting places, taking advantage of community sporting and recreational activities and participating as desired in any activity in the general community which is commonplace for those of us without this disability.

The literature describes “boredom” as one of the several triggers for challenging behaviour. In almost every home I visited at different times of the day, residents were usually grouped before the television set except in one case where a disturbed resident had destroyed it on the previous night and it was in the process of being replaced when I arrived.

There are NGO agencies which specialise in the provision of community access. Because of the importance of access in the further development of the individual person, the capacity of that person to live in the community and to join in the usual life of the community must continually be enhanced as a matter of priority. The transition from institutional life to community life will have failed so long as the person living in a suburban house in the community is effectively separated from it or at best given limited access in accordance with some “common programmatic template” designed by others, the execution of which is in the hands of another and in respect of which the person with intellectual disability is a passive participant.

I had the advantage of helpful consultation with one NGO provider which specialises in community access. Their work is impressive and very relevant and meaningful. The emphasis is always on “participation” in community affairs so as to develop in the person a real sense of “belonging”. There are other advantages. “Inclusion” in a practical and meaningful way can ensure the “safety” of the person. Being included in community affairs with others engenders friendship and concern for the person. Any concerns relating to the “safety” of that person in their living environment will soon be detected and reported. The range of community environments into which the person can be included are endless.

Since community access is a statutory disability service it has to have a high and very meaningful profile so that its utility can be optimised in the life of the person. At worst, it can be something taken for granted and its availability to the person made subject to the convenience of others.

Its availability, how best it should be managed in the best interest of the person and how best this disability service should be “designed” and “implemented” should be the

subject of research and policy development within the Centre. There are NGOs which can professionally inform that process.

It is acknowledged that a minority may be able to have limited access only and at times be effectively contained in the best interests of the person and of the community. The provision of community access to this minority however should be continually under review and the objective set that members of this minority should also be developed to the point where such access is a reality. The service option developed here, based as it is on comprehensive assessment and ongoing intervention has as its objective for each person in the cohort the capacity to live a useful life in the community to the maximum of that person's capacities.

To do nothing or to accept a less than effective attempt in this respect is not acceptable.

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**CHAPTER 6****Implementation Proposals**

The terms of reference do not require that this Report present detailed financial modelling of its proposals. At the same time one remains conscious of the fact that the implementation of the Report's proposals will involve significant change and may require both a redeployment of existing resources and/or the investment of additional funds. The Report also recognises that there has already been dialogue with the Community (Have Your say: On improving disability services in Queensland December 2004 – April 2005) concerning an improved strategy for, inter alia, the funding of programs and that those issues are currently being addressed. I had beneficial and helpful meetings with the relevant DSQ personnel.

Cost benefit analysis is a necessary process for determining whether outcomes are consistent with the funds invested and whether changes in service delivery which will involve additional capital investment will produce a satisfactory return or outcome from the additional investment.

In the context of this report one is convinced that much better outcomes can be anticipated by a redeployment of the existing funding and the investment of new funds. In any discussion about "outcomes" in this context the focus has to be on improved service delivery which will more effectively allow individual persons with intellectual disability to develop acceptable lifestyles in the community free of the disturbed behaviours which separate them from participation in community living and which have the capacity to perpetuate a life of disturbed isolation. Positive behaviour support is designed to diminish and/or eliminate the behaviour which has such a destructive influence on the life of the individual. It is that outcome which the financial investment is designed to procure.

This Report has attempted to provide a realistic assessment of the value of the past and current investment of public funds in respect of the cohort not in financial terms, but in terms of outcomes for individual persons. The historical context makes it abundantly clear that the huge changes brought about by deinstitutionalisation in the 1990's required the investment of both State and Commonwealth funding. How successful that investment has been is and will continue to be a fit subject for evaluation. For instance the DSQ service delivery arm AS&RS has recently been the subject of review and evaluation and was, no doubt, designed to assess the quality of the service and its outcomes in the light of the significant financial investment in the service. So too is the process of program development and management a fit subject at the present time for evaluation in the light of the relevant financial investment and the quality of present outcomes.

That is why in the course of this project it has been an essential requirement to examine and investigate the present regime of service delivery to this cohort, to examine that in its historical context and to make some assessment of the present cost effectiveness of the sizeable financial commitment to dealing with and managing the troublesome behaviours which are the product of intellectual, cognitive and physical disability.

Crisis management is inevitably expensive. Any service regime which requires the employment of 2 persons in the care of 1 on a 24/7 basis indefinitely is so obviously unsustainable that it must be seriously questioned. It is really necessary? Is there a more effective way of producing a better outcome? Are the moneys invested in such a regime being wisely and appropriately spent? Is this best practice?

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This Report strongly recommends a process of reform and renewal and a regeneration of effort because it is readily apparent that current structures and processes have produced little or nil outcomes for many in this cohort in spite of the huge investment of public moneys.

That is not intended as a criticism. The difficulty in service delivery to the cohort is well recognised. It is however to confront the reality. The need for change and significant change is readily obvious. A continuation of the present fragmented approach has nothing to commend it. Its outcomes have been mediocre at best and a poor return in the light of the significant financial investment.

That is why the emphasis has been to develop an acceptable service option which is effectively responsive to the current problems and at the same time much more cost effective.

In the context of cost effectiveness issues, it is readily apparent that a huge financial commitment is directed at managing behavioural crises and issues when they have become imminent or have already become manifest and hence demand an emergency response which necessarily requires a considerable funding outlay. And this is a repetitive situation which is replicated over and over and the outcome is invariably mediocre from the person's individual point of view. In short a huge financial investment with a poor outcome.

In my view that process has to be reversed. It is unduly expensive to be only reactive. It is to be cost efficient to address the problem of positive behaviour support in a way which is essentially proactive. This is best illustrated by the need for early intervention not only in respect of young persons but also in the case of adults at the first emerging signs of troublesome behaviour. This may require an additional investment at the "front end" but if that investment is deployed in implementing best practice the best outcome is achievable for the person and the cost in the longer term will necessarily be less. Proper behaviour support which necessarily requires valid assessment and effective intervention will keep the person in the community in an acceptable lifestyle which will itself have the capacity to ensure the better management and control of the behaviours which previously have been so difficult to control and so expensive to manage.

There is one other aspect that is relevant in this context.

This Report has noted the urgent need for challenging behaviour and intellectual disability to become the focus of across government attention and collaboration. It has also noted the disturbing fact that a significant proportion of the present cohort are young males, many of whom have become socially dysfunctional and whose history of disability and disturbed behaviour reaches back to their infancy. On that account the need for early intervention in terms of life years has been emphasised. Appropriate support across government departments through a process of cooperation and collaboration has been less than effective but is an urgent requirement.

Again it is not only a matter of better and more effectively intervening appropriately in the life of that person to optimise his/her development, it remains an effective and, indeed, a more cost effective way of addressing the whole issue. It is a matter of great significance that so many of those persons whose life is at crisis point and who are presently cared for and managed in inappropriate facilities are young men not yet out of their teens. DSQ is aware of the fact that others, equally disturbed, will soon become the responsibility of DSQ. The cost of supporting and managing them will also prove to be hugely excessive.

One can only speculate about what their present status might have been had these young men been the subject of effective intervention and positive behaviour support in their earlier years. One thing is certain and that is that the probabilities are that early intervention would have significantly reduced the level of funding which their present plight has demanded of DSQ.

It is confidently submitted that the establishment of the proposed Centre for Best Practice and the processes of reform which are the core features of this Report will prove to be a most cost effective initiative and that its several features should be implemented as soon as possible.

The total package which is a core feature of the proposal has an essential unity. Each part of it is interrelated to the other. At the same time I recognise practical difficulties in implementing it at the one time. Implementation may require its development in 2 phases.

#### Phase 1 – to commence as soon as possible

- (i) the development of the Centre for Best Practice in Positive Behaviour Support and its infrastructure;
- (ii) the appointment of the Centre's Leader and Reference Group;
- (iii) the adoption and implementation of the Train the Trainer proposals of the Institute of Applied Behaviour Analysis; North Carolina U.S.A. or similar professional resource;
- (iv) the immediate identification of and comprehensive assessment of those persons in immediate need of more specialised accommodation;
- (v) the development of Emergency and "Secure Care" Accommodation facilities;
- (vi) the training of selected staff to manage and service these facilities;
- (vii) urgent liaison with tertiary institutions to develop Graduate Diplomas in Applied Behaviour Analysis for the relevant disciplines or some other appropriate tertiary mechanism;
- (viii) review current community living accommodation facilities and determine the required range of accommodation options to ensure effective Positive Behaviour Support in the community.

#### Phase 2

- (i) establish Assessment and Community Intervention teams and regional coordinators;
- (ii) develop the research facility within the Centre;
- (iii) develop and institute the Training Programs for specialist and direct care staff;
- (iv) Commence the development of suitable community housing which provide the suitable environment for successful intervention.

I cannot overemphasise the importance of establishing as a matter of urgency within DSQ the high level professional expertise which will be the driver, overseer and facilitator of and which will begin to direct the provision of the quality care and support to all persons in Queensland with intellectual disability and disturbed behaviour. The proposed Centre of Excellence should be developed immediately and the processes for appointment of the Centre's Leader instituted without unnecessary delay. This is a matter of such urgency because of the present need to comprehensively address this issue rather than perpetuate ad hoc and fragmented decision making which is poorly

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informed and lacking valid content and which is and has been productive only of mediocre and unacceptably poor quality outcomes. Many other related components of the total required response can be progressed concurrently.

I hesitate to indicate a specific time frame for the completion of the total response because so often that is the time which is allowed to expire, even more, when more concentrated effort could have completed it sooner. It therefore suffices to say that the present circumstances require an immediate commencement and that it be completed and able to operate responsively as soon as practicable.

### Structural Change

This report has emphasised the need for reform, renewal and regeneration in the provision of support and services to people with an intellectual/cognitive disability and severely challenging behaviour. For this to occur a continuum of service responses which includes early intervention, in terms of both age and first presentation of challenging behaviour, and the provision of a planned response to assessed need that will ensure that appropriate services and support are available across the State, is urgently required.

For real reform to take place service delivery needs to be driven by innovative thinking, best practice, critical analysis and the drive for continual improvement. To achieve this, the organisation should be structured in such a way as to clearly define those “strategic/creative thinking” roles and to unambiguously separate them from service delivery. So too is there a requirement to clearly delineate support, accountability and operational roles.

It may be argued on an initial reading of the Terms of Reference that my suggestions within this part of my Report go beyond what has been requested of me. However, it seems to me that one of the most significant impediments to successful implementation of the reform proposed in this Report is the way in which DSQ is currently structured. As stated earlier much of the business of the Department is driven by crisis and ad-hoc responses in reaction to critical needs that constantly arise. As a result service delivery, in particular the need to respond to emergencies, unreasonably dominates the operations of the organisation. This situation demands attention if I am to provide true guidance on the appropriate response to the issues surrounding supporting people with intellectual disability who develop challenging behaviour or who are at risk of developing that behaviour.

The revised business model for DSQ, announced in May 2003, was designed to clarify its role and improve efficiency and effectiveness. That model proposed the five future roles for DSQ to be:

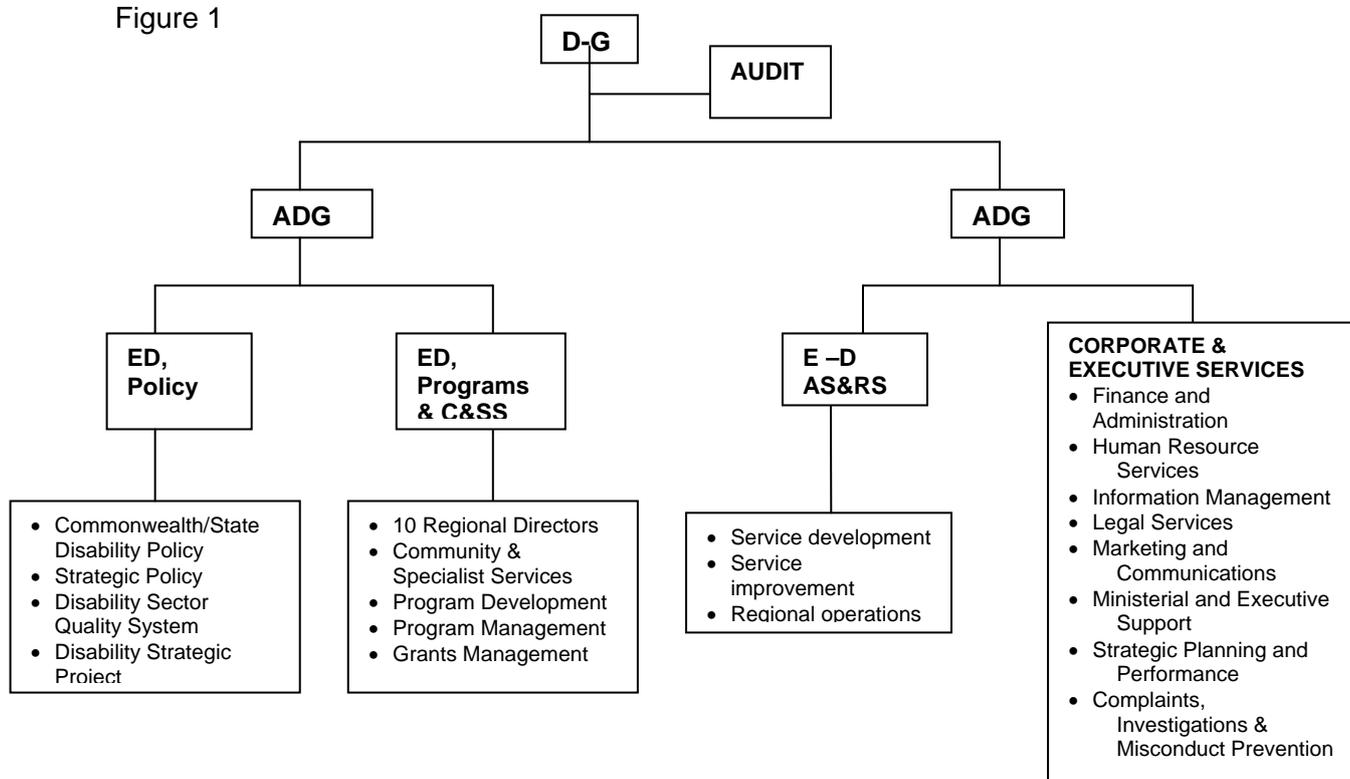
- Developing strategy and policy;
- Funding acquisition and allocation;
- Purchasing and procuring services;
- Assessing need; and
- Providing services.

The policy area was intended to have an increased emphasis on innovation and research and development. In addition, the model proposed the separation of the functions of assessor, funder, purchaser and provider. To support this it was proposed that an Assessment and Intake Unit be implemented in the longer-term, that the accommodation support and respite function be set up as a separate directorate and a

Programs Directorate be established under the leadership of an Executive Director, separate from service delivery, to focus specifically on purchasing and contract management functions.

The current organisational structure (Figure 1) reflects some of these proposed changes but not all. An Assessment and Intake Unit has not as yet been established. The lack of a professional assessment of needs and the delivery of positive behaviour support has been a consistent theme throughout this Report and needs to be the immediate focus of the reform. Whilst a functional area was established to focus specifically on purchasing and contract management, it is not substantially separate from service delivery. The Program Management Branch undertakes the functions proposed for the Programs Directorate but reports along with the regional service delivery function (10 Regional Directors) through an Executive Director to an Assistant Director-General. The Policy Directorate also reports to the same Assistant Director-General. The Accommodation Support and Respite Service (AS&RS) is a separate directorate reporting to an Assistant Director-General who is also responsible for the corporate support function of the organisation.

Figure 1



AS&RS operates in an environment where it is one service provider amongst a number of providers, the majority of whom are non-government agencies supported by government funding. However, the recent review of AS&RS found that there was a significant lack of clarity around the role of AS&RS and recommended that “Government needs to accept a leadership role within the sector as one of the largest and most enduring providers and in so doing accept the risk of supporting clients with the highest level of needs”. In this way AS&RS would be established as a specialist provider of services for clients with high and complex accommodation and support needs. I support this recommendation.

The current alignment of AS&RS with Corporate and Executive Services effectively isolates AS&RS from learning from ideas and best practice within other service delivery

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areas within DSQ and across the sector and places a barrier between this and other service delivery areas. Clearly if the AS&RS Review recommendation is adopted then AS&RS will no longer operate within a true competitive environment with other service providers and there will be no rationale for it to be separated from other areas of service provision within the organisation.

The proposed change to DSQ's organisational structure is based on the following premises:

- There is an urgent need to ameliorate the stranglehold that crisis in service delivery has on the overall effective operations of the organisation;
- Excellence in service delivery can only be achieved if it is professionally informed by innovation and best practice;
- The developmental, support, accountability and operational roles of the organisation should be clearly distinguished in both their roles and reporting structures;
- Services should be developed and implemented with a specific focus on developing the individual person;
- The key to effective service delivery is a comprehensive multi-disciplinary assessment with a view to the development and implementation of an individualised Plan, a component of which for this cohort is an Individualised Positive Behaviour Support Plan;
- One of the key determinants for successfully managing severely challenging behaviour is the skill and expertise of staff;
- There is a need for fully trained and experienced staff in assessment, positive behaviour support and care and support of people with challenging behaviour and this training and development needs to be both ongoing and based on best practice operating nationally and internationally; and
- The organisation needs to create an environment where professional, direct care and other staff aspire to work and develop the means for "growing" the necessary staffing expertise by working with both tertiary education bodies and other professional areas to encourage skill development and knowledge in this field.

Figure 2 at the end of this chapter depicts the suggested functional structure for DSQ which would best suit the successful implementation of the reform proposed throughout this Report. It presents a breakdown for the organisation as a whole as well as a functional structure for the regions. I necessarily recognise that DSQ deals with people other than those with intellectual disability and challenging behaviour, but in line with the Terms of Reference, I have considered the importance of focussing operations to deal with people with high and complex needs, while still engaging with the rest of the community.

The structure establishes a **Centre for Best Practice in Positive Behaviour Support** as a centre of excellence with a role in developing and monitoring best practice in assessment and development and implementation of Personalised Individual Plans, conducting and disseminating academic and applied research and providing training and professional development. The focus on the development of expertise will use strategies including the rotation of professional and direct care staff through the Centre for work and research experience and the provision of training to generic service providers to increase their knowledge and expertise in working with people with a disability. It will also involve liaison with Universities to establish appropriate undergraduate and post-graduate courses and in arranging post graduate student placements within the centre and DSQ generally. The Centre will also liaise with all relevant government departments and agencies, NGO service providers and disability peak bodies in the community with a view to establishing a whole of government and

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sector response and the effective collaboration and cooperation of all bodies concerned in any respect with the well being and development of those in Queensland with intellectual disability and challenging behaviour.

The **Policy and Strategy Development** function allows all policy and developmental activity to be concentrated in the one area, without the distraction of the inevitable crises that occur within the service delivery area. This function combines the program development function with policy development and increases the emphasis on applied research and future planning for policy and service requirements. This area would be responsible for the development and management of strategic policy both internally to DSQ and representing DSQ at a whole-of-government level, development and review of disability-related legislation, Intergovernmental relations, services and program development and evaluation, applied/operations research, future planning, including predictive modelling of future need for services and the Disability Sector Quality System.

The **Service Delivery** area combines a Specialist Accommodation Support and Respite Service Directorate (SAS&RS) with Regional Operations delivered through the 10 Regions. The SAS&RS directorate would develop operational policy, systems and processes for direct service delivery, coordinate training and development for SAS&RS staff, manage special systems projects eg Business analysis of RCO rostering, pay and management of client's financial affairs (MCFA) systems and develop reporting requirements and a performance reporting framework. The Specialist Accommodation Support and Respite Service would include accommodation, support and respite services provided through secure housing, the Innovative Support and Housing Program and the Accommodation Support and Respite Service. The direct service delivery within these areas though would report through the regional structure to Regional Directors.

The Regional Offices would have a functional structure which clearly shows a focus on assessment, Individual Plan implementation, provision of multi-disciplinary specialist advice and service around positive behaviour support and the provision of accommodation, support and respite services provided through the Accommodation Support and Respite Service or secure housing or the Innovative Support and Housing Program if located in that region. The Specialist Accommodation Support and Respite Service function would include referral for intervention by specialist services for clients with complex needs, particularly where the development of a Positive Behaviour Support Plan is required. It is acknowledged that there will be varying degrees of skill and expertise required for the more complex accommodation and support functions of secure care and Innovative Support and Housing. As such it would be desirable for consideration to be given to requiring additional qualifications and experience for the direct care positions within these housing arrangements and for more intensive training to be provided. These positions could be seen as a specialist role requiring a higher level of proficiency and attracting a higher level of pay.

The Intake and Assessment function would be the entry point for access to disability services and would provide information on funding options. It would provide assistance to unfunded families to apply for funding as well as determining eligibility for services. This functional area would undertake an assessment of the individual's need and develop the Personalised Individual Plan. The more complex cases would be referred to Specialist Services for assessment and development of an Individual Plan with a Positive Behaviour Support Plan as a component.

The Individual Plan Management function would be responsible for implementing the Personalised Individual Plans. This would include providing links to generic services or to other non-disability Government services, service brokerage and the coordination of access to services, equipment and other related matters. For the more complex cases it

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would include referral to and brokerage of specialist services for development and implementation of Positive Behaviour Support Plans.

The Specialist Advice and Services function would comprise a multi-disciplinary team of professional staff who would be responsible for developing Personalised Individual Plans, including Positive Behaviour Support Plans for those people with challenging behaviours. In developing these plans this area, when necessary, would work collaboratively with the Best Practice Broker to negotiate access to specialist services outside DSQ, for example mental health services within Queensland Health. Their role would also include the management of the implementation of the Personalised Individual Plans in complex cases. The advice and support on positive behaviour support would be provided across the board to both Government and NGO service providers. The professional intervention regarding positive behaviour support would also need to occur on both a short-term and long term basis, dependent on the specific need of the individual.

The Best Practice Brokerage function in each region would be a key “trouble shooter” role which has dual reporting, directly to the Leader of the Centre and to the Regional Director. The role would involve the coordination of access to professional services within DSQ, Queensland Health or other service providers, liaison with the Centre for Best Practice and coordination of regional access to training and development through the Centre for Best Practice. This role has been discussed in more detail in this report. In view of the key role of this area it would be expected that the position would need to be classified at around the AO8 or PO6 level and in the larger more populous regions more than one person may be required in the role.

The **Purchasing and Grants Management** function should be clearly separated from service delivery, although it could be aligned with the corporate support service function for expediency.

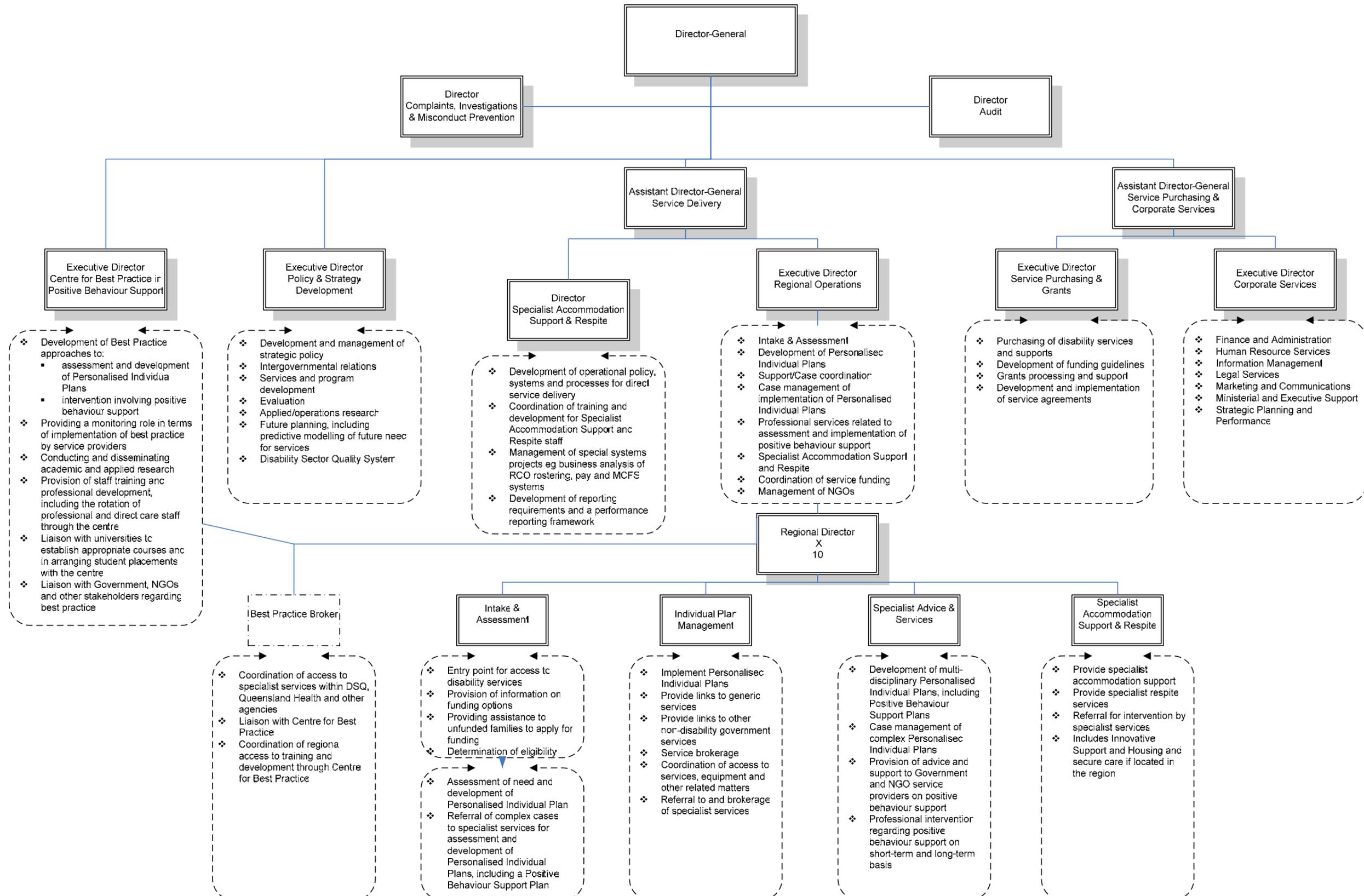
The **Corporate Services** function would remain as current with the exception that the Complaints, Investigations and Misconduct Prevention Branch should be a direct report to the Director-General. This follows general organisational design principles for best practice in accountability processes and reflects discussions that I had with Mr Bob Seamer, an independent consultant engaged to recommend best practice for workplace breaches and misconduct within the Disability Services sector.

Adoption of this proposed structural change within the organisation will ensure that DSQ is well equipped to implement the significant reform, renewal and regeneration required and well positioned to be a real leader in the field of disability and in particular in the management of people with an intellectual/cognitive disability and challenging behaviours.

# Disability Services Queensland

## Functional Structure

Figure 2



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**CHAPTER 7****Legislative Framework – Principles**

The Mental Health Act 2000 provides a statutory scheme for involuntary care in appropriate cases for persons with a mental illness. This process is a response to such issues as the need to detain mentally ill persons in a mental health service for treatment, to seclude that person in defined circumstances and to use restraints, both chemical and mechanical, where necessary. These restrictive practices, which frankly impinge upon the fundamental rights of the person to personal freedom and not to be deprived of his/her liberty contrary to law, are essentially discriminatory and disadvantage the persons not for what he/she has done but because of what they might do. But they are justifiable in the best interests of the person requiring treatment for the mental illness.

The same fundamental concerns attach in many cases to persons with intellectual disability who are in fact the subject of civil containment and other forms of restrictive practice. The rationale for such practices has been that these are matters of practical necessity to ensure the well being of the individual person with intellectual disability and to protect others who are potentially the victims of that person's challenging behaviours which are often characterised by personal violence and serious property damage including injury to family members, carers and support workers, other co-tenants who are also persons with intellectual disability, and not infrequently unwitting members of the public. Practical measures, not dissimilar from those lawfully available in the case of persons with mental illness, to contain the potentially damaging consequences of challenging behaviour, are not uncommon in the care and support of those with intellectual disability. Locked doors, which ensure detention and containment in a specific area subject to supervision around the clock and other lesser forms of restriction, are used and on a daily basis impact on and are an essential feature of the lifestyle of many who are persons with intellectual disability. I saw several instances of such practices in the course of this review. Such practices are in use across the sector.

The concern is that these practices, which have no legislative support such as can be found in the Mental Health Act for the proper care of those with mental illness, are unlawful or at best are supported by legal paradigms which are of doubtful validity.

That is not to say that appropriate restrictive practices cannot be justified in appropriate cases in the proper care and support of a small minority of persons with intellectual disability. The case studies include some where appropriate restrictive practices can be justified. But justification, the consequences of which will necessarily impact on the fundamental human rights of the affected persons, is to be found and will be supportable only in the proper case and subject to the proper criteria and only in a small minority of cases.

Violent behaviour, particularly when unprovoked, is not acceptable in any community. In the case of a person with severe intellectual disability characterised by disturbing and often violent behaviours, such violence or other behaviour may be explicable and perhaps not culpable in the eyes of the criminal law, but it remains unacceptable to the community. It therefore has to be addressed and managed in a way which is also acceptable to the community. Those who work in caring for and supporting such persons on a daily basis are entitled to a safe workplace – not one in which violent or disturbed behaviour is likely to erupt at anytime.

As already pointed out, the not infrequent occurrence of inappropriate behaviour, and its consequences for others, on the part of a particular individual person with intellectual

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disability needs to be addressed in the same context as that in which an insistence upon the maintenance of the fundamental human rights of that person is mandated by the principles expressed in the Disability Services Act 2006.

It must be emphasised that to restate the need to recognise the rights of the individual as integral in this context, is basic and fundamental. Just as it would be wrong to pay lip service to the need to protect the rights of others to live and to work free of violent and other potentially damaging behaviour, so too would it be wrong to pay mere lip service to the need to respect the rights of the person which are recognised universally and in Queensland mandated by legislation.

The community has to accept that apparently competing and ambiguous objectives have to be resolved in the best interests of the individual and of the community. That is precisely what has been attempted in the construction of the proposed legislative framework. Therefore one is obliged to state explicitly the principles which have governed the deliberations and which must be incorporated in the design of the proposed outcome. Those principles will be set out below.

At this point one needs to address a related concern. Earlier I referred to the CJC Report in respect of Basil Stafford Centre (the Stewart Report 1994-5) and the consequential CJC Review (2000). That experience confirmed the vulnerability of persons with intellectual disability and the corrupt and abusive practices to which so many were subjected. The power imbalance between the so called carers and those in receipt of “care and support” is immense. The BSC experience is now not only of historical interest but serves as a constant reminder that the exercise of power and influence is readily corruptible in the case of those who are vulnerable and often powerless. Whether the “insidious institutional culture” rejected by Stewart as synonymous with BSC has survived the Stewart Report is a moot point. There are not a few who will allege that it has.

Therefore to provide legislative support for any regime of restrictive practice, which is prima facie discriminatory, might be thought to assist in entrenching and protecting that which is unacceptable. Power, even legislative power, can be misused and when vested in human hands may well be. Matters of sheer convenience and ad hoc utility may be enough for some wrongdoer to treat the rights of a fellow human, albeit a vulnerable fellow human, with contempt and as having no substantial rights, particularly where the other is seen as a nuisance or a problem. For the wrongdoer to attempt to seek protection from the Statute in such a case only compounds the default.

Nor is this insidious malpractice necessarily corrected by a host of stated policies which asserts “the right thing”. Theory and practice do not always coincide. It is well to note the remarks of Brennan J (as he then was) in the High Court of Australia in *The Secretary Department of Health and Community Service v JWB and SMB* (Marions Case) (1992) 175 CLR 218 @ 277.

**“The history of intellectually disabled people contains a surfeit of examples of degrading treatment administered under laws which reflect the standards of the time – standards which were a reproach to the civilisation then enjoyed.**

**If equality under the law, human rights and the protection of minorities are more than the incantations of legal rhetoric, it is in this area of the law that they have real work to do”**

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If therefore there needs to be inserted into the Disability Services Act 2006 an acceptable legal framework or structure which legitimately addresses the question of restrictive practices for appropriate cases and in defined circumstances, the other provisions of the same Act which state the “Human Rights Principles”, the “Service Delivery Principles” and the “Disability Service Standards” are not to be disregarded, compromised or even modified as the mere “incantations of legal rhetoric”. Rather they must provide the solid foundation for sound policy development and for the design of the framework. This Report has proceeded accordingly.

In *Chu Kheng Lim v Minister for Immigration*, Brennan Deane and Dawson JJ said (1992) 176 CLR 1 @t 27-28, that, putting to one side the power of the legislature to punish for contempt and of military tribunals to punish for breach of military discipline, and the exceptional cases of mental illness or infectious disease which are non-punitive in character, involuntary detention of a citizen in the custody of the State is penal or punitive in character.

In *Kable v DPP (NSW)* (1996) 189 CLR 1 @ 55. Gummow J at page 55 cited the remarks of Gaudron J in *Chu Kheng Lim*:-

**“Detention in custody in circumstances not involving some breach of the criminal law and not coming within well accepted categories of the kind (referred to above) is offensive to ordinary notions of what is involved in a just society”.**

Therefore the principles which are fundamental to the legislative scheme proposed in this Report are:

1. The human rights and service delivery principles set out in part 2 Divisions 1 and 2 of the Disability Services Act 2006 are to be applied expressly to the extent that the same are relevant to this issue.
2. Since the legislative focus is on the development of the individual person, and the services to be delivered have to be designed and implemented for the purpose of developing the individual and enhancing the person’s opportunity for a quality life, restrictive practices can only be justified as part of a specific individualised positive behaviour model of care and support which will be of benefit to the individual and will assist in the achievement of that objective.
3. Any such plan for the care and support of the individual person must be developed by the appropriate specialists in association with the individual and where necessary his/her parent or guardian.
4. Approval for such a plan, if it contains provisions for the use of restrictive practices must be given by an independent body consisting of persons with the requisite skill, knowledge and/or experience and such approval shall operate only for a limited time, at which time it shall be reviewed and the continuance or otherwise of the restrictive practice considered anew in the light of the material to be provided to the independent body.
5. Whilst the approval remains in operation, the use of the approved restrictive practice(s) shall be monitored by an independent person(s) who shall report to the independent body upon each review.

Except in those cases where restrictive practices as defined are approved in accordance with and subject to the relevant provisions of that part of the Act, there will be a statutory prohibition upon the use of any restrictive practice in the provision of care and support to any person with a “disability” as defined in section 11 of the Disability

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### **The location of the legislative provisions**

The legislative framework for the permitted use of restrictive practices for persons with intellectual disability and challenging behaviour has to be located as a new Part of the *Disability Services Act 2006* assented to on 4 April 2006 and which came into effect on 1 July 2006. The Act is described as “An Act to protect and promote the rights of people with a disability and for other persons”. The “disability services” defined by the *Disability Services Act 2006* include, inter alia,

- accommodation support services
- community support services
- community access
- research training or development services.

These are the stated services to be provided “for persons with a disability”.

The persons, the primary focus of this Report, are among those persons for whom these disability services are to be provided. The services comprehended by the targeted service response which this Report recommends, include the disability services referred to above – the comprehensive assessment of individual needs as an essential preliminary to the proper provision of “community support services”; the process of intervention and coordination on behalf of the person living in the community as part of a positive behaviour “support” strategy; the provision of the required “accommodation support services” for the person which will best enhance the “development” of the individual, the need for relevant “research” in optimising the quality of the service and the development of best practice in service delivery by the proper “training” of both professional and care staff for more effective service delivery – all of this with the sole but focussed objective of ensuring the proper “development” of the individual person so that that person can better enjoy the exercise of his/her human rights expressed in the Act.

The perceived need for any such person to be the subject of any restrictive practice defined in the Act, as the second stated principle provides, “can only be justified as part of a specific individualised model of care and support which will be of benefit to the individual and will assist in the achievement of the objective” expressly stated in that principle. In short, any restrictive practice which better ensures the implementation of the community support for the well being of that person and which protects him/her and others from the potentially damaging consequences of the behaviour has to be designed and implemented only as part of the “positive behaviour support plan” for that person. The legislative scheme is therefore a related part of the “disability services” which *Disability Services Act 2006* has mandated for the benefit of this group of persons with intellectual disability.

Furthermore the use of any restrictive practice in the context of this legislative scheme, whereby restrictive practices are prima facie unlawful unless implemented as part of a targeted service response for the particular person, is entirely consistent with the human rights principles stated in the *Disability Services Act 2006* and in the UN Declaration of the Rights of the Intellectually Disabled 1971 and 1975. Such a scheme is better validated and made more acceptable if it sits beside the human rights and service delivery principles expressly stated in the same Act as that which states the requirements for the lawful use of a restrictive practice.

There is no sound basis for separating the legislative scheme from the *Disability Services Act 2006* and enacting separate legislation. On the contrary there are sound reasons for avoiding that. Consequential amendments to other legislation will or may be

required depending upon the acceptance or otherwise of the recommended service options. The short point is that this Report both in respect of its stated service delivery option and the legislative framework required to support it is focussed on the provision of “disability services”. It seems logical to include it in the Disability Services Act into which it can be easily incorporated.

### **The Core Legislative Framework**

Pursuant to the human rights and service delivery principles stated in the *Disability Services Act 2006* it is of the utmost importance that any long term legislative provision which authorises the use of restrictive practices in respect of any person with intellectual disability, be integrated into and form part of the Positive Behaviour Support Plan (PBSP) developed in respect of that person. The service delivery option proposed by this Report is designed to ensure that it conforms with the relevant statutory principles in the *Disability Services Act 2006*. Its essential feature is the development of an individualised PBSP for the particular person consequential upon comprehensive assessment and the construction of an intervention model detailed in the plan which will be executed in the course of the day to day lifestyle of that person.

It is only in the development of that plan that justification will be found for the use of a restrictive practice. Restrictive practice is not an end in itself. It will be permissible only if necessary for the proper care and support of the person with the objective of the plan being the overall well being and welfare of the person. The objective of that Plan has to be to eliminate the need for the restrictive practice in the life of the person; so too its use, pursuant to a “least restrictive alternative” policy, will only be available as part of a well developed Positive Behaviour Support Plan after comprehensive assessment of the needs of the person and their relevance to the disturbed behaviour which is of concern.

This acceptable process is entirely consistent with the view expressed by the Victorian Law Reform Commission (VLRC) report:-

**“The requirement of benefit differentiates the proposed framework from civil detention laws that allow people to be detained solely for the purpose of preventing them from committing crimes that will harm others”<sup>46</sup>**

and again

**“In the Commissions view beneficial treatment should be understood as including professional service interventions that:**

- **deal in a way that is therapeutic and rehabilitative with aspects of that person’s impairment that are associated with their behaviour; or**
- **enable the person to live a less restricted lifestyle than would be possible if the treatment was not provided.**

**Neither detention nor use of restrictive practices should produce outcomes for the affected individual that are anti-therapeutic or undermine the person’s potential to change his or her behaviour”<sup>47</sup>.**

The plan and its provision for the use of a restrictive practice(s) will have to be approved independently of those who constructed the plan. The determination of the preferable

<sup>46</sup> VLRC: People with Intellectual Disability at Risk: A Legal Framework for compulsory care November 2003 page 43.

<sup>47</sup> VLRC: People with Intellectual Disability at Risk: A Legal Framework for compulsory care November 2003 pages 44-45.

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approving body is a matter for debate. The Public Advocate submitted in the course of a discussion that, if the restrictive practices proposed for use included detention then a Judge of the Supreme Court only should be required to give such approval. "Detention" for the purposes of this legislative framework means "any process whereby the means of entry, access to or exit from the premises where the person is living are dealt with so as to prevent the free and uninterrupted movement of the person from the premises." It is the intention of this Report that any premises within which a person may be detained will present a home-like appearance and its internal appointments as those of a conventional home. Doors and windows will be locked or barred and the person will leave the premises only under supervision and will be supervised outside the premises such as to prevent the person from leaving the premises or its precincts of his/her own free will. Other restrictive practices include mechanical, chemical and physical restraint and seclusion. Such practices have been acceptably defined by the VLRC. For the purposes of the legislative framework proposed here the term "restrictive practice" should be defined to include these and also detention.

The primary function of the independent approving body will be to approve a Positive Behaviour Support Plan which includes a provision for restrictive practices as part of a behaviour support strategy for the person who will in the normal course live in the community or in a community like environment. Such a plan will also be likely to contain provisions for Community access. It will require review every 6 months although the approving body may require its review at a shorter interval depending on the circumstances. It will not be uncommon for an application for PBSP approval to be made as a matter of urgency and with a minimum of formality in order to respond to a crisis situation in which the well being of the person or of others is thought to be at risk. The making of an interim approval should be included in the approving body's jurisdiction.

Access to the Supreme Court is relatively formal, costly and not always expeditious. So too is access to administrative or quasi-judicial tribunals. Since the provisions for a restrictive practice can be approved only as part and parcel of a Positive Behaviour Support Plan for the proper care and support of a person with intellectual disability, it is in my view more appropriate that the approval not require the intervention of the Supreme or other Court, nor do the circumstances of the case require it. The exigencies of the situation can be more suitably met by vesting the jurisdiction to approve in the Guardianship and Administration Tribunal (GAAT). This is a specialist tribunal whose jurisdiction includes decision making in respect of the health and personal affairs of vulnerable persons. The Tribunal itself is presided over by a respected lawyer and its membership is heavily invested with considerable and reputable expertise by specially selected persons. Lengthy discussion with the former President and Deputy President and other specialist members can leave one in no doubt that the Tribunal is well equipped with the specialist knowledge and expertise as to be well able to provide not only the independence but also the specialist skills in ensuring a proper judgement in respect of a behaviour support plan for a person with intellectual disability and challenging behaviour which includes a provision for the use of a restrictive practice as part of that plan. The ongoing development of specialist expertise by the membership of GAAT is obviously one of its strengths and if invested with this approval power in this context it will no doubt develop a much needed overseeing expertise in this particular area. One can be certain that progressively the GAAT through the exercise of this jurisdiction will come to have a real and beneficial influence in this area of interest particularly in relation to the proper use or otherwise of restrictive practices in the case of persons with intellectual disability and challenging behaviour.

The recommendation therefore favours the use of GAAT as the appropriate body to best exercise an independent approval jurisdiction in these circumstances.

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As pointed out elsewhere in the Report, the person, parent or guardian and service provider must necessarily be part of the assessment and plan development process. Consent to the totality of the plan may be available on the part of the person, parent or guardian or it may not be. For instance discussions with the Adult Guardian and staff make it clear that this agency does not consider that approval or consent to such a plan is within its legislative functions nor should it be. This point of view is to be respected because of the sensitive powers given to the Adult Guardian. However, the independent approval jurisdiction, if given to the GAAT, can provide the most effective and efficient safeguard. An additional safeguard, if seen to be necessary, would be to require notice of a service provider's application for a plan including the use of a restrictive practice to be given to the Public Advocate although it should be noted that the Public Advocate's role is systemic advocacy rather than advocacy on the part of an individual. If the guardian of the person is the Adult Guardian not only should notice of the application be given to that official but as pointed out the Adult Guardian must be made aware of the process of assessment and plan development and given the opportunity to participate, at the same time recognising the present inability of the Adult Guardian to consent to any such plan which may contain a provision for use of a restrictive practice. At the same time the Adult Guardian in a particular case can advocate on behalf of the person in the course of the approval process in the GAAT.

The Tribunal's approval should operate for and be subject to review after a limited period. A reasonable period would be 6 months and in the course of that review the Tribunal would have the capacity to determine whether that part of the plan which provided for the restrictive practice should be extended, modified or removed.

Since it will be the obligation of the Community Visitor Program to monitor the operation of the restrictive practice periodically and report to the service provider it will be a requirement that such reports be provided to the Tribunal in the course of any review.

Therefore the integral features of the scheme for the proposed lawful use of restrictive practices are:

- a prima facie prohibition on the use of restrictive practices unless approved as part of an individualised positive behaviour support plan;
- comprehensive assessment of the person and the development of an individualised positive behaviour support plan which must include any proposal for the use of restrictive practices;
- such a plan requires the approval of GAAT and the application for approval by the service provider will require the submission of material in support of the use of the restrictive practices sought as part of the plan;
- the jurisdiction of GAAT can be accessed in an emergency and should include the power to make an interim order;
- such approval shall normally operate, except in the case of an interim approval, for 6 months. If it is intended that the service provider seeks an extension of the restriction that application will be a necessary part of the statutory review by the Tribunal at the expiration of the stated period;
- during the operation of any approval the Community Visitor program will monitor the use of the practice in accordance with its statutory powers and obligations and the relevant reports to the service provider shall be available to the GAAT.

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**Matters of detail**

Definition of the relevant terms is necessary. There is much to be said for a legislative scheme which does not distinguish between “detention” and other forms of “restrictive practice” and which relies solely on the one term “restrictive practice”. A separation of these terms was recommended by the VLRC and the operation of each required different criteria for their application. “Detention” in Victoria means detention “in a prescribed facility” so as to reduce the risk of serious harm to others whereas “restrictive practice” is said to have a wider application to include mechanical, physical or chemical restraint and seclusion. “Locking of doors” is also included as a restrictive practice.

One can question the need for a “prescribed facility”. It probably refers to an institution or a prison-like facility rather than the type of accommodation facility which is referred to in Chapter 5 as having the capacity to provide “secure care”. Those persons with intellectual disability who are presently contained whether by DSQ or NGO service provider or family are accommodated appropriately in homes of varying standards but few of which assume the character of a secure institution. That is not to say that they do not have the capacity to provide secure care. Some of the potentially more serious cases are housed safely in the suburban community of a city.

Bearing in mind that the core feature of the service delivery option presented in this Report is not focussed on restrictive practices but on positive behaviour support planning and on restrictive practices only as ancillary to that strategy, it is not considered appropriate to provide a “facility” which bears all of the characteristics of incarceration. As pointed out, the accommodation option for the person or the environment in which the appropriate support interventions have to occur is of critical importance and for that reason Chapter 5 states the requirement for a variety of accommodation, in particular, housing which will be able to provide for the needs of various individuals. The provision of the one secure facility which is prison like and designed as a “congregate care” facility is entirely rejected as an option. The unambiguous world experience is that this type of facility is counter productive and the very antithesis of the type of accommodation environment which is essential if effective positive behaviour support is to be provided efficiently in the course of reducing and eliminating challenging behaviour in the individual. Providing the acceptable housing model which can satisfy a requirement for secure care remains a challenge for the design professionals. Such an accommodation model should allow for privacy and private space but permit of social interaction between persons.

The Purpose Design Housing project which this Report proposes should be developed urgently at the BSC site and which has been intended as the preferred housing for some who currently present as the more serious cases is a much preferable environment than a “prescribed facility” or the accommodation in which they are presently living. In practical terms they are “detained” in their present accommodation and access places outside their home only in strictly supervised conditions.

It is preferable to include “detention” as a “restrictive practice”. It is more relevant to and in keeping with the accommodation option which the Report considers ought to be available and which will better facilitate successful positive behaviour support interventions. That is not to say that the most difficult case may not at times require a highly secure environment.

This Report has already noted the need to provide experienced and well trained staff to assist and service the needs of the cohort.

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There should also be a recognition legislatively of the criteria to which regard must be had in deciding whether and what form of restrictive practice is considered necessary in the individual case. It is fundamental that any acceptable system involving the use of restrictive practices must recognise and protect the rights of those with intellectual disability. The legislative structure or framework set out above attempts to do that. It should also detail the relevant criteria for use of any chosen restrictive intervention.

It follows that any application for approval of a plan must provide to GAAT the evidentiary support for any relevant criteria said to support the particular practice(s).

The suggested criteria are:-

- appropriate professional opinion which details the basis for a significant concern that injury to self or to another person(s) is likely to result in the absence of specific intervention involving specific restrictive practices; and
- a recent history of challenging behaviour that has resulted in injury or the risk of injury to self or another; or
- a history or pattern of challenging behaviour that has resulted in injury or the risk of injury to self or another; or
- a history of challenging behaviour that is shown to have escalated in its intensity and which puts the person or another at risk of injury.

### **Legislation for the status quo**

Because a critical element of the desirable long term legislative framework involves having in place an assessment process of the kind envisaged by Chapter 5 of the Report and also the relevant infrastructure and since this will take time to develop, the question arises as to whether an interim legislative proposal should be considered. The main features of the long term scheme proposed above are, firstly, the enactment of an express statutory prohibition upon any form of restrictive practice unless it is approved as an integral part of a positive behaviour support plan; secondly, the comprehensive assessment of the person and thirdly the development of the relevant plan and its approval by the GAAT. There is a direct relationship between the outright prohibition of the use of restrictive practices and the development and approval of the plan. Only in the event of the latter process being in place is the unlawfulness which prima facie attaches to an unapproved restrictive practice removed.

The general prohibition by law of the use of any unapproved restrictive practice sends a clear message to service providers whether family member, direct care giver or service provider that the person who imposes an unapproved restrictive practice or who is a party to its imposition commits an offence which would attract a significant criminal sanction. The impact of that is to establish beyond question within the sector that such practices are to be condemned and only tolerated by way of exception and then only in circumstances where comprehensive individual assessment supports inclusion of the practice in a plan which is independently approved by GAAT.

The practical consequence of this is to protect and confirm the fundamental human rights of the person with intellectual disability and on that basis the proposed legislative scheme is strongly supportable.

A practical difficulty however becomes apparent because of the time which will necessarily elapse from the time of the enactment of such legislative provisions and having in place the assessment and plan development processes across the State. In Chapter 6 of the Report a phased program is put forward which envisages that the

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Centre for Best Practice and the processes of assessment and related matters could be in place within a period of 2 years at the outside required by the Acts Interpretation Act but preferably within 1 year. It is appreciated that machinery of government matters are relevant in this respect. It is acknowledged that in the event of government acceptance of the basic proposals there will necessarily be a lapse of time for the implementation of the proposals. It is envisaged however that it could be in place in 1 year. In any event its implementation is urgent. But it is not unlikely that there will necessarily be some delay.

The question of an interim legislative scheme arises because it is known that across the disability sector a variety of restrictive practices are now used and have been in use for many many years and have been employed by many persons and service providers in a variety of circumstances. It is necessary therefore to address it.

To enact legislation as above would immediately upon enactment and unless its operation is postponed create illegality on the part of the many who believed or were led to believe that the use of such practices in the care and management of persons with intellectual disability was not unlawful or was a matter beyond the application of the criminal law of the State. Further the practices have been and are presently used by some persons who honestly and reasonably believe that their use is in the best interests of the person concerned and these include fellow family members, other care givers and service providers both within government and non-government services.

Therefore in further consideration of this issue this Report proposes 3 options.

#### Option A

This option has 2 main features:-

- the immediate enactment of the legislation which includes the legislative scheme for express prohibition of restrictive practices unless approval is given by GAAT consequential upon assessment and the development of an individual Positive Behaviour Support Plan;
- the commencement of the Act to be fixed by Proclamation on a stated date which will be subject to Sections 15D and 15DA of the Acts Interpretation Act.

#### **Matters relevant to the Proposed Legislation**

The principles for the preferred legislative framework which are set out in this chapter require that the permissible use of any restrictive practice must be intimately related to and form part of the preferred service delivery option the details of which are set out in this Report. The primary legislative impact will be that upon the coming into operation of this legislative provision, the use of any restrictive practice, which should be defined to include any form of detention e.g. the locking of doors, mechanical and chemical restraint, physical restraint and seclusion, will be prohibited and rendered unlawful unless the use of any such practice(s) is independently approved as part of an individualised Positive Behaviour Support Plan consequential upon a comprehensive assessment of the individual person and his/her needs.

This service delivery component of the Report will take time to implement and it will have to be effectively in place before the core legislative provision becomes effective. I have already indicated the urgency of proceeding with its establishment as soon as possible. However it is clear that the coming into operation of the amending provisions will need to be postponed and the date for its commencement can be fixed by Proclamation (Section 15D of the *Acts Interpretation Act* 1954). Accordingly the provisions to be inserted in a new part of the Disability Services Act 2006 will be enacted as a “postponed law” within

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the meaning of Section 15DA of the Acts Interpretation Act. By section 15DA(2), if a postponed law has not commenced within 1 year of the assent day, the postponed law automatically commences on the next day. There is a further proviso in section 15DA(3) that within the 1 year period a regulation made under the Disability Services Act 2006 may extend the period of 1 year to “not more than 2 years of the assent day”, that is for a further period of 1 year only.

The consequence of this is therefore, that the service delivery process will need to be in place and effective within 1 year of the date when the amending provisions receive the Royal Assent or at the latest within a further period of 1 year. Such a course may be publicly acceptable provided immediate action was taken to begin to implement the relevant service delivery requirements.

Since some measure of delay is inevitable because of the need to implement those requirements, it follows that the status quo will be maintained and that raises the important question as to how current restrictive practices should be addressed legislatively or at all in the short term.

I will return to this issue below.

Accordingly the enactment of the amending provisions could be conveniently delayed for a period because of the operations.

#### Advantages

- The immediate enactment publicly proclaims that restrictive practices use in respect of those with a “disability”, as defined in the Act, is wholly unacceptable and unlawful unless approved.
- This legislative scheme presents as the fundamental ingredient in establishing a new and very different culture in the care and support of persons with a disability.
- Deferral for a period provides the time for adjustments to be made on the part of the users of restrictive practices and for consideration of the need to re-adjust past practices and the adoption of preferable strategies, in the knowledge that after a lapse of time unlawfulness may attach unless a more professional and valid process is adopted. Appropriate government publicity will address both the need for changed practices and the desirable adoption of more professionally based strategies.
- Deferral will relieve the immediate concerns of many elderly carers in respect of a potential immediate liability for unlawfulness.
- Deferral will allow the GAAT to ensure that it has in place the necessary resources and procedures to ensure an efficient Tribunal process.

#### Disadvantages

- The perpetuation, albeit for the short term, of, in some cases, the unacceptable and unjustifiable use of restrictive practices which are unlawful.
- Postponement may give rise to public criticism.

Such a proposal will perpetuate the present widespread illegality until the amended provisions become operative. That means that any carer or service provider may be liable to prosecution for unlawful assault or for unlawful deprivation of liberty. The use of any forms of restraint without the consent of the person will usually constitute the offence of assault (section 245 of the Criminal Code) and any form of detention including the use of locked doors will usually constitute the offence of deprivation of liberty (Section 355 of the Criminal Code).

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In respect of the use of any restrictive practice which prima facie will constitute an assault, the provisions of the Criminal Code provide little by way of a defence. Provocation (Section 268) has no real relevance. The self-defence provisions (Sections 271, 272) may arguably be relevant but only in very limited circumstances. At the same time other provisions of the Code recognise that in special circumstances the use of force which is prima facie unlawful may, because of the special circumstances or of a special relationship, be lawful, e.g. domestic discipline (Section 280).

Therefore one needs to consider whether the use of force which might otherwise constitute an assault under the Criminal Code should be protected in the event that a service provider/carer, whether family member or otherwise, might in the circumstance consider it to be reasonably necessary for the well being of the person or of the service provider/carer to use a particular restrictive practice such as mechanical or physical constraint. There are no doubt many instances when the application of some form of force to a person with intellectual disability and challenging behaviour is required to protect that person from injury or to protect the service provider, carer or other person from injury. Provided that the application of force in the circumstances is reasonably necessary for the protection of the person or of other persons then it is clearly arguable that that application of force should be protected.

The point is that such a defence to a charge of assault in these special circumstances will apply only for the period for which the operation of the key legislative scheme will need to be postponed.

The legislation will provide that once the key provisions become operative the special defence provisions will cease to be applicable.

The relevant provision might take this or a like form.

- (i) It is lawful for a service provider in the course of providing disability services to a person with a disability to use a restrictive practice in respect of such person which might otherwise constitute an assault provided that the use of the restrictive practice is on the balance of probabilities reasonably necessary to protect that person or any other person from the risk of injury or harm.

Section 355 of the Criminal Code makes it an offence to unlawfully detain a person against his/her will or to deprive a person of personal liberty. Any form of detention therefore which is used to contain a person with intellectual disability and challenging behaviour is prima facie unlawful.

Again an interim provision of a like kind can be enacted to protect the use of a restrictive practice such as detention in the proper circumstances. Such a legislative provision might take this form.

- (i) It is lawful for a service provider in the course of providing disability services to a person with a disability to use a restrictive practice in respect of such person, which restrictive practice might otherwise constitute an offence under section 355 of the Criminal Code, provided that the use of the restrictive practice is on the balance of probabilities reasonably necessary to protect that person or any other person from the risk of injury or harm.
- (ii) For the purpose of the application of these sections, the term "restrictive practice" shall have the meaning given in this Act.

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The terms “service provider”, “disability services” and “disability” already defined in Sections 11, 12 and 13 of *Disability Services Act 2006*. Both suggested provisions should be included in that Act.

The advantages of postponing the commencement of the key legislative package until the infrastructure is in place and in the interim providing defences for the use of restrictive practices based on “reasonable necessity” are seen to be:-

- A commitment to the fundamental human rights issues inherent in an express prohibition upon the use of restrictive practices unless independently approved as part of a positive behaviour support plan;
- The period of postponement during which appropriate publicity to the community and the sector can assist in preparing the way for a cultural change of practices and the development of a new mindset;
- In the interim addressing the legal issues inherent in the Code provisions and the use of restrictive practices and giving short term protection to those cases where justification is available on the basis of reasonable necessity. This in itself will be instrumental in preparing the sector in addressing and managing change.

One can be confident that the Director of Prosecutions will not present indictments in those cases where there are reasonable grounds for a defence. It will only be in those cases where offences are committed and where there has been a total disregard of the circumstances and the rights of the person that the Director will pursue the offender. This in itself will be a salutary reminder to those who might be inclined to disregard matters of fundamental principle in the care and support of persons with intellectual disability and challenging behaviour.

### Option B

This option has 4 main features:-

- It seeks to address the status quo by requiring each carer and service provider who currently employs or has in place a restrictive practice to develop a positive behaviour support plan for the person.
- Application for approval of the plan would be made to GAAT.
- The full implementation of this process would be delayed for a period of 12 months during which period there would be an amnesty in place during which time no action would be taken against any person who on reasonable grounds employed a restrictive practice.
- During the period of 12 months DSQ would conduct an awareness/publicity campaign designed to educate the public generally and carers and service providers in particular about issues relating to the use of restrictive practices and the requirements of the long term legislation.

### Advantages

- The process of facilitation by DSQ during the 12 months period can usefully better educate and prepare carers/service providers to modify or remedy any undesirable existing practices and to accept the use of such practices which restrict the life of the person only as a last resort;
- Those who act reasonably would avoid prosecution.

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### Disadvantages

- There will be concern on the part of family carers and small NGOs who have limited funds to employ whatever professional assistance is required to formulate a positive behaviour support plan.
- Any developed plan will have its limitations and may not be valid in the absence of comprehensive assessment. To obtain a valid assessment is probably beyond the capacity of most carers/service providers.
- To legislate the terms of any amnesty will be a challenge for even the most competent parliamentary draftsman.
- Public criticism may attend the provision for an amnesty as an attempt to protect the present use of restrictive practices.
- Public criticism may attend any DSQ facilitation of issues relating to the use of restrictive practices because DSQ itself is a service provider and has itself employed restrictive practices.

### Option C

This option has 3 main features:-

- The immediate implementation of an interim scheme to operate for 2 years or until the long term legislation is proclaimed.
- The process of immediate plan development and plan approval.
- Since the GAAT will have insufficient time and resources to respond immediately to a significant but unknown, increase in its work load, the interim approving authority will be, say, the Director-General of DSQ who will be required to consult with any one of a panel of professional experts appointed by the Minister and experienced in behavioural management issues, before granting approval or otherwise.

### Advantages

- This option provides for an immediate response to the use of restrictive practices.
- It requires carers/service providers to immediately address their use of such practices.
- It may cause carers/service providers to immediately re-assess their use of the practices and decide whether to continue their use and seek approval or to discontinue such practices.
- It provides for the development of a plan if the practices are sought to be continued.

### Disadvantages

- Those carers and NGOs which are not well resourced may well seek to avoid any response to an immediate requirement that they themselves attempt plan development or that they engage professional assistance.
- Any plan development which may involve the use of restrictive practices will necessarily have to occur generally without adequate assessment or only with an inadequate one.
- Immediate implementation may be seen to give rise to hardship issues for many and this may give the opportunity for public criticism.
- A proposal for approval of a plan in the immediate future may be seen to be unduly harsh on family and small NGO carers, given their long use of such practices in the past when providing reasonable care, who now have to immediately change their pattern of care. Some may make the attempt; many may not.
- The approval decision making may be seen to lack independence particularly in relation to approvals sought by DSQ itself as a service provider.

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### **Commentary**

The primary concern is whether, given the fact that the long term legislation cannot be made to operate immediately because of the required delay in implementing key functions which are a necessary part of it, some interim scheme can sensibly be implemented on a short term basis.

What is proposed as the permanent legislative scheme governing the use of restrictive practices in Queensland represents a somewhat dramatic change of culture. Restrictive practices has been freely used by all sections of the disability sector for a variety of purposes and in a wide range of circumstances for a very long time. The use of such practices has never been seriously questioned until in recent years. Perhaps the Mental Health legislation was always seen to provide lawful coercion in circumstances of emergency and that changed when intellectual disability was excluded from the operation of the *Mental Health Act* in 2000.

Also the greater emphasis on the protection of the individual's human rights and the greater recognition of the rights of persons with intellectual disability, which have more recently acquired a higher profile in the public mind, have caused closer attention to be given to the issue. Public Inquiry exposures and media coverage, such as occurred with the CJC Stewart Inquiry in 1994/5 no doubt hastened the need to more closely scrutinise the way in which persons with intellectual disability with challenging behaviour were cared for and their behaviours managed.

Much of the official and public apathy about the past use of restrictive practices seems to have been driven by resort to irrelevant but nonetheless palatable legal clichés such as “the doctrine of necessity”. Because it was necessary to protect others from the challenging behaviour of the disabled person, it was acceptable to restrain or detain, not only in the best interests of the person with intellectual disability but also of the community.

One can easily recognise in relatively recent times the poor public perception or image concerning such persons and the intensely negative response given if a person was the victim of unprovoked aggression on the part of a person with intellectual disability.

The notion that it was acceptable on the alleged ground of “necessity” to detain or restrain such a person seems to have been widely accepted. In Queensland in 1992 the Disability Services Act spelt out the need to resort to fundamental human rights principles in service delivery to persons with “disability”. One cannot be confident however that that had an immediate impact or was given universal acceptance or whether it has, even now.

In any event it is now clear that a significant cultural change in the public mindset must occur if the rights of persons with intellectual disability are to be recognised and respected. To give only lip service is to endorse a less than acceptable standard and in light of the legislative intent manifest in the *Disability Services Act* 2006 and in the Ministerial Service Standards published by the present Minister, to give lip service only has to be totally rejected.

That is why the legislative scheme proposed here has to confront the residue of any cultural mindset that the unrestricted use of coercive practices can be justified at will or on a whim. It does that by declaring that any use of a restrictive practice is unlawful unless its use is approved for use subject to clear guidelines and principles.

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Such a legislative proposal will obtain majority acceptance if the need for it is supported by government and presented to the public persuasively and effectively. A serious question arises as to whether such a legislative proposal is best delivered, as it were, overnight or in the course of or after wider community consultation.

There are compelling reasons for supporting the requirement of comprehensive individual assessment before considering the introduction of any form of restrictive practice. This Report has raised serious doubts about the validity and utility of some of the behaviour management plans which purport now to be in place. The need for quality outcomes in this area of professional interest can be met only by the introduction of an integrated process of Positive Behaviour Support for individuals such as this Report proposes, and that has an initial requirement for proper assessment.

Therefore any interim scheme which requires the provision of a plan must be seen to be less than effective if not supported by a system of assessment of the kind envisaged here. In individual cases it may be able to occur; one can hypothesise that in the great majority of cases it cannot in the short time and will not. Therefore can one justify the implementation in the interim of a less than acceptable scheme solely to address the status quo and the cases which will emerge in the interim? Individual views will vary. In my view whilst the matter is one of major concern and the maintenance of the status quo generally unacceptable, the preferable long term outcome can best be achieved by enacting the legislation in its most desirable form and deferring its introduction only for so long as to permit of its effective implementation. The necessary lead time can be well occupied with better preparing the public mind and better permitting the sector to best adjust its service delivery and practices in anticipation of the legislation.

Any option for immediate implementation which requires an amnesty-type arrangement has little to commend it. To decide not to apply the law either generally or in individual cases is a grave step and can give rise to disturbing inconsistencies. The Criminal Code provisions relating to the restriction or deprivation of a persons liberty are general provisions of the law presently in operation. A special law which relates to persons with intellectual disability if enacted, should either be implemented upon enactment or deferred only for good reason. To make an amnesty-like declaration that an enacted law which is in force will not be applied can only be justified in special circumstances. In all of the relevant circumstances it is difficult to justify such a course here. If the amnesty is to be made subject to conditions then the wit of any draftsman will be tested in ensuring consistency in its application.

In my view, Option A, is the preferred Option.

### **The Mental Health Act 2000 – Proposed Amendments**

Major problems confront both the Mental Health Court and mental health services within Queensland Health because, although the Mental Health Court has jurisdiction to determine questions of unsoundness of mind and fitness to plead in respect of persons with intellectual disability who are alleged to have committed an indictable offence, the Court if it makes a forensic order, is limited to ordering detention in a “stated authorised mental health service for involuntary treatment or care” (S288). The person with intellectual disability may not have a diagnosable mental illness or may be the subject of a dual diagnosis.

It is beyond argument that a person with intellectual disability who has not been diagnosed with a mental illness will be inappropriately housed or accommodated in a mental health service whose core function is the treatment of mental illness. The fundamental difference between mental illness and intellectual disability has been

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emphasised elsewhere in this Report. Not surprisingly the need for a mental health service to have to accommodate, care for and manage in a mental health service a person with intellectual disability but not a mental illness has been the cause of significant inter-departmental dialogue and tension. That in itself should be the cause for re-assessment. But there are more cogent and fundamental reasons for accepting that the statutory process which limits the discretion of the Mental Health Court and consequently causes major professional difficulties for a mental health service, is not sustainable. A mental health service has nothing to offer a person who does not have a mental illness; the serious behavioural issues which so often attend intellectual disability are not likely to be addressed within an irrelevant discipline, the person with the intellectual disability is likely to be disadvantaged and the behaviours likely to escalate. The persons there with mental illness are also disadvantaged because their proper care treatment is likely to be distracted or interrupted by the disturbed behaviour of a person with intellectual disability. Those with the relevant expertise could easily list many others.

The substance of this Report has been directed at the establishment within DSQ of a service modality which is directed specifically at addressing the behavioural issues of each individual person and which is underpinned by the delivery of specialist services – comprehensive assessment, individualised positive behaviour support planning, coordinated and well managed intervention in the appropriate environment by skilled carers. The service objective to be in the pursuit of excellence is the diminution and/or elimination of the behaviour which in so many more cases is likely to bring the person into contact with the criminal justice system.

The service delivery response for the cohort of clients has to be available to all with intellectual disability, wherever they live. Those who come to the Mental Health Court are no exception. This service response has much to offer them. Because its core feature is Positive Behaviour Support as expressed in the literature and successfully pursued elsewhere, this proposed DSQ model has so much more to offer the person than does a mental health service.

Sheer logic, the welfare of the individual and respect for the human rights of the person and/or the Court require that the Mental Health Court have the power to divert the person with intellectual disability who is not mentally ill into a more suitable treatment regime and to where the person can be more appropriately housed having regard to the persons unmet needs. It follows that DSQ should have available the appropriate accommodation which meets the expectations of the Court and any concerns it may have in relation to any unacceptable risk to the person or to others.

Questions concerning those with dual diagnosis necessarily impinge on the interface between DSQ and mental health services.

This Report in Chapter 4 advocates the building of a new and collaborative relationship. In respect of the Assessment component of the service model proposed. There is a primary need for the specialist services of both agencies to interact for the purposes of assessment. A fortiori is this the case in relation to those with both mental illness and intellectual disability. Any such person who is the concern of the Mental Health Court should obviously become the subject of effective planning in relation to his/her treatment and/or support not only in the best interests of the individual but also for better informing the Court as to the relevant options available to the Court in the making of a forensic order. This of course is only possible if the proposals for more professional service delivery are put in place and supported by the development of the necessary and appropriate infrastructure.

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The same matters are relevant in relation to “limited community treatment” provided for in the *Mental Health Act 2000*.

I need to emphasise that it is a matter for the Honourable the Minister for Health, whose portfolio responsibilities comprehend the MHA, as to whether this Act should be amended in line with the above framework. My purpose is to ensure that the Honourable the Minister for Disability Services is aware of the current problems in the Mental Health Court for persons with intellectual disability and which impact so significantly on mental health services.

I have had very cordial and useful discussions with the Director of Mental Health and I believe we are in general agreement with the contents of this part of the Report.

To adopt this broad proposal for appropriate amendment of the MHA 2000 in relation to the making of a forensic order, there will of course be the need for consequential amendments such as providing to the MHRT the power to review and to make appropriate decisions in the light of the service delivery and accommodation options to persons with intellectual disability which this Report recommends.

I respectfully suggest that this matter might, with advantage, be the subject of consultation between the relevant Ministers.

### **Other Legislation – Victoria & New Zealand**

The VLRC in 2003 reviewed the Victorian Law relating to the provision of secure care and the use of restrictive practices in the provision of services to persons with intellectual disability / cognitive impairment. It recognised the fundamental concern which must attach to any legal system or legislative structure which allows persons with intellectual disability to be detained, as if in prison, or otherwise have their freedom restricted on the basis of what they might do rather than being incarcerated for what they have done. In the latter case the restriction is essentially punitive. In the case of the person who is detained because of what he/she might do, the restriction is likewise punitive; a matter about which the High Court of Australia has expressed its concerns.

In recent years, therefore, legislatures have sought to construct statutory schemes which recognise this concern but which at the same time take account of the risk to others if the person's conduct or behaviour is not appropriately contained or managed.

The legislative schemes proposed by this Report is closely modelled on the recent Victorian experience although there are differences. Victoria, unlike other Australian States, had enacted legislation in 1986 and 1991 in respect of services to persons with an intellectual disability as distinct from those for persons with mental illness. The 1986 Act purported to deal with persons on the basis that services were delivered on a voluntary basis although that legislation contained provisions for the use of restrictive practices and seclusion subject to certain controls. Detention, as an ongoing restriction of liberty was not lawfully provided for. The notion that a person had lawfully consented to the use of a restrictive practice, such as seclusion or for example, chemical constraint, came to be recognised as something of a legal fiction and in 2003 there was a perceived need for change. Victoria already had some facilities of an institutional nature where “difficult” clients were housed and the VLRC report and the subsequent legislation seemingly sought to address the reality of the treatment regimes then in place at the same time recognising the need to give due weight to the fundamental rights of the person and to the more developed service options and practices recognised in more recent times in the care and support of persons with intellectual disability and challenging behaviour.

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Victoria drew a distinction between “detention” and “restrictive practices”. Detention refers to the detention of a person in a “prescribed facility” that will reduce the risk that that person will seriously harm others. Restrictive practices include mechanical and chemical constraint, seclusion, physical constraint and “locking doors” to prevent a person from leaving a facility. With respect there is a certain artificiality in distinguishing between “detention” and what might qualify as a “restrictive practice” and the use of the latter is said to be relevant for the purpose only of preventing persons from harming themselves or other residents where they are living or from injuring their carers. Hence the Victorian Act proposes a legislative scheme for detention in a prescribed facility and a different scheme for the use of restrictive practices in the course of the person receiving services under the disability legislation.

In this context one has to recognise the considerable developments which have in recent years advanced the nature and content of behavioural support services for the proper care of persons with intellectual disability. Whilst there is a general recognition that a very small minority of persons will be regarded as extremely difficult to manage and that a more coercive form of restrictive practice will be required, nonetheless that small group should remain subject to positive behaviour support strategies and planning in the same way as others whose behaviour, although challenging, is less problematic. Positive behaviour support has as its objective the elimination or diminution of the severely challenging conduct which is often a disturbing characteristic of intellectual disability or cognitive impairment. In short this approach is “positive” and remains so in the face of challenging situations. There is a significant risk that overly and unnecessary coercive practices might more readily be resorted to and negatively rather than persisting with a more positive approach.

Further the research is clearly against the establishment of institutionalised accommodation facilities and structures which congregate people, albeit in a more cosmetically attractive “facility” or “structured environment”. Such facilities are anti therapeutic and clash with the core elements of positive behaviour support which is adopted as the required service option for the cohort.

Furthermore not one of the “high end” cases visited in the course of this project can be seen to provide justification for a special regime of “detention” in a prescribed facility. Each is living in a home either alone or with another person. One of the higher profile cases will in the near future be accommodated in new accommodation in a rural environment in Queensland supported by well trained and experienced carers. Another presently lives in a small home in a suburban street also with experienced and competent support.

One recognises the worth of the Victorian experience. At the same time it is important to construct the appropriate service and legislative options for the “here and now” in this State and to ensure that the responses, both in terms of service delivery and legislatively, are realistic and relevant. For that reason the proposed legislative response which is modelled on the Victorian legislation, is significantly different from but not inconsistent in terms of inherent principle and content with recently enacted Victorian legislation.

In 2003 the New Zealand Parliament enacted 2 separate pieces of legislation, the *Intellectual Disability (Compulsory Care and Rehabilitation) Act* and the *Criminal Procedure (Mentally Impaired Persons) Act*.

The Compulsory Care and Rehabilitation Act is designed for the compulsory care and rehabilitation of those who have an intellectual disability and who have been charged

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with or convicted of a criminal offence. There are two ways for a person to become subject to this Act; either by an order of the Court in the course of a criminal proceeding or by changing the regime applicable to the person from either the Corrections Act or the *Mental Health (Compulsory Assessment and Treatment) Act 1992* to the regime provided for under the Compulsory Care and Rehabilitation Act.

The purposes of this Act are threefold:-

- To give to Courts compulsory care and rehabilitation options for persons who have an intellectual disability and who are charged with or convicted of an offence;
- To recognise and safeguard the special rights of persons subject to the Act; and
- To provide for the appropriate risk of different levels of care for individuals who whilst no longer subject to criminal justice system, remain subject to this Act.

The *Criminal Procedure (Mentally Impaired Persons) Act 2003* is akin to the Queensland Mental Health Act provisions which more specifically invests in the Mental Health Court, the jurisdiction to determine fitness for trial and unsoundness of mind.

Elsewhere in this Report reference is made to the present difficulties for the Mental Health Court in making a forensic order in respect of a person with intellectual disability but who does not have a mental illness and for the Magistrates Court in deciding questions relating to bail. In Chapter 5 the Report recommends the development of accommodation more suitably designed to provide more secure care for those whose challenging behaviour may put either the person or others at risk. The Report adopts the expressed concerns of the Court and the MHRT that a mental health service or prison is an inappropriate option for a person with an intellectual disability but who is unfit for trial or found to be of unsound mind when the offence was committed.

The Mentally Impaired Persons Act (NZ) therefore addresses the same issues which in Queensland are dealt with by the Mental Health Court and if the accommodation options recommended by this Report are adopted the practical outcomes will be the same as those operating in NZ as a consequence of its legislation. This will necessarily involve amendments to the *Mental Health Act 2000*.

Further reference should be made to the Compulsory Care and Rehabilitation Act (NZ). One of the purposes of that Act is to vest in the Family Court (NZ) the jurisdiction to order the transfer of a person from the Corrections system to a facility or regime provided for under the NZ Act. In this Report it is stated that one can find no sound justification for DSQ to establish a discrete corrections facility for those with intellectual disability who are convicted of an offence. The assumption is made in the case of such persons that the person was fit to plead and was not entitled to rely on the unsoundness of mind provisions of the Criminal Code. Accordingly it is said that imprisonment, if imposed, should follow the normal course and that it remained the statutory obligation of the Department of Corrective Services to appropriately house and care for such persons. Whilst there remains considerable scope for collaboration between the two departments in ensuring that the person is humanely contained given the fact that the person has an intellectual disability, considerable legislative and administrative change in Queensland would be required for the establishment of a special and separate corrections regime. Clearly the consideration of such a regime is outside the Terms of Reference for this project.

It should be noted however that the NZ Compulsory Care and Rehabilitation Act requires that those persons dealt with under that Act have to be subject to “needs assessments”

and the development of “Care and rehabilitation plans”. It is a central feature of this Report that comprehensive assessment and the development of a positive behaviour support plan for the person with challenging behaviour is an essential requirement of service delivery to this client group. This Report also recommends that the Mental Health Court and the Magistrates Court be better resourced in the exercise of their respective jurisdictions in respect of persons with intellectual disability only, by DSQ providing more appropriate accommodation options for the relevant group. That option, as this Report asserts, is part only of a process of individualised assessment of the needs of the person and the development of an appropriate positive behaviour support plan.

There is an obvious similarity in direction between this piece of NZ legislation and what this Report proposes.

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**CHAPTER 8****CONCLUSION**

The keynote of this Report is reform, renewal and regeneration; that is, the reform of present, unsustainable and unproductive processes which have produced less than acceptable and inadequate outcomes; a process of renewal which revisits existing programs and structures and reshapes them into a new paradigm of service delivery which is driven, maintained and to be evaluated only by achievement and excellence; a regeneration of effort which is better and more relevantly focussed and in which there is real content in those who purport to make or influence decisions in the best interests of the individual person but which now so readily forms part of a matrix of bureaucratic decision making which is stale and predictable and which at best produces only questionable outcomes.

The core of this Report is unmistakably the need to have the capacity to respond properly to the unmet needs of each individual person who falls within its purview. Its response is undeniably targeted, that is targeted at individual human persons, who have a name and whose needs have so far not been relevantly identified or met. It is not to be understood as responding to a target group to which has been added just another tag such as “the Cohort”. Regrettably the language and the relevant vocabulary is likely to mislead or to fail adequately to reflect real intention.

There should not be the slightest hint of equivocation about what this Report recommends and what it asserts to be the desired outcomes – no, the urgent unambiguous and essentially necessary outcomes which have to be pursued in the pursuit of excellence, rather than perpetuate a systemic modality which is much less than effective, too often the subject of valid criticism by persons whose views command respect and which is horrendously expensive.

The needs of each individual person with a disability which are still unmet and which negatively impact on that person’s life every day have to be met and they will remain unmet unless there is urgent reform, renewal and regeneration of effort which is the single and most influential driver of what is said here – nothing else!

The proposed service response in the Report may not be perfection; any process of reform seldom is. But if it is principled and soundly based and its proposals legitimate and relevant and are seen to be responsive to unmet human needs, then it is entitled to respect and due consideration. Nor should its worth be tested only on the basis that it is too narrow or too focussed because it deals only with what is seen to be a specific problem and relevant only to a particular “cohort”.

In the Introduction to this Report it is noted that the specific problems had to be addressed in a wider context of the services delivered across the entire population of those fellow members of our community with intellectual disability whether their behaviour is challenging or not. That means that the relationship between the response proposals here and the total matrix of services to the whole sector cannot be ignored. To reform, renew and to regenerate effort in respect of one part of the whole necessarily requires reassessment of the totality. If the existing systems and processes have so far produced less than optimal outcomes or, at best, questionable ones only, and this is undeniable in respect of this “cohort”, then the total effort will require re-evaluation. Nor should one be distracted from this course by a blind adherence to the past nor by assuming entrenched positions in which self-justification is the dominant mindset and which rejects change as too threatening.

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This Report is sensitive to such issues but in its final form its central intent is to ensure as far as possible that the needs of individual persons with intellectual disability and disturbed behaviour are met, not by “common programmatic templates” but by reformed processes which focus on the individual and which respond effectively to individual needs.

In that event excellence is achievable. Without it, mediocrity will become entrenched.

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## **REPORTS**

During the course of the project various reports relevant to the issue came to light from a variety of sources. They are identified below:-

1. The Joachim Documents
  - Report on Visits to personnel and facilities providing services for people with an Intellectual Handicap who have challenging behaviours: Joachim - 14 April 1989.
  - An Alternative Approach to reducing Challenging behaviours: A model for the Community: Attwood - April 1989.
  - Survey of Challenging Behaviour: Joachim - July 1989.
  - Psychiatric clinic in Brisbane for people with an Intellectual Disability: Attwood - May 1990.
  - Letter Deputy Director of Psychiatric Services to Mr R. Joachim, Executive Director (Disability Support) Department of Family Services 20 - February 1991.
  - Letter Mr R. Joachim to Deputy Director of Psychiatric services - 18 April 1991.
2. Discussion Paper: Managing Individuals with Seriously Harmful Behaviours – Department of Families, Youth and Community Care (DFYCC) – May 1998.
3. Managing and Supporting Individuals with Extremely Complex and Dangerous Behaviour – A draft report prepared by Ipswich and South West Queensland Region, Disability Services Queensland – January 2001.  
Cessation of DSQ/QH Pilot Assessment Service Proposal Project – Project Report – January 2004.
4. Lennox and Edwards: Lessons from the Labyrinth: 2001, Report to Disability Services Queensland.  
Lennox and Edwards: Sand in Society’s Machine: Models of Service Provision to Adults with an Intellectual Disability with Co-existing Mental illness (Dual Diagnosis): August 2002. Report on Project conducted jointly by Queensland Health, Disability Services Queensland and Housing Queensland.  
Lennox and Edwards: “Not on the Same Page”: Report of the Dual Diagnosis Project 2002.

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## **SUBMISSIONS RECEIVED**

ACROD

Australian Workers Union

Autism Queensland

Brain Injury Association of Qld. Inc.

Brisbane North Lifestyle Support Service

Child and Youth Forensic Outreach Service

Community Resource Unit Inc

Community Visitor Program

Disability Council of Queensland (Fitzroy & Central Western Qld RDC & Regional & Greater Brisbane)

Disability Law Project (Toowoomba)

Endeavour Foundation

Legal Aid Queensland

Mental Health Review Tribunal

Office of the Adult Guardian

Office of the Public Advocate (Draft only)

QCIDD

Queensland Advocacy Inc

Queensland Disability Housing Coalition

Queensland Health

Queenslanders with Disability Network

Ms Alice Corcoran

Ms Nikki Edwards

Ms Tanya Hunt

Mr Peter Neame

## CONSULTATION

<u>DATE</u>	<u>PEOPLE CONSULTED/ORGANISATION</u>
26.04.06	Paul Grevell South Coast Region, DSQ
26.04.06	Evan Klatt, Ken Gall & Carl Patterson Accommodation, Support & Respite Services Directorate, DSQ
27.04.06	Paula Scully Office of the Adult Guardian
28.04.06	Michelle Howard Office of the Public Advocate
28.04.06	Christine Manttan, John Smith & Amanda Ryder Brisbane West, AS&RS (Visit to Basil Stafford Site)
02.05.06	Carol Beml Moreton Region, DSQ David Makinson, Darlene Murphy & RCO staff Moreton Region, DSQ (Site visit)  Peter Elden & John van Lent AWU
03.05.06	Pauline Davis Brisbane Region, DSQ
04.05.06	Samantha Hassall AS&RS Maryborough Office, DSQ
04.05.06	Keith Ballin & DSQ staff member AWU Maryborough Office
04.05.06	Pam Steele-Wareham Central Qld. and Wide Bay Region, DSQ
04.05.06	Andrew Thomas & Alicia Birch Bay Support Service, Hervey Bay (Site visit)
09.05.06	Viki Bebington AS&RS, Loganlea (Site visit)
09.05.06	Damion Lipman AS&RS, Gold Coast (Site visit)
11.05.06	Greg Neilson, Dr Nicki Stephens & Christine Child & other staff Baillie Henderson Hospital, Toowoomba Queensland Health (Site visit)
11.05.06	Peter Collins AS&RS Toowoomba (Site visit)
11.05.06	Marie New Darling Downs/ SW Qld Region
12.05.06	Hilary Martin, Charlie Ryan House With No Steps, Morayfield (Site visit)
15.05.06	Justice Holmes Mental Health Court
16.05.06	Raeleen Bougoure Fitzroy & Central West Region, DSQ
16.05.06	Debbie Bowen Stanwell Rural Property (Site visit)
16.05.06	Theresa Brogan AS&RS Rockhampton (Site visit)

<b><u>DATE</u></b>	<b><u>PEOPLE CONSULTED/ORGANISATION</u></b>
18.05.06	Dr Terry Steadman, Kevin Fjeldsoe, Dr Paul White, Dr Pam Van de Hoff, Irene Francisco & Jenny Hearle The Park – Centre for Mental Health Queensland Health (Site visit)
18.05.06	Denise Alexander House With No Steps, Wacol (Site visit)
19.05.06	Valmae Rose ACROD Paige Armstrong Endeavour
22.05.06	Janet Benson, Catherine Baldwin, Paul Coonan, Katherine Saffioti, Liz Ainsworth, Sharon Kenyon, Sue Simpson & John Wright Department of Housing
23.05.06	John Dickinson Brain Injury Association of Queensland Inc.
23.05.06	Justice Ann Lyons GAAT
24.05.06	Assoc. Prof. Nicholas Lennox & Dr Madonna Tucker QCIDD
25.05.06	Jeff Cheverton Qld. Alliance of Mental Illness and Psychiatric Disability
25.05.06	Kevin Spiller, Katie Eagle, Michelle Moss, Michael Hutchinson & Paige Armstrong Endeavour Foundation
26.05.06	DSQ psychologists at their regular forum Ipswich FECS
26.05.06	Penny Beeston, Glenda Watkins & Liz Packer Autism Queensland
29.05.06	Kevin Cocks QAI
29.05.06	Paul Larcombe & Leonie Saunders Disability Council of Queensland
30.05.06	Justice Ann Lyons, Ron Joachim, Susan Gardiner, Prof. Adrian Ashman, Elissa Morriss, Dr Janene Suttee, Jim Cockerill Guardianship and Administration Tribunal
31.05.06	Valmae Rose ACROD Bruce Milligan, Cerebral Palsy League Mark Hanley & Donna Harris, Spinal Injury Association Prof. Lesley Chenoweth, Griffith University Snr. Sgt. Glenn Allen, Queensland Police Service
31.05.06	Prof. Tony Holland Chair in Learning Disabilities Departmental Psychiatry University of Cambridge
01.06.06	Pat Cartwright Community Visitors Program
01.06.06	Dianne Pendergrast, Kay McInnes, Susan Kerr, Louise Logan, Gerry Cassimatis, Susan Masotti, Therese Chin, Lara King, Robin Arthur & Alison Wolff Office of the Adult Guardian

02.06.06	Parents of Client
02.06.06	Michelle Howard, Lindsay Irons, Beverley Funnell & Deborah Barrett Office of the Public Advocate
05.06.06	Judge Irwin Chief Magistrate
05.06.06	Julian Porter, QAI Di Toohey, SUFY
06.06.06	Robyn Greatrex Moreton Region, DSQ
07.06.06	Parents of Client
08.06.06	Greg McKay & Ann Cross Uniting Care Office
08.06.06	Parents of Client
13.06.06	Helen Ferguson, Peter Tones & Susan Brady Disability Strategy Project, Policy Directorate, DSQ
14.06.06	Dan Toombs, Disability Law Project, Toowoomba
15.06.06	Paul Grevell South Coast Region, DSQ
16.06.06	Kathy Dunning Programs & C&SS Directorate, DSQ
16.06.06	Michael Keates & Lyn Farrell Community & Specialist Services Directorate, DSQ Carl Patterson AS&RS Directorate, DSQ
19.06.06	Dr Paul White The Park – Centre for Mental Health Queensland Health
20.06.06	Jane Sherwin, Linda Cheveller & Mike Duggan Community Resource Unit
20.06.06	Roy Beak and a group of parents Brisbane North Lifestyle Support Group
22.06.06	Madonna Cuthbert, Dr Aaron Groves, Jeremy Kirby & Katherine Braddock-Hatfield Queensland Health
22.06.06	Ann Greer
23.06.06	Dr Gary Lavigna Institute for Applied Behavior Analysis Los Angeles, USA
23.06.06	Bob Seamer Undertaking a review of DSQ Work place Breaches and Misconduct Management System
27.06.06	Mike Duggan & Karen Swift Qld Disability Housing Coalition
29.06.06	Brendan Butler, Cheryl Furner & Katherine Braddock-Hatfield Review of Mental Health Act
30.06.06	Ray Sutherland Assistant Director-General, DSQ
05.07.06	Kris Lumsden RISC
06.07.06	Niki Edwards (QCMHR)

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07.07.06	Bernadette McDermott & Dr Ness McVie Child & Youth Forensic Outreach Service Queensland Health
10.07.06	Gill Parmenter Director, Child Safety, DSQ
19.07.06	Professor Eric Emerson Professor of Disability & Health Research Institute for Health Research Lancaster University
20.07.06	Group of parents, Cleveland
25.07.06	Assoc. Professor Nick Lennox QCIDD