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**Evaluation report on the
Developmental Psychiatry Clinic: A Partnership between
The Children's Hospital at Westmead and Statewide Behaviour
Intervention Service (ADHC)**

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Evaluation report on the Developmental Psychiatry Clinic

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Section 1: Introduction

Arising from a Developmental Psychiatry Partnership Agreement (“DP Partnership”), the Developmental Psychiatry Clinic service (“DP Clinic”) is a collaboration primarily between the Developmental Psychiatry Team (“DP Team”), Department of Psychological Medicine of the Children’s Hospital Westmead (CHW), and the Children’s Team, Statewide Behaviour Intervention Service (SBIS), Ageing Disability and Home Care (ADHC), NSW Family and Community Services. There is also representation from the NSW Department of Education and Communities (DEC). The DP Partnership was initially based on good will, and later formalised under a MoU. There is no funding associated with the agreement, and other initiatives have received start-up funding from a range of service providers. The DP Clinic does not have any funding specifically for its operation.

The DP Clinic service provides tertiary consultation to paediatricians, psychiatrists and other practitioners regarding children and adolescents with intellectual disability and mental health conditions. The DP Clinic holds 10 extended consultations per year, provided by a multi-agency, multi-disciplinary group and offers professionals an opportunity to discuss concerns they have about the clinical and systemic progress of a case. It also provides the opportunity to consider a range of alternate hypotheses about behavioural difficulties and to explore options for intervention. The family, child/adolescent and local service providers are invited to attend.

The DP Clinic has been providing a service since 2000 and many of its original contributors continue to participate in monthly clinics. The DP Clinic is known for working with children and adolescents with intellectual disability and autism spectrum disorder who required highly specialised clinical case management. The DP Clinic’s key activity is the monthly joint case conference where a complex case referred to the DP Clinic is reviewed in a multi-disciplinary case formulation with the “core panel”.

Several projects have also arisen from the collaboration that was initiated through the DP Clinic (now formalised through the DP Partnership Agreement). There are different levels of involvement from the various partners in the related projects. Figure 1 outlines the DP Partnership and related activities.

These projects have been;

- The School-Link Initiative, including collaboration on the Group Stepping Stones Parent Training (SSP) Research Project, the School-Link Newsletter and Website, and presentations at School-Link Conferences in metro and regional centres. The initiative includes a cross agency steering group and cross agency editorial group for the CHW School-Link Newsletter.
- The Training Curriculum Project (2007-2010), developed a framework of core clinical interventions and an evaluated two-day seminar that had a significant impact on the knowledge, skills and attitudes of over five hundred multidisciplinary

professionals that attended the five training events conducted in 2009-2010. The project also included the publication of the text, *Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities* (Dossetor, White & Whatson, 2011). All core panel DP Clinic members contributed to the project as authors, peer reviewers, seminar presenters and/or facilitators at training events.

- The development, delivery, and evaluation of Emotions-Based Social Skills Training (EBSST). This includes treatment programs, researched since 2004, that aim to promote the well-being of young people with Autism Spectrum Disorders (ASD) and prevent the onset of mental health concerns. EBSST has been developed and delivered in NSW Department of Education and Communities (DEC) schools for children with high functioning Autism Spectrum Disorders, Autism Spectrum Disorder and mild intellectual disability, and adolescents with intellectual disability and emotional and behavioural concerns. EBSST curricula have been developed for children, parents, teachers as well as EBSST professional training workshops for facilitators. Also arising from the collaboration is networking and support between DP Clinic team members across the host organisations and ADHC.

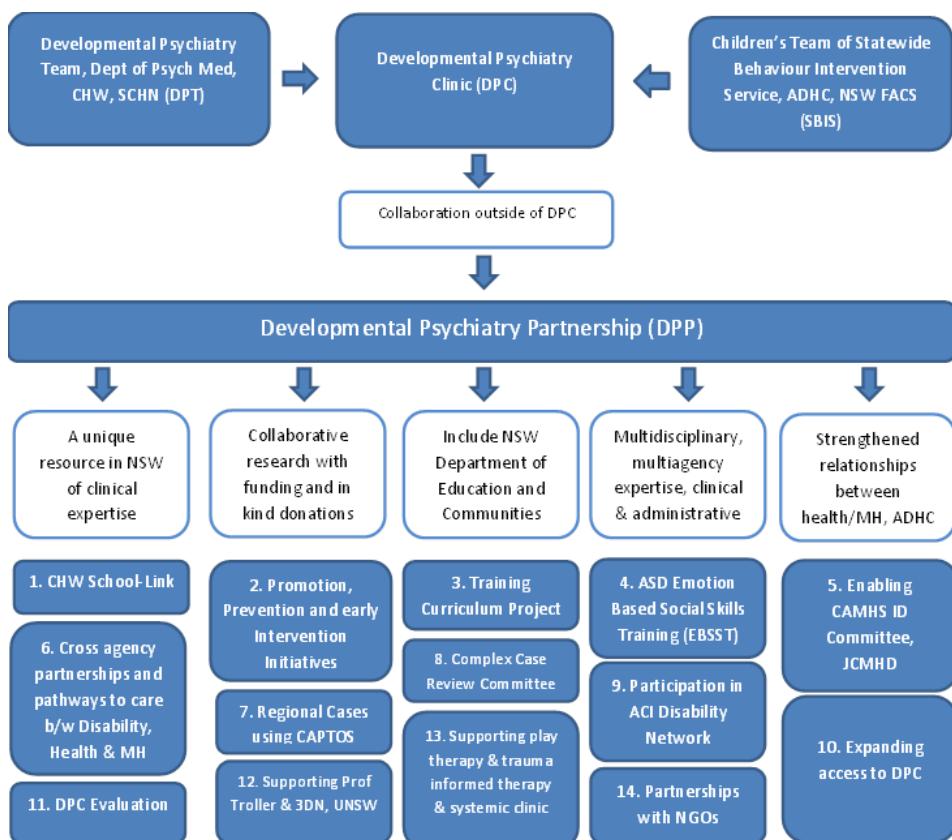


Figure 1: An overview of the DP Partnership and related activities

The CHW DP Team

Specifically the members of the DP Team that support children and young people with Autism Spectrum Disorder (ASD) and Intellectual Disability (ID) comprises a psychiatrist, two clinical psychologists, a part-time occupational therapist, one session a week for a general paediatrician and half a paediatric registrar. There is support from other members of the team including a cross cultural consultant, a pharmacist and another psychiatrist. The core team members also have other significant responsibilities and contribute approximately half their time to ASD and ID cases. They are also committed to on-call responsibilities for the Emergency Department and consultation to the mental health ward and wider paediatric hospital and regular sessions to the CAPTOS (telepsychiatry service). Individually they also carry significant leadership and administrative responsibilities, highly valued subspecialty clinical research (including EBSST), teaching and support the CHW School-Link Project.

The ASD and ID DP Team members see approximately 120 new ASD/ID cases a year. This includes 10 from the Cross Agency Partnership DP Clinic and approximately another 15 a year in which there is cross agency discussion or collaboration outside of the allocated clinics. Other cases are tertiary cases in severity and service usage and referred mainly by a network of experienced developmental or general paediatricians. Referrals are only accepted if the paediatrician will continue to provide the on-going case management. Although many of these are from Western Sydney, they include paediatricians from across the metropolitan area and regional NSW. There are approximately another 120 long term patients who keep returning to this subspecialty team for up to 10 years.

The SBIS Children's Team

The SBIS is a specialist service within the Clinical Innovation & Governance (CIG) Directorate of NSW Ageing Disability and Home Care (ADHC), Family and Community Services (FACS). SBIS provides person centred behaviour support to enable quality outcomes for people with disability across the state. SBIS also manages the Client Monitoring and Review System, the Therapeutic Brokerage Pool and the Practice Improvement Framework (see Fact Sheets available on the ADHC website).

SBIS provides support to people with disability and complex behaviour support needs, their families, those in their support networks, and associated support services (government and non-government). SBIS provides support to address behaviours of concern; plan within complex systems; decrease risk of placement breakdown; improve

health and well-being and increase capacity within the service system. SBIS does this through four main areas of work:

- Individual behaviour support (primary, secondary, and tertiary support)
- Information and training
- Research and development
- Systems consultation and review

The Children's team is one of four teams within SBIS, including the Adult team, the Specialist Training and Resource team, and the Client Monitoring and Review System.

Section 2: Review plan

The Centre for Disability Studies was approached by the DP Clinic to conduct a review of the services it delivers. The project plan outlined the objectives of the review to include:

- i. Explore the value and effectiveness of the DP Clinic to key referring agents, i.e. paediatricians, psychiatrists and ADHC Managers Behaviour Support
- ii. Examine the DP Clinic (its purpose, activities, structure and governance) by considering a range of factors, potentially including:
 - Leadership
 - Division of tasks (roles and responsibilities)
 - Multi-agency contributions
 - Multi-disciplinary contributions
 - Relationships – within the context of the DP Clinic and beyond
 - Lifespan of the DP Clinic; important milestones and evolution of the group
 - Ideas for maintenance and change
- iii. Underpin the above enquiries with an exploration of the literature specific to tertiary consultation models. What can be learned? What can this group contribute?
- iv. Make recommendations regarding how the Developmental Psychiatry Clinic could evolve to meet changing demands and priorities

Section 3: Approach - what we did

A series of interviews were conducted by the CDS team assigned to the project with members of the DP Clinic team, stakeholders and families who had benefited from the DP Clinic.

The CDS team was composed of:

- Prof. Patricia O'Brien
 - Professor of Disability Studies, University of Sydney and Director of CDS
- Assoc. Prof. Vivienne Riches

- Psychologist, CDS, and Clinical Associate Professor, University of Sydney
- Debbie Espiner
 - Principal Lecturer, School of Counselling, Human Services and Social Work, Faculty of Education, University of Auckland
- Samuel Arnold
 - Psychologist, CDS, and Research Affiliate and Doctoral Candidate, University of Sydney

The following people were interviewed over a three day period, with each interview typically an hour in length. Interview material was also verified and compared and contrasted with a series of documents relevant to the work of the DP Clinic (see Appendix B). To maintain anonymity, for some interviewees only the role or relationship of the interviewee with the DP Clinic is listed:

- Assoc. Prof. David Dossetor, Area Director of Mental Health, Children's Hospital at Westmead
- Lesley Whatson, Team Co-ordinator, ADHC Statewide Behaviour Intervention Service
- Jodie Caruana, Co-ordinator, CHW School Link
- Members of the ADHC Statewide Behaviour Intervention Service
- Two parents of DP Clinic patients
- Five Senior ADHC staff, including Executive Directors, Managers of Behaviour Support and Managers of Community Access
- Two members of the ADHC Regional Behavioural Intervention Teams
- Director of Psychological Services, Community Services
- Two allied health professionals from school settings
- A school teacher

A focus group was also conducted with 10 of the DP Clinic core panel members.

The questions asked in the interviews and focus group drew upon material from person centred and solution-focused approaches, and where time permitted, the Disability Service Standards. Questioning began by asking the interviewee to outline their role and the relationship or interaction with the DP Clinic. Interviewees were then generally asked:

- what was working or not working at the DP Clinic from their perspective
- what would happen if the DP Clinic would cease to exist
- what would happen if the DP Clinic could increase the services it had to offer
- were there any specific strategies the interviewee would recommend
- and then questions relating to the standards of
 - Rights
 - Participation and Inclusion
 - Individual Outcomes
 - Feedback and Complaints

- Service Access and
- Service Management.

The focus group discussion was also graphically recorded and its outcomes, which can be seen in Figure 2 of this report, have been incorporated into Section 4.

At the end of the three days of interviewing the three members of the evaluation team, following a consensus meeting, gave and discussed preliminary feedback to panel preliminary with A/ Prof. Dr. David Dossetor, Area Director of Mental Health, The Children's Hospital at Westmead, Dr Michelle Wong, Clinical Psychologist, and Lesley Whatson, Team Co-ordinator, ADHC Statewide Behaviour Intervention Service. A report was then forwarded and later presented by the evaluation team to the same group for discussion and modification. Changes and modifications were then made by the evaluation team followed by delivery of the Final Report.

Section 4: Stakeholder perspectives on the DP Clinic

The interview and focus group material was analysed in keeping with the administration of the interview schedules and is now presented under the headings: What is working? What areas could grow? What should we do about it? Recommendations then grew out of the later two areas. The graphic recording from the focus group, presented in Figure 2, also highlights key themes.



Figure 2: Graph recording of focus group

What is working?

4.1 DP Clinic Meetings

Referral to the DP Clinic can be made from anywhere in the state, and are made by paediatricians or the SBIS Children's Team. Only complex cases whose needs are not met within the general health and disability supports system are accepted. Some referrals are supported by DP Partnership team members alleviating the need for a full DP Clinic meeting based on clinical judgements.

The DP Clinic was described to be a responsive process. The DP Clinic identifies key people (from the core team) in an attempt to reduce the number of people who are physically in the room with families. This is seen as most important as family members often share intimate information in these clinics so the smaller the group, the more respectful the situation. The core team typically consists of a Psychiatrist, a DEC representative, an ADHC SBIS representative, a Clinical Psychologist, a Paediatrician, a Pharmacist (usually), a Speech Pathologist and a Cultural Clinical Consultant (when appropriate).

Clinicians (in addition to the core team) observe the process through a one way mirror from an adjoining room (if available, i.e. at CHW) and have opportunities to ask questions and give feedback at the formulation meeting when recommendations are being discussed. Typically the family interviews are led by the Psychiatrist shared on occasions by the Clinical Psychologist or Paediatrician.

DP Clinics are increasingly being facilitated at more local venues, other than the CHW, for example, at the child's school. Other venues include Fairfield and Burwood. This innovation reduces travel time for all, especially children who find travelling long distances difficult and the stress this can place on families before the DP Clinic. The facilitation of DP Clinics at a more local and accessible venue increases the likelihood that parents and their children can attend more relaxed and focussed. Local clinicians and teachers find it easier to attend as less time away from work is required. However some local venues were felt not to be an appropriate setting for lack of the availability of an observation room with one way mirror, thereby leading to crowded sessions.

From the DP Clinic, a report with recommendations is generated. This report captures the team's deliberations in a 'single voice'. The DP Clinic does not have wide ranging jurisdiction to monitor the implementation of the plan. Four main follow up options were however discussed positively:

- The local network to manage the recommendations with the DP Clinic transferring responsibility and not necessarily seeing the child/family again
- SBIS children's team provides follow-up consultation and has direct involvement in on-going support to local clinicians
- The DP Clinic consults with the referring Paediatrician and strongly advocates to get the recommendation actioned at the local level
- Arising out of the above options the Paediatrician refers back to DP Clinic for another formal DP Clinic meeting.

The process of the DP Clinic is summarised in Figure 3 below:

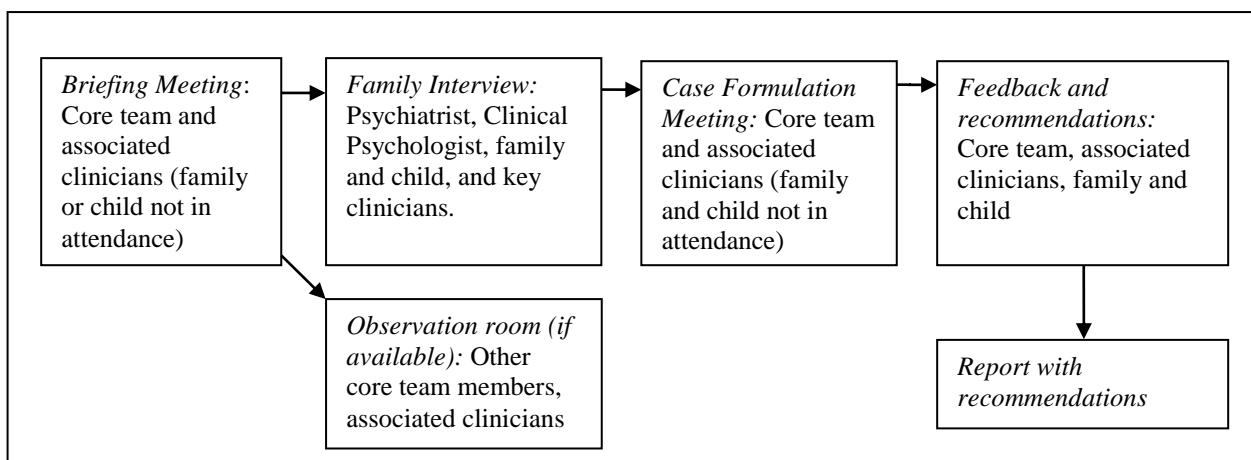


Figure 3: Flow of DP Clinic Panel Meeting

4.2 Enablers and Barriers

According to the members of the DP Partnership the enablers for successful professional interagency collaboration were:

- A belief we can help
- A 'good enough' quality of life
- Reciprocity
- A common language
- Mutual professional trust and respect
- Tolerance and patience
- Creativity
- Valuing different skills
- Family centred practice
- Life span and future orientated
- A capacity to prioritise
- Respect within one's own agency
- Evidence-based approaches

- Practice based expertise
- An assumption of the beneficence
- Systemic approaches
- Personal professional engagement
- Service prioritisation
- Support from senior management
- Practically orientated.

Barriers that prevent the replication of professional interagency collaboration were identified as:

- Challenged by the severity
- A lack of conceptualisation
- Not willing to try
- Lack of interagency open communication
- A professionally ego-centric view
- Lack of MDT peer support
- Despair
- Professional isolation and stigmatisation
- Decline of services
- Business models rather than clinical need
- Lack of pathways to care & service responsiveness
- Lack of a system of prioritisation
- Lack governance structure
- Lack of recognition of the special population needs
- Beginning with construction of rules and terms of engagement
- Individual partners contributing as individuals
- Lack of specialty professional skills and services.

The members of the DP Partnership go on to suggest that if the DP Clinic was to be replicated, the five following conditions are required;

The Five Conditions of Collective Success:

1. **Common Agenda:** where all participants have a shared vision for change, share common understanding of the problem and utilise a joint approach to solving it through agreed upon actions.
2. **Shared Measurement Systems:** collecting data and measuring results consistently on a short list of indicators at the community level and across all participating organizations not only ensures that all efforts remain aligned, it also enables the participants to hold each other accountable and learn from each other's successes and failures.
3. **Mutually Reinforcing Activities:** collective impact initiatives depend on a diverse group of stakeholders working together, not by requiring that all participants do the same thing, but by encouraging each participant to undertake the specific set of activities at which it excels in a way that supports and is coordinated with the actions of others.

4. **Continuous Communication:** based on trust, regular meetings and shared experiences, language and appreciation of motivations, interests, decisions and skills.
5. **Supporting infrastructure:** Currently the clinic does not have a specific funded administrative support. It operates from the goodwill of the partnership members. Any future replication would require supporting infrastructure.

4.3 A beacon of hope

The DP Clinic has a strong family centred focus, and works from a theoretical bio developmental psycho social cultural model. Skilled and accomplished staff, a collaborative multi-disciplinary team, and a well developed community outreach approach support the work of the DP Clinic. Family input and involvement along with a cross agency focus adds to the inclusive nature of the DP Clinic. The DP Clinic has the capacity to very quickly convene a senior trans-disciplinary team, when prompt decisions are made for children who are in crisis.

Parents and support professionals all acknowledged the importance of the DP Clinic's presence. The DP Clinic brings a sense of relief - the knowledge that the DP Clinic exists to support and guide, meeting the combined challenging needs of children and adolescents with intellectual and developmental disabilities with mental health problems - is most comforting. The DP Clinic was described during the interview process as 'a purveyor of hope'. The DP Clinic is easily contactable and parents and professionals alike remarked on the availability and promptness of the staff in responding to queries, calls and emergencies.

An important feature of the DP Clinic's presence is the knowledge of family and individual circumstances obviating the need for parents to repeat their story and start over time and time again with their child's history. The holistic and ongoing picture of the child and their needs and the detailed case notes that the DP Clinic collates is a feature families and many professionals commented upon.

4.4 The DP Clinic has a *visible presence*

The DP Clinic provides a referral point for a specific group of children, their parents and support professionals. One of the most important features of the DP Clinic is the way in which it highlights the children with the most complex needs, keeping this group of children at the forefront of public and policy attention. The multi-faceted needs and supports required by the children and adolescents who attend the DP Clinic are easily overlooked, remaining invisible to policy makers and funders.

The DP Clinic is comprised of a group of professionals who make up a most prestigious panel. They are respected and listened to, and are thus often able to break down barriers

that have been misunderstood, overlooked or ignored. This panel is able to effectively articulate the needs of this group of children and young people, gaining access to community resources that have previously not been made available.

All interviewees commented on the availability and commitment of staff of the Developmental Psychiatry Clinic. Parents in particular commented on the effective and efficient assistance especially in times of crisis. The most stated circumstance was in times of highest need, for example, over holiday breaks and when the family required emergency medication.

4.5 Developing skill and expertise

The DP Clinic is renowned through the skill and expertise it provides to stakeholders. This is especially important as in the general community there is a paucity of current and accurate information regarding the specific needs of the type of children and adolescents the DP Clinic supports, that is the child/adolescent with “high end complex behavioural needs”. This skill and expertise permeates all levels of the sector, especially at local levels, promoting a more preventative approach to supporting children and their families. The preventative approach advocated by the DP Clinic highlights the importance of earlier intervention to reduce the likelihood of problems escalating. The DP Clinic maintains a database that documents clients who have been seen at the clinic, and decisions made that are clinically driven.

The skill and expertise of the PD Clinic members is highlighted by the related projects arising from the DP Partnerships. One such innovative project under the auspices of the DP Partnership was training provided through the Training Curriculum Project. This project provided professional development for over 500 multidisciplinary clinicians providing a core base of skilled trained clinicians in the area of intellectual disability and mental health.

The leadership and expertise of staff was also demonstrated in a DP Partnership project with the publication of a text book- *Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A Framework for Professional Practice* (Dossetor, White & Whatson, 2011). This project had separate funding and was associated with the Training Curriculum Project. This publication is regarded as a key development that has proved to be an invaluable resource as it provides diverse information about intellectual disability and its relationship to comorbidity with mental health in the one resource. It provides a comprehensive framework for addressing complex needs of children and adults with intellectual and developmental disabilities and mental health needs.

Recommendation: It is important the Training Curriculum Project continue with a view to develop communities of practice across NSW that can address the unmet need of people with intellectual disabilities who experience mental health issues.

4.6 Cross Cultural Sensitivity

The inclusion of a Cultural Clinical Consultant was identified as a strength during the interview processes. Seeking to understand the cultural background of families requires specific knowledge, attitudes and skills in intercultural communication. The Cultural Clinical Consultant successfully works to honour cultural diversity through the acts of bridging, linking, and mediating between groups of people of differing cultural backgrounds that are referred to the DP Clinic.

The Cultural Clinical Consultant was reported to be responsive to families by having the knowledge, skills, sensitivity and awareness of cross cultural variables to work in a culturally competent manner with families from specific cultural backgrounds. She was reported as giving families confidence to participate in the case conference process.

Within the DP Clinic, the Cultural Clinical Consultant explained procedures and processes to families in accessible ways and provided advice and guidance to clinicians on the cultural beliefs of clients. As one interviewee explained:

Some concepts like counselling are Western concepts and many families are not always ready for these. Families might prefer to join a cross cultural support group to establish the thought ‘I am not alone’ and then be more receptive of counselling.

4.7 Team approach

The DP Clinic brings together people from a variety of backgrounds and agencies - clinicians, family members and the child. The child attends the DP Clinic meeting but if distressed or would become overwhelmed, will spend time in another room during the interview / case formulation process with known clinicians. The collaborative team approach has been fostered by a common language, motivation, mutual professional trust and respect, and a belief that the DP Clinic can help children even with highly complex needs based on clinical best practice.

The team approach brings expertise into the one location enabling the sharing of knowledge, experiences, new ideas and fresh perspectives. The DP Clinics and interactions between group members was described by all as “respectful and collaborative”. Professional development is fostered as team members learn much from one another through connections with the DP Clinic, learning more about one another’s expertise and knowledge and updating current practices. The sharing of information at the local level while up-skilling staff is also instrumental in avoiding ‘bottlenecks’ at the local level. Therapists and teachers reported instances where knowledge and skills learned at

the DP Clinic could be replicated with other children displaying similar behaviours, or transferred to similar situations. This enabled intervention at an earlier stage, reducing the escalation of behaviours. Resolving situations at the local level also reduced the need for the more intensive input of the DP Clinic. The DP Clinic facilitated opportunity for medical and allied health trainees to gain insight into systematic and clinical issues in the area of ID.

The DP Team and SBIS Children's Team have a culture of reflecting on their professional practice. Time for reflection is often difficult to build into busy schedules, however the teams value the opportunity and importance of pausing and considering different ways and new ideas for implementation. Such reflection is even more necessary when supporting children with high and complex needs as more creative and thoughtful practices are often required.

4.8 Networking

Professional networking flows from the DP Clinic both inside the DP Clinic and out into the wider community. Interconnections permeate into the wider community, fostering trust, building confidence, collaboration and networking. Busy clinicians and family members appreciate the opportunity to connect and build relationships as this fosters more informal contact between people. An example given was the use of email and Skype to discuss a situation more informally, putting some strategies in place that can reduce the need for a full DP Clinic meeting. One interviewee stated: "It's not always about the DP Clinic- it's about partnerships."

Section 5: Future growth and development

5.1 Governance

The essence of governance is direction – providing and championing the vision. Discussions with a varied group of stakeholders highlighted ways in which governance could further support the DP Clinic in the delivery of support to children and adolescence with intellectual disabilities and mental health concerns.

5.1.1 Promotion of intellectual disability and mental health as a professional area

The area of intellectual disability and mental health is not seen as a high interest area by potential clinicians. Students in universities are not selecting this area of specialisation as a career option, tending to focus on mainstream opportunities where clients typically present with only one 'concern'. Potential clinicians see the area of intellectual disability

and mental health as more complex than mainstream mental health, an area that is currently providing more opportunity for career advancement.

Recommendations

- At a higher level promote the profile of intellectual disability and mental health as a clinical specialism acknowledging other developments in this area, such as the University Chair in Behaviour Support and Mental Health.
- Promote the study of intellectual disability and mental health within tertiary institutions as a potential career option. Offer student placements to tertiary institutions, potentially exploring scholarships or employment attached to increase the attractiveness of the placement.
- DP Partnership at the outset to take the lead in working with children who have complex and high behavioural needs, such as providing on-going training through mechanisms such as the Training Curriculum Project.

5.1.2 Statewide service

The DP Clinic has a statewide brief to provide service and support to children and adolescents with intellectual disability and mental health concerns, although historically only some children have come from regional areas with most from the metropolitan area. The structure provides a valuable opportunity for cross-agency collaboration at a statewide level. The development of a stronger strategic vision and operational strategy aligned with operational partners would clarify the role of the DP Clinic and build statewide effectiveness. While it is assumed that a statewide service will promote equity of access there are areas of the state where families are not supported. This is the situation especially in the rural and remote areas. This creates gaps in the service where families do not have access to support. Furthermore clinicians and educational staff do not have the same access to professional input and collaboration.

Recommendations

- Secure funding to enable a strategic framework with infrastructure across the state area that gives clear visibility to position the DP Clinic for the future.
- Establish more local services and resources to support families and professionals, particularly in rural remote areas.
- Explore funding for families in remote and rural areas to cover additional expenses such as travel and accommodation, or seek out philanthropic supports which may be able to assist rural families with accommodation whilst attending the DP Clinic. Alternatively or in combination explore telemed service delivery offered by CHW to facilitate regional DP Clinic meetings.

5.1.3 Funding

The new models of funding that will be available raise uncertainty. The National Disability Insurance Scheme (NDIS) (previously known as DisabilityCare Australia) sets out to ensure that Australians with significant and permanent disabilities get the support they need to live with choice and dignity. This initiative will give people with a disability, their families and carers greater choice and control over the services they receive and who delivers them.

The DP Clinic is well positioned as a service of choice due in part to the specialist nature of the service and the empathy and sensitivity that underpins the service. However, the DP Clinic with its large multidisciplinary team is an expensive model in terms of attendance of clinicians and one that families may not choose as an option if the Clinic meeting had to be funded from the person's support package. Moreover, the cost of these DP Clinics would be difficult to allocate within individualised packages as the intense support needs for some children are recurring and on an irregular basis. Funding models must also acknowledge additional expenses incurred, for example payment of teacher release to attend meetings, and expenses for families from rural and remote areas. Action is required to advocate for centralised funding to meet cost related expenses that are specific to the successful design and implementation of support plans for the complex needs of the children the DP Clinic supports. Currently the DP Clinic is a cost neutral service hosted by the DP Partnership, with no specific funding for the establishment or maintenance of the current or additional clinics.

It became apparent that the DP Clinic continues to work with adolescents and their families after the child turns 18 years. A close bond of trust and support develops due to the closeness of the relationship between families and DP Clinic personnel. Transferring this trust and confidence base takes time and must not be hurried. Funding avenues to support adolescents and their families who are transitioning to adult services could be explored to provide a funded seamless transition. The positive stories reported by families of finding the DP Clinic did not resonate well with the apprehension expressed that the journey of searching for the right type of support may have to start again. The DP Clinic had supported families to regain a sense of equilibrium in both their lives and that of their children.

There was a general response from the interviewees that more local DP Clinics were required to meet the unmet need of children and adolescents with complex behavioural needs. Additional DP Clinics could provide a more accurate picture of need. Some children are not presenting as there is not the opportunity at the local level. DP Clinics at the local level would also work to enhance capacity and responsibility of local clinicians to build stronger networks and more specialised expertise.

Recommendations

- Advocate for funding to support the specific features of DP Clinic for example teacher release, clinicians attendance at DP Clinics and collaboration time, expenses for families from rural and remote areas, cultural support.
- Advocate for funding to increase the number of local DP Clinics.
- Time for DP Clinic clinicians to get together - preparation, meeting, liaising, follow-up. Confirm how this will be funded into the future.
- Ensure interpreters (cultural and social) to support families.
- Advocate for funding avenues to provide a funded seamless transition process for adolescents and their families who are transitioning to adult services.

5.2 Consultation Process

5.2.1 Preparation for the consultation meeting

Many interviewees commented that more notice of the DP Clinic Meeting dates would be beneficial. Professionals commented that a greater lead in time would have enabled them to assemble any necessary documentation and prepare families for the meeting. Families indicated that time to make arrangements and to gather their thoughts would support them when attending the meeting. It was recognised that teachers can make a valuable contribution and time was needed to arrange release. One person stated:

More notice of when the clinic was to be held. I received a last minute invitation, it happened to be on a day when I was available... it is very important to include the class room teacher... they know the person best... but we need to be able to release the teacher. In future to involve a special needs teacher it is important to give a lot of notice. A higher teacher [who does teach the student] might not know the particular students as well ... teachers spend every day with the young person.

Interviewees commented that a skilled administrator could send out information via phone, post or email informing those who would be attending the meeting of the time and venue well in advance. An information package detailing the specific venue, transport and parking options, the purpose of the DP Clinic, the process of the meeting, and advising of preparation they might undertake for the meeting could also be provided. The information package might also include a questionnaire that enabled attendees the opportunity to provide relevant information, advise of concerns they had or particular points they wished to discuss. The information on the questionnaire might shorten the meeting, reduce its intensity and involve more attendees in prioritising the agenda. An information package was developed in the past, but not routinely sent to families prior to the clinic.

The preplanning considerations could determine on a case-by-case basis if the child needed to be physically present at the meeting. Although it can be beneficial to observe

the child in develop the case formulation, it was acknowledged that the child's presence can add pressure to the family in getting to the meeting, especially when long travel was involved, and then being at the meeting. Particularly in some instances it appears the child was mostly kept busy in a separate room minded by a DP Clinic team member who otherwise may have attended and contributed to the DP Clinic meeting, although in other cases this was an opportunity for a clinician to observe the child. A portrait of the child could be provided through another format, for example video or video link for observation of the child at the meeting. Sufficient time is also required for the family interview in addition to the child observation.

Recommendations

- Notify attendees of the DP Clinic Meeting in advance.
- Ensure attendees receive an information package that details the meeting time and venue, the purpose and process of the meeting.
- Appoint a skilled administrative person to be responsible for coordinating preparation for the meeting.
- Design a questionnaire that will act as a preliminary information gathering tool for the meeting.
- Provide opportunity for families to have input into the agenda.
- Determine alternative ways in which a portrait of the child could be provided without the child being physically present at the meeting.

5.2.2 The DP Clinic Meeting

The DP Clinic meeting generated a lot of discussion. Interviewees commented that the meeting is facilitated in a family focussed way and in a most sensitive manner. Meetings are sometimes held away from Westmead Hospital site in more local venues to increase accessibility for families and the availability of professionals especially teachers. Attendees believed they could be better supported to attend the meeting if there was accessible parking and somewhere the child could go and someone to be with when not required at the meeting. The meetings involve a comprehensive range of people and there is a well thought out process. Some team members look to the senior specialists of the DP Clinic Meeting for ideas and decisions. The encouragement of ideas from people who spend considerable time with the child – the carer, parent, and teacher would provide a wider perspective and continue to develop expertise at the local level. At the conclusion of the meeting there is a letter of recommendation sent to the child's paediatrician that details a way forward.

Many of the interviewees commented that the DP Clinic Meeting can be a 'daunting' experience for many family members. They often do not know who will be attending the meeting and who some of the professionals are who are attending the meeting. Attempts

have been made to reduce the number of professionals who are present in the interview stage of the meeting with the family and child. Professionals, other than the core team, observe the interview from an adjoining room. Not all venues have observation rooms and questions were raised about what happens in these instances. Generally family members were aware the professionals were in observation, and how professionals in the observation rooms could inform the meeting in a direct fashion was the challenge.

Recommendations

- Facilitate meetings at local venues whenever possible.
- Provide accessible parking and quiet spaces for family members.
- Provide a room/space for the child to go and a carer when not in attendance at the meeting.
- Nominate a core team member, who is usually the paediatrician or a key clinician, for each individual child who can be the contact person for the family (Hastings & Beck, 2004).
- Reduce the number of people at the DP Clinic Meeting without jeopardising effectiveness.
- Ensure family members know who and how many people are in the observation room.
- Encourage choice by family members regarding who they would like to be in attendance from local service, e.g. school, respite, ADHC.
- Explore creative ways of obtaining input from all members at the meeting.

5.2.3 Review and follow-up of the DP Clinic Meeting

The DP Clinic Meeting is a time of high energy, high aspirations and hope. The meeting generates involvement of a wide range of people and expectations are raised along with feelings that something will happen. Specific follow-up would capitalise on this energy and involvement to advance the aspirations and hopes that were raised at the meeting. From the DP Clinic Meeting a letter of recommendation is forwarded to the child's paediatrician that summarises each agency's commitments. Medical responsibility lies with the referring paediatrician and although other agencies are not obligated to follow the recommendations, the collaborative relationship is supportive of the process. Each agency receives feedback on the progress of the recommendations which is informally discussed at DP Clinic meetings.

The DP Clinic has little oversight or authority for ensuring the recommendations are followed through. An alternative outcome for the meeting might be the wider distribution and more targeted action of these recommendations. Acknowledging that it is beyond the prerogative of the DP Clinic to implement some recommendations, the recommendations arising could be written as an action plan specifying what needs to be done, how it might

be done, who might do it, and when it might be done. A broader group could translate these onto the child's individual educational plan to ensure they are more widely actioned.

The introduction of satisfaction surveys and outcome measures (families and clinicians) would provide valuable information for the effectiveness of the support received and would inform future development of a proactive service. The results could enhance accountability measures.

Recommendations

- Explore if the DP Clinic should have greater mandate to oversee follow up of the implementation of recommendations.
- Explore ways in which the DP Clinic can have more oversight in actioning the recommendations from the meeting.
- Develop a plan that clearly outlines actions and responsibilities.
- Encourage teaching staff to translate the plan into individualised education plans.
- Schedule follow-up meetings (when necessary) or phone check-ins at the conclusion of the DP Clinic Meeting.
- Design and introduce satisfaction surveys (families and clinicians)
- Routinely begin gathering outcome measures where possible using standardised tools, for example the Developmental Behaviour Checklist (DBC) and Beach Family Quality of Life measures.

5.3 Infrastructure

5.3.1 Advertising and marketing the DP Clinic

Generally, it was felt that more could be done to promote the DP Clinic, the work it undertakes and the support it provides. While wider marketing of the service would promote the work of the DP Clinic, it was nevertheless felt it could also generate longer waiting lists without further resourcing. However, clear statements could be made in the advertising materials that direct referral to the DP Clinic was not possible, and state that referrals came through the DP Team (CHW), SBIS Children's Team or Paediatricians. Information on the vision and purpose of the DP Clinic would give the clinic a greater visibility within the public domain and promote its mission. Marketing may be targeted at a professional audience, rather than the general public. Information on personnel associated with the DP Clinic and their roles would give a human face to the DP Clinic. Information on location, processes, purpose and support provided would give a practical focus. This type of information would provide families, clinicians, associated professionals, community members and potential professionals who might be looking to specialise in this area a clearer picture of the DP Clinic. This information could be made available in a variety of ways through the internet, facebook, blogs, brochures, or posters. These promotion materials could also include testimonials and stories of people who have attended the DP

Clinic. Information must be provided in a highly accessible manner and one that reflects the cultural backgrounds of readers. The school link initiative does advertise some aspects of the DP Partnership activities, and can promote access to local services.

Recommendations

- Explore suitable ways of promoting the DP Clinic and DP Partnership activities to organisations and relevant professionals.
- Develop and fund promotional materials that are engaging, informative and accessible to readers, including a factsheet that explains what the DPC is and referral pathways..

5.4 Educative role

5.4.1 Training and professional development

The DP Clinic has an invaluable and active role in training expertise at the local level. This is a role that must be continued to be supported and grown as there is little opportunity for clinicians and community members to up-skill in complex case management, intellectual disability and mental health specialist expertise. Keeping up to date and abreast of research and current specialist practice is paramount. Training happens informally through the DP Clinic meeting and formally through the networks that radiate from The Children's Hospital at Westmead and SBIS. The DP Partnership has been instrumental in developing educative and clinical programmes to bridge the knowledge gap associated with working with children with intellectual disabilities with mental health concerns. Three programmes are now outlined that are associated with the work of the DP Partnership.

The Training Curriculum Project has trained over 500 multidisciplinary professionals from education, health and disability services. Those trained included community clinicians from allied health (Speech Pathologists, Occupational Therapists, Physiotherapists), behaviour support, case management, nursing, psychology, management, paediatrics, psychiatry and teachers/ principals. The aim of the training was to increase the confidence, knowledge and skills of professionals working with children and adolescents with intellectual disability and emotional/ behavioural disorders. The project was initially funded by MHDAO and ADHC for 2 years (2007-2009), with additional funding provided by ADHC SBIS to continue the project for an additional 1 year (2010). The published text book (2011) was a significant outcome of this project.

Emotion-based social skills training (EBSST) (Wong et al., 2004) is a program designed to improve the mental health and wellbeing of children with ASD and their parents through the development of social and emotional skills. EBSST is based on theories of emotional development and emotional intelligence and teaches children with ASD to have insight into their own emotions during social interactions to be able to develop strategies for self-

regulation. EBSST has been adapted to meet the needs of children with ASD and co-morbid mild intellectual disability (Ratcliffe et al., 2010). This programme is well positioned to be published and marketed outside of New South Wales across Australia and internationally. In recent times the programme has lapsed due to lack of funding and organisational issues, and there is a need to explicitly request its continued role.

Children's Hospital Westmead (CHW) School Link is a program that was designed to support the mental health of children and adolescents with an intellectual disability. It builds on the NSW school-link initiative which has been addressing mental health in NSW schools since 1999. The specific scope of the CHW School Link program is:

- Assisting in the pathways of care for students with mental health problems and disorders.
- Supporting the implementation of school based mental health promotion, prevention programs, and early intervention programs.
- The training and education needs of school counsellors (Children's Hospital at Westmead, 2011)

CHW School link has been funded by NSW Health Mental Health and Drug and Alcohol Office (MHDAO) over four years and partners with MH-KIDs, The NSW Department of Education and Training and ADHC to

- Develop a communication plan to raise awareness to a wider constituency on the mental health needs of children and adolescents with an intellectual disability.
- Develop better understanding of criteria for identifying children and adolescents who have an intellectual disability and mental health problems.
- Support improvements in pathways to care for children and adolescents with an intellectual disability.
- Develop a learning module to address the needs of school and mental health staff working with children and adolescents with mental health problems and disorders and an intellectual disability.
- Support school and mental health staff who work with students with mental health problems and disorders and an intellectual disability.
- Support the development of prevention and early intervention programmes/strategies for students with an intellectual disability in SSPs.

The involvement of the DP Partnership in the above training initiatives is indicative of its capacity to develop, implement and create solutions to the gap in information knowledge associated with intellectual disability and mental health.

Recommendations

- Re-establish the training offered through the Training Curriculum Project and further encourage training more broadly through mechanisms such as the Workforce Development Strategy.
- Review the Training Curriculum and explore other delivery formats, for example, e-learning, web based distance learning.
- Market the area of intellectual disability and mental health as a credible specialism.
- Develop training programmes for parents and carers, and siblings. .
- Establish Communities of Practice at the local level to provide leadership, networking and ongoing skill development opportunities.
- Explore the establishment of support groups led by culturally appropriate local personnel.
- Approach a publishing house to package and promote the EBST programme and materials
- Work in partnership with a tertiary provider to gain approval and accreditation of the Training Curriculum programme as a workforce qualification both in education, disability and mental health services.
- CHW School Links to consider ways in which an Adult Links version could be developed. Consultation with National Disability Co-ordinating Officers could be a starting place.

5.4.2 Research

The ability of the DP Partnership to further contribute to relevant information associated with intellectual disability and mental health can be found in the text edited by three core staff of the DP Partnership entitled, *Mental Health Children and Adolescents with Intellectual and Developmental Disabilities* (Dossetor, White & Whatson, 2010). This text is a well researched and scholarly guide to understanding as well as working with children and adults with intellectual disability and mental health conditions. The contributors of the text are all collegially associated with the DP Clinic and form the nucleus of a community of practice which, if the DP Clinic strengthened its research role could fill a gap in international research on intellectual disability and mental health.

Recommendation

1. That the DP Partnership work collaboratively with other research units across New South Wales which have an interest in disability research.
2. That in the context of collaborative relationships, the DP Partnership apply for ARC and NHMRC grants that focus on exploring the clinical, educational and lifespan needs of children and adults with intellectual disability and mental health needs.

3. That the core team of the DP Clinic explore other research funding avenues particularly associated with grant funding arising from the NDIS that is yet to be announced.

5.5 Model

5.5.1 Refining the DP Clinic model

With the above areas identified within the evaluation as being worthy of recommendations for change and within the context of the introduction of the NDIS, it appears an opportune time to review or refine the model and structure of the DP Clinic. It is important that any new model reflects a community developmental bio psycho social model modelling collaborative practice as exemplified in the DP partnership and clinic. This approach would acknowledge the complex interactions between the biological, psychological, and social factors that relate to individual children and their families. Such an approach provides a sound basis for the understanding and support required by the children and their families, mindful of their social and cultural contexts and the impact of the child's presence. In developing a new model, community profiling would be important to reflect regional differences, especially those of rural and remote communities.

The DP Clinic and DP Partnership developed organically and projects and activities evolved alongside, for example, School Link, Training Curriculum Project and Adaptive Social Skills (EBSST) project. The timing is now right to review the model taking into consideration such developments. One that emerged during the interview process was that of a Centre of Excellence. A Centre of Excellence would be the centralised body for developing, monitoring and reviewing quality improvement associated with types and level of clinical intervention, educative functions, and family support for children and adults with intellectual disability and highly complex mental health issues. It would include the DP Clinic, training, research and advocacy.

Local hubs, perhaps situated in other hospitals or community clinics, could align with the Developmental Psychiatric Centre of Excellence informing one another, collaborating together and providing greater accessibility. See Figure 4 below:



Figure 4: A DP partnership Centre for Excellence

Prior to expanding upon or making any recommendations about this model, a scan of current literature has focused on tertiary services for children and young people with intellectual disabilities who have mental health concerns. However, in sourcing literature, a range of descriptive terms was used that coupled with intellectual disability, such as behavioural difficulties, disruptive behaviour, dual diagnosis, mental health concerns, comorbidity. The literature is reported using the respective terms of the authors, laying open the opportunity for a position paper to be written that defines and distinguishes the difference between current use of such language, particularly in relation to Australian services where the term mental health appears to be used more consistently (Dossetor, White & Whatson, 2011; Torr, 2013). Further literature on evidence based collaborative practice could further enhance the model.

Section 6: Learning from a scan of literature on tertiary consultation models

6.1 Introduction

Given the extensive psychological, community, economic and social costs of difficult childhood and adolescent behaviours (e.g. Foster & Jones, 2005; Scott, Knapp, Henderson & Maughan, 2001), several clinical models have been developed to assess and manage co morbid emotional, behavioural and psychiatric problems. This scan aimed to outline treatment models for children and adolescents with intellectual disability and such co-morbid conditions. A summary of the results are presented, with Appendix A containing a description of the material as well as a source of web links.

6.2 Mental health and behavioural difficulties in children and adolescents with intellectual disability

Young Australians with intellectual disability experience approximately three times (Einfeld & Tonge, 1996) the rate of mental health difficulties than young Australians in the general population (Sawyer et al., 2001). In particular, the rate of conduct disorder in children and adolescents with intellectual disability is nearly six times the rate of typically developing young people (Emerson, 2003b). Mothers of children and adolescents with intellectual disability also have poorer psychological outcomes than mothers with children without intellectual disability (Emerson, 2003a). In addition, mothers of children with intellectual disability who were experiencing poorer mental health, were also more likely to report poorer family functioning (Emerson, 2003a). In general, parents of children with behaviour disorders experience greater levels of stress than parents with children without disruptive behaviours (Dumas, Wolf, Fisman & Culligan, 1991). There is also a bidirectional relationship between disruptive childhood behaviours and parental and family stress. Raising children and adolescents with intellectual disability and challenging behaviours increases stress in the household, and increased parental stress results in less beneficial parenting practices and treatment outcomes for children and adolescents with intellectual disability and disruptive behaviour problems (Hastings & Beck, 2004).

In summary, children and adolescents with intellectual disability experience more disruptive behaviours than typically-developing young people, and their families are also at higher risk of poorer psychological health and increased dysfunction. Thus services that address both parental stress and child and adolescent behaviour problems are likely to lead to increased benefits for the family as a whole. A review of stress interventions for parents of children with intellectual disability reveals that standard models of care such as respite care or case management are probably beneficial for parental stress, however when dealing with a multidisciplinary team, a family may benefit from a central contact person to reduce conflicting information and parental stress (Hastings & Beck, 2004). Although there is limited empirical evidence to date, the Parent-to-Parent model in the United States appears promising for reducing parental stress as parents act as social supports for other parents of children with intellectual disability (Hastings & Beck, 2004). Finally, group CBT programs according to Hastings and Beck (2004) are the most effective treatment for reducing parental stress and improving parental health.

6.3 Treatment programmes

There have been a few studies that have investigated the effectiveness of treatment programs for challenging behaviours in children and adolescents with intellectual disability directly. For instance, Signposts is an Australian family-centred approach to help parents of children with intellectual disability and challenging behaviours learn strategies to manage their children's behaviour (Hudson et al., 2003). The program is effective in either group, self-directed or via telephone support format in reducing parental stress and improving child behaviour (Hudson, et al., 2003). Parent child interaction therapy, which focused on building relationships between the parent and child, child social skills and parent behaviour management resulted in improved child behaviour and reduced

parenting stress in children with intellectual disability and disruptive behaviours relative to a wait-list control (Bagner & Eyberg, 2007). Finally, an adapted version of the family behavioural program Triple P has also found to be effective in improving behaviours in children with developmental disabilities (Caruana, Fleming, Saleh, Goltzoff & Dossetor, 2010; Roberts, Mazzucchelli, Studman & Sanders, 2006). Thus, there is evidence for treatment programs that specifically target challenging behaviours in children and adolescents with intellectual disability.

6.4 Clinical models of care

There is a paucity of research on evidence-based clinical models of care for severe childhood behaviour problems that have led to family disruption, safety and risk issues, and police and court involvement. This is likely due to the multifaceted and complex nature of severe childhood behavioural problems and the difficulty in recruiting and maintaining the participation of these families in randomised controlled trials, which are needed to investigate the effectiveness of a treatment. In practice, there are several clinical care models locally and internationally, which offer services to manage disruptive childhood behaviours that have led to family dysfunction. The following section of this review provides a summary of models of care identified for disruptive behaviours in both typically-developing and disabled children and adolescents both domestically and in the United States, United Kingdom and Canada.

Given the parameters of this study, this review is limited to a descriptive analysis. It is likely that additional models of care and clinical consultation exist. Those which do not have readily available public information and evaluative studies have not been identified in the search conducted. Table X reports a summary of the models that were identified in the search, with further description in Appendix A. The following search terms were used in various combinations in attempt to identify models of care; “Psychiatric clinic, children/adolescents with intellectual/developmental disabilities, behaviour problems, challenging behaviours, clinical care models, consultation, assessment, interdisciplinary team, tertiary clinic, specialty clinic, complex cases”. Although there is a strong research base on behaviours of concern in individuals with disabilities (particularly the use of behaviour support teams for aggressive behaviours in adults with intellectual disability in the UK), the type of mental health presentations seen, caregiver stress etc., there was few articles on the evaluation or description of specialty clinics or treatment models for children/adolescents with challenging behaviours.

Location	Program	Type of Model	Treatment Approach	Comments
Australia	Coral Tree Family Service	Residential, day program,	Multi-systemic	Evidence-based program

		school program		
	Rivendell Child and Adolescent Mental Health Service	Residential, day program, school program	Individual	
	CBRC	Outpatient	Child and parent training	Evidence-based program
	Mercy Family Services	Residential	Trauma and relationship/attachment approach	
United States	Alternate Family Care, Inc.	Residential	Child and family	
	University of Miami Parent-Child Interaction Therapy Program	Outpatient	Parent management	Evidence-based program
United Kingdom	Childhood First: Healing Hurt Minds	Residential	Integrated Systemic Therapy	Good outcome measures reported. “Outstanding” rating on an inspection report.
	Croft Child and Family Unit Cambridge	Residential	Family	Specific for children with developmental disabilities
	Kisimul	Residential, school	Individual program	Specific for autism or learning disabilities and challenging behaviours. “Outstanding” rating on an inspection

				report.
Pegasus School	Residential school	Individual program	Specific for autism, challenging behaviours and communication and learning difficulties.	
Ridgeview Children's Home Inc.	Residential	Individual program	Specific for children with developmental disabilities.	
Young Foundations	Residential	Individual Program		
Canada	Better Behaviour Services (BBS) at the Centre for Addiction and Mental Health (CAMH)	Outpatient	Parent and child program	Evidence-based program
	Peel Children's Centre	Outpatient	Family program	Unique “wrap-around process”

Table 1: Summary of local and international models of care in practice for children and young people with behavioural and mental health concerns

In summary the domestic and international models identified cover a range of approaches from outpatient clinics through to residential settings as well as community outreach programmes. A common feature for a number of programmes was that they were multi faceted combining all of the later characteristics. Evidence based programmes were claimed but often with limited documentation, and few case consultation services identified, making comparison to the DP Clinic unproductive at this point.

6.5 Specialised tiered systems approaches for children and adolescents with intellectual disability and co morbid disruptive behaviour

As early as 2002, arising from a Dual Diagnosis Project funded by the Queensland Government, Specialised or Tertiary Services were supported where highly trained professionals were available to provide specialised assessment and guidance in a flexible manner. “Tertiary services may be delivered through clinics that exercise mobile outreach, assertive community treatment and or specialised outreach teams, community based residential programmes, such as, day services, or inpatient assessment and treatment services” (Queensland Health and the Department of the Premier and Cabinet, 2002, p. 13).

Over the last decade the issues of specialised services for children, young people and adults with intellectual disability/mental health concerns continue under discussion as evidenced by a National Roundtable on the Mental Health of People with Intellectual Disability (NSW Council for Intellectual Disability, 2013) where five proposed elements of an effective system were documented. *Element 4, Specialists in intellectual disability mental health* included four pointers that are either already being fulfilled by the DP Clinic or where the DP CLINIC is well positioned to play a role in the suggested actions. In response to the first sub element, which is to develop a multidisciplinary national network on intellectual/developmental disability mental health, DP Clinic is well linked in disability/mental health across Australia. The second sub element of developing a model of specialist service provision is already well established. Finally, the third and fourth sub elements that relate to the Royal Australian & New Zealand College of Psychiatrists taking responsibility for training and funding intellectual disability psychiatry as a priority area under the DOHA Specialist Training Programme resonates with the work of the DP Clinic, which already has an educative function through the School Links programme. Of note is the Training Curriculum Project where over 500 multidisciplinary professionals were trained to increase their knowledge, skills and confidence when working with children and adolescents with intellectual disability and emotional/behavioural disorders.

Across Australia there is a growing recognition of the need for specialised services to be embedded in Mental Health Frameworks to meet the needs of people with intellectual disability who experience mental health concern (see Appendix B for an overview of a growing response to this need across Australia). In some states current developments are at the stage of recognising the need as a health issue with the writing of position papers whereas in other states and territories capacity building has begun and models are being staffed and put in place. One such model in NSW is a tiered system entitled *The NSW Health Service Framework for People with Intellectual Disability and Their Carers* (NSW Ministry of Health 2012). It was developed by NSW Health and the NSW Department of Family and Community Services – Ageing, Disability and Home Care, in collaboration with the NSW Council for Intellectual Disability and consultation with wide ranging stakeholders. This framework has been actioned with a view to “establishing specialised services for people with intellectual disability and complex health problems” (NSW Ministry of Health, 2012, n.p.). The DP Clinic operates at Tier 4 providing “a cross-agency, multidisciplinary management decision-making capacity that involves both intellectual disability and mental

health specialist expertise" (Dossetor, 2011, p. 311). Within this Tier, the DP Clinic provides a service to children and young people with extremely complex needs that existing agencies and individual specialists refer to for complex case management.

Evidence of the expertise of the DP Clinic in relation to the role that it plays at Tier 4 can be seen in the following case studies. These case studies were collected as part of the CDS evaluation and portray the work of the team at the DP Clinic which is inclusive of collaboration with the SBIS Children's team. The need for a multi-disciplinary highly skilled responsive team is illustrated in these brief scenarios which were reinforced by the stakeholder interviews with families, their supporters, and professionals inclusive of referral paediatricians, ADHC psychologists, teachers etc.

6.6 Case studies that illustrate work of DP partnership and DP Clinic as a Level 4 Tertiary Service

6.6.1 Case One: Team work within DP Clinic and local partnerships.

DE, a 15 year old adolescent, was presented to the DP Clinic by NGO care staff to CHW Emergency Dept because of violence over the weekend. This boy previously known to the DP Clinic with Severe ID, ASD, Aggression and SIB came from a professional family. He was placed in a Residential Special School for 5 years with continued family visits every weekend until the facility was closed in 2011. Following consultation no additional mental illness was identified, and medication was reviewed. He stayed in the Emergency Department for 36 hours, as admission to the hospital was not indicated and this led to his family feeling under pressure to take him home. The Director of the DP Team was the on-call psychiatrist for the weekend and the hospital made contact to seek help.

Also being a weekend, a time when DP partners are not on call¹, the ADHC Statewide BIS partner was contacted and as an exceptional circumstance, rang the Manager Behaviour Support, Metro North, who was then able to contact ADHC senior management. At this point, the details underpinning the brokerage arrangement were shared with the SBIS partner who began to liaise across CHW, the NGO provider and ADHC. It was agreed that, for the weekend, DE would be admitted to a medical bed and more robust discharge plans would be negotiated Monday morning. The SBIS partner was able to connect key ADHC clinical staff and management with the non-government provider's management and it was agreed that a referral to both the Region's Behaviour Intervention Team (RBIT) and SBIS would be useful. These referrals were immediately allocated. Liaison continued across ADHC clinical services, ADHC funding staff, CHW Psychiatry and the non-government provider. This immediate response during the weekend was only possible due

¹ It should be noted that this case was an exception to the rule, SBIS do not have on-call on the weekend or at any time and this outcome was achieved through the long term partnership between SBIS and CHW

to the enormous amount of goodwill and collaboration generated by the DP Clinic and DP partnership. There was acknowledgement and validation of the non-government provider's systemic stress.

The young man was taken back to his residential NGO, with in home regular visits by a psychiatrist to monitor medication needs, to look at carer skills and attitudes and relationship with family. ADHC provided professional back up to the care staff and provided a small amount of supplementary funding for extra staff, to give *worn out* staff a break and a chance for additional training. In-home weekly psychiatry visits occurred for 6 weeks, to prevent placement breakdown. Family issues explored and established the need for visits to be entirely predictable for DE to prevent this leading to further aggression.

This case presented as a placement breakdown, when hospital admission would not solve anything and was inappropriate. There are no long term or suitable mental health beds for cases like this (especially under 18). Intensive, high expertise, cross collaboration, with emergency additional funding prevented placement breakdown. DE remains a high risk and demanding case for the foreseeable long term. Ultimately, it was sturdy inter-agency relationships, responsiveness and flexibility that led to a shift in this case. The value of expert advocacy, and a good working knowledge of a number of service systems and agencies cannot be underestimated.

6.6.2 Case Two: Highly specialised case management

Another case that was not seen through the clinic but that was supported by the DP partnership and illustrates the need for collaborative practice involved a 10 year old boy with Asperger's and ADHD of normal intellect and diagnosed by local child developmental unit. This boy's diagnosis was confirmed by a clinician in an NGO that concentrates on services for students with Autism. His behaviours were causing concern under the care of a General Paediatrician for two years with recurrent episodes of violence. Initially, he was being managed as an outpatient. However, episodes of violence were getting more serious and of greater duration, leading to a crescendo of problems and recurrent attendances at emergency services and presentations to the local general hospital in a non-metropolitan area. Episodes of anger and aggression had been lasting for several hours at a time with multiple minor injuries to his parents and destructiveness to the home, including holes in the wall and the destruction of furniture. The most dangerous incident is when he took a hammer to his mother's hand leading to a fracture, and attempts to stab her with a screwdriver. The most recent event required an Ambulance and the Police, the use of capsicum spray and handcuffs, and transport by a Police paddy wagon to the Emergency Department. The boy was kept in the Emergency Department with special nursing support for six days before transfer to a paediatric ward because the paediatrician was too worried to risk such violence in a paediatric setting. He was deemed too young for adult mental health setting as the Local Health District (LHD) had no Child and Adolescent

Mental Health Services (CAMHS). He was seen briefly by a psychiatric registrar who consulted his consultant. This did not progress the situation.

On Day 2 in the Emergency Department the CHW DP Team was contacted by the paediatrician requesting an urgent admission to Hall Ward, as the only designated Mental Health Unit in NSW eligible to take those under 12. Hall Ward was full over the entire period. The main Children's Hospital was also full, so a transfer to a paediatric setting was also not even possible, even if that was considered appropriate. There were considerable urgent multi-agency discussions, particularly with FaCS. There was already a private psychologist involved. FaCS was unable to provide any alternative accommodation. The Director of the DP Team provided telephone advice on medication and added other medication with an urgent Outpatient assessment scheduled for 2 days later. The boy's family was not able to take him home for fear of assault. He was brought to the DP team by the family from the Emergency Department of the district hospital and taken back there afterwards. There was a case conference on the Monday morning involving the Assertive Outreach Team of CAMHS of the local health district. Two weeks later there was a further multi-agency, multi-disciplinary case conference involving 20 people. This particularly focused on improving acute sedation management regime with a capacity for this to be done by the Emergency services to avoid Police containment as an Emergency procedure. The protocol was based on advice given by the Director of the DP Team on acute management which was followed up in an outpatient appointment 4 weeks after the initial consult, and medication intervention had avoided any further acute or dangerous episodes.

There is still significant work to be done on the optimising of the boy's medication but his level of improvement means that alternative behavioural approaches may have a greater capacity when previously they were functionless because of the frequency and rapidity with which he exploded. He had also been out of school for most of the year and a new placement had been found in a multi-categorical class currently attending one hour per day. The family are highly committed to their only child and had already received parent training interventions without benefit. The father had ceased working to become the primary caregiver as his wife was in such danger from the assaults. Both parents had become quite dejected with an antidepressant prescribed for the father to counter a level of burnout and depression.

This case illustrates the severity of behaviour difficulty that can occur from Autism in the context of ADHD and anxiety despite the best endeavours and good will of local generic services. This case used a huge array of resources from several agencies and became difficult to contain and locate the child under a paediatric service. Input from a psychiatrist, supported by a psychologist through the DP partnership both skilled in the special needs of young people with Autism led to a greater attention to detail with the pharmacological management also through the DP partnership modifying the trajectory and enabling the young person to return home. This scenario is not uncharacteristic of the success of the

DP partnership, indicating that collaboration is more than assessment and case conferencing but rather case management.

6.6.3 Case Three: Transferring knowledge to local specialists

This year a similar case was dealt with from the southern highlands following the ministerial inquiry and a dispute between a private child psychiatrist and the local CAMHS IP mental health services over whether admission was warranted for a boy with Autism and Moderate Intellectual Disability, on the basis of putative diagnosis of bipolar disorder. The case was assessed within a week by specialists associated with the DP partnership and DP Clinic, specifically a sub-specialist psychiatrist with a sub-specialist psychologist and a member of SBIS team.

Similar intervention occurred through attention to understanding the complexity of the developmental disorders, with ASD, ID, Developmental coordination disorder, Anxiety and labiality of mood, plus focusing on other elements of community support and intervention. The modification of medication management and other community interventions resolved the crisis. Parents are delighted with improvement and care has been resumed by the private psychiatrist, indicating the role that the DP Clinic plays in transferring specialised knowledge to local specialists.

6.6.4 Case Four: Value of pharmacological management

Another boy was seen by a registrar in the CHW's emergency department and a priority referral was requested for the DP team. The boy had had severe Intellectual Disability, Autism, ADHD and extremely severe injurious behaviour. Again the parents are highly committed with their son being seen by several developmental paediatricians. The constant hyperactivity, aggression and self-injurious behaviour were distressing to all involved. Pharmacological management of ADHD, anxiety and self-injurious behaviours improved so that it is no longer an acute issue and enabled a return to school.

6.6.5 Cases through CAPTOS (Telepsychiatry) in Rural and Regional NSW.

The DP partnership has been involved in further examples in several regional centres through the use of telepsychiatry. In those in whom there is intellectual disability and major behavioural problems, partnership with the SBIS ensures collaboration with ADHC at the highest level even if there are local problems in implementation. Many of these cases have difficulty in gaining adequate CAMHS support for a range of reasons.

6.6.6 Long term cases of the DP Clinic

There are cases more acute, more distressing and more alarming than those described above that are brought to the attention of the DP partnership and Clinic. Like several of the cases above, these cases are dependent upon a partnership with the highest level of disability expertise of SBIS Children's Team as well as that of the DP Team. For example, twins diagnosed with Autism, severe intellectual disability, hyperactivity, aggression, and self-injurious behaviour; as well as a group of young people whose management needs have led them to be placed in long term care and who remain highly challenging to manage, despite long term care placements with continued undue pressure on the education system. The long term support and partnership between the DP Team and SBIS has enabled these cases to be maintained in NGO placements and avert further Ministerial complaints. The partnership enables the bringing together of the full range of multidisciplinary skills and a capacity to advocate for a flexibility of case and business management from ADHC.

6.6.7 Broader partnership with Statewide Behaviour Intervention Service

There are a number of cases each year which are triaged in conjunction with SBIS, enabling access to paediatric services or CAMHS cases to ADHC or ADHC cases to paediatricians or CAMHS, supporting the growth of local partnerships.

Section 7: Where to from here?

The overall scan of literature has outlined several approaches to disruptive child and adolescent behaviour problems locally and internationally that offer treatment to children and young people with intellectual disabilities and their families who haven't benefited from standard local mental health services. The key characteristics of models, services, frameworks reviewed include

- Multi-disciplinary team approach involving for example, Psychiatrists, nurses, social workers, teachers and music and art therapists
- Multi-faceted approach involving both individual and group clinical programmes as well as and /or linked with educational and community based programmes
- Community outreach programmes supported by clinical teams
- Short term intensive residential programmes
- Both Individualised and structured group approaches
- Family therapy and respite
- Observation, clinical, behavioural and environmental assessment
- Partnerships within/across clinical teams and community based services
- Wrap approach with relevant community base services
- Highly specialised government initiated services arising from gaps in the system
- Capacity building arising from the need for staffing with specialist skills across a range of disciplines

- Relationship building and transfer of knowledge between generic services and developing specialist programmes

In mapping the DP Clinic to the above characteristics it is a *good fit* but in addition what needs also to be stressed is that the DP Clinic plays a critical role and service that families and clinicians can access when there is an impasse in progress for the service system or when there is uncertainty regarding the next steps due to the complexity of the presenting issues. The family and professional stakeholders of the DP Clinic confirmed that referral to the DP Clinic as a tertiary service had led to improved outcomes, relieving acute alarm and distress as well as cost cutting. Tertiary referral as well as ongoing access to the staff of the DP Clinic was considered to be less costly when compared to public emergency services being called upon by families when children young people were in crisis.

The members of the DP Clinic stressed the role of partnerships in their work with organisations, such as, Aspect, Family and Community Services (FACS) (including Intensive Support Services), NGOs (Giant Steps, Northcott and IDS). Within such partnerships the DP Clinic is committed to joint consultation as a means of sharing its expertise and transferring knowledge to the presenting clinicians as well as to other Tier 4 agencies, such as Fairfield Specialist Health Services for Intellectual Disability and the Northern Intellectual Disability Health at Cremorne. As a group DP Clinic staff are also involved in training doctors in the mental health of children and adolescents with ID/ASD promoted through Fellowships in Mental Health and Intellectual Disability, funded by ADHC, CIG. The role of the DP Clinic in advancing knowledge within the field of intellectual disability and mental health is vital, particularly in this time of change with the introduction of the National Disability Insurance Scheme (NDIS). What is to happen to partnerships such as the DP Clinic under the reform of the NDIS? How will specialist groups like it be funded? The ethos of the NDIS is that people with disabilities will gain choice and control through individualised packages. Will people choose intensive services? Or should certain services be ring fenced for funding to ensure that people with disabilities can gain access to highly specialised services as a means of gaining ongoing support required if they are to remain healthy enabling full participation and a high level of decision making that underlies the ethos of NDIS as well as the UN Convention on the Rights of Person with Disabilities. Choice and full community participation for some people will mean ongoing access to specialised services like the DP Clinic. Improved outcomes for people to live valued lives that they have control over will also depend on partnerships between NDIS and Medicare Locals and general practitioners, and specialist health and mental health services. Improved access and outcomes for some people and their families will be dependent upon ongoing support and expertise from specialist intellectual disability health and mental health services. **Promoting emotional wellbeing and behavioural independence is key to recognising and developing the human rights that the NDIS is premised upon.**

It is within this context arising from the earlier recommendations and the lens of literature scanned and reviewed that the following recommendations for consideration about the model of the DP Clinic are made:

Recommendations

1. That the DP Partnership between Department of Psychological Medicine of the Children's Hospital Westmead (CHW), and the Ageing Disability and Home Care (ADHC) SBIS develop a business case for the DP Clinic to be expanded as a regional/state wide support agency for children and young people with intellectual disability and complex mental health problems that require highly specialised multi-disciplinary case management.
2. That in expanding, the DP Clinic undertakes a state wide research and development function that reflects its community developmental biopsychosocial focus.
3. That the DP Partnership continues to build research, development and training links with other CHW Departments and external agencies in the development of new ways to meet the needs of its cohort group, much as it has done with School Links, Training Curriculum and EBBST programme.
4. That the DP Clinic develops a hub and spoke model where the hub, being the present DP Clinic, supports the development of regional activity transferring and building capacity within regional areas to manage highly complex cases.
5. That the regional spoke model be developed in keeping with the strengths and needs of the area both from capacity building and cultural dimensions.
6. That the DP partnership hub develop capacity beyond being a tertiary consultative model, to also provide intensive short term stay residential programmes with intensive short term goals.
7. That the partnership with SBIS, Clinical Innovation and Governance, ADHC be continued until ADHC closes with consideration being given to utilising its highly experienced staff to build the capacity required by the DP Clinic model within both regional and remote areas.
8. That the DP Partnership responds to the gaps in training for professionals working with highly complex cases of children and young people with intellectual disabilities and mental health problems. That training be offered on site at both CHW and ADHC but also through working in partnership with tertiary educational providers in the development of accredited courses such as a targeted Post Graduate Diploma.

9. That the proposed expansion of the DP Clinic differentiates a model that takes into consideration the role of the three pilot, specialised ID multidisciplinary health clinics, building in ongoing joint consultation.
10. That the expanded DP Clinic model be premised upon the need to transfer its knowledge and expertise in building a state profile of professional practice to meet the needs of children and young people with intellectual disabilities and highly complex mental health needs.

Section 8: Final Words

The DP Clinic is highly successful, driven by professionals who have a passion for this specialised area. It is important, in the new funding environment of the NDIS to formalise the structure of the DP Clinic across CHW and ADHC agencies to avoid the reliance on the current MoU and good will arising from interpersonal relationships.

It was difficult to determine from the review the ways in which the DP Clinic verifies accountability. The ongoing development of the DP Clinic and its proposed expansion will be enhanced if there is clear and transparent evidence of the achievements and effectiveness of the service and support provided.

Recommendations

- Formalise the arrangement between CHW and ADHC in the ongoing development of the DP Clinic.
- Consider strategies for information translation on the role of the DP Clinic to relevant stakeholders.
- Review and develop accountability processes.
- Develop systematic outcomes measurement to demonstrate the effectiveness of the DP Clinic. This could also be a prompt to check on progress at six months, and celebrate effectiveness of the team.

8.1 Conclusion

The DP Clinic needs to expand its capacity to work with children and young adults who have the most complex needs in relation to intellectual disability and mental health concerns. A community developmental bio psycho social approach must be embraced and supported by necessary specific funding, cross agency, multidisciplinary decision-making and planned action. To champion this sector of the population there is an aligned role of capacity building and resource development. The quality of life of children and families is at stake. The DP Clinic provides a holistic opportunity for “working, learning and growing

together". A general sentiment from the review was expressed by one interviewee: "without it we would all be in the dark ... this shows a shared way forward".

Section 9: Appendices

Appendix A: Description of identified local and international models of care in practice for children and young people with behavioural and mental health concerns

Domestic Models of Clinical Care

Coral Tree Family Service, NSW. The Coral Tree Family Service is a unit of Northern Sydney Child and Adolescent Mental Health. This is a funded tertiary service which offers intensive family support for severe mental health difficulties, which can't be managed by local community services. Coral Tree offers a comprehensive assessment, and a week-long family admission for families and children aged 2-12 years. The program uses a multi-systemic treatment approach (i.e. addresses family, education, community and friendship networks in the individual's life). Multi-systemic therapy was developed to treat chronic juvenile offenders and has found to be effective in increasing family cohesion and decreasing youth aggression, offenses and arrests, relative to usual services (Henggeler, Melton & Smith, 1992).

At Coral Tree, families receive individual and group sessions with clinical staff, and also receive support from day and night-shift family workers to effectively manage daily interactions such as meal and bedtimes. Coral Tree also offers a day treatment program and attendance at Ardnell School for children aged 5-10 years. On average, families will enter the program 3-4 times over a 12 month period.

Rivendell Child and Adolescent Mental Health Service, Concord Hospital, NSW. This clinical care model offers a multidisciplinary approach to the treatment and care of the individual primarily, however their family is also involved in weekly review meetings. The program is funded and offered residentially or as a day program, and adolescents attend the attached school during their treatment.

Child Behaviour Research Clinic (CBRC), NSW. CBRC is a university based clinic outpatient research and training unit run through the University of New South Wales. This clinical model offers free treatment in exchange for research participation and offers predominately parent management training on an outpatient basis for 3-16 year olds with conduct problems. As outlined in the literature review, parenting training programs are one of the most effective treatment models of childhood conduct problems (Eyberg, Nelson, & Boggs, 2008).

Mercy Family Services, QLD. Mercy Family Services in Queensland offers a residential care program for young people who are out of care of their biological family, but are unable to be placed in foster or residential care because of challenging behaviours. Mercy

Family Services offers a therapeutic residential care program for 12-15 year olds for 18 months. The treatment program uses a trauma and relationship/attachment approach and involves individual strategies for emotional and behavioural management and reconnection with family where possible. There is limited empirical evidence on the effectiveness of attachment therapies and further research is warranted (Chaffin et al., 2006). Referrals for Mercy Family Services are only made through the Department of Child Safety Services.

International Models of Clinical Care

United States

Alternate Family Care, Inc. Alternate Family Care, Inc. in Florida offers a combined therapeutic and educational residential program for children with emotional and behavioural difficulties aged 6-14 years old. Alternate Family Care, Inc. also offers group homes where children receive weekly individual, group and family therapy, and continue to attend their local school, with additional educational support offered by the program.

University of Miami Parent-Child Interaction Therapy Program. The University of Miami offers a free treatment program for children aged 2-7 years old. It offers the evidence-based Parent-Child-Interaction Therapy which focuses on the therapist coaching more effective parent-child interactions through a wireless headphone from a one-way mirror during parent-child sessions. Parent-Child-Interaction Therapy has been found to be more beneficial than a wait-list control for improving child behaviour problems, with gains maintained at 4-month follow-up (Schuhmann, Foote, Eyeberg, Boggs & Algina, 1998).

United Kingdom

Childhood First: Healing Hurt Minds. The “Childhood First: Healing hurt minds” is a therapeutic program to manage challenging childhood behaviours which have resulted from trauma and attachment issues in early life. The program uses Integrated Systemic Therapy (i.e. looking at the relationship dynamics in the individual’s life) and includes several residential facilities throughout the UK. The treatment program focuses on individual therapy for the child while also working with the family where possible, and involves an educational curriculum and ongoing contact with local schools. To the author’s knowledge, there has been no empirical study that has looked at the effectiveness of Integrated Systemic Therapy on childhood behaviour problems.

The Childhood First program reported a significant reduction in the total number of difficulties reported by the child’s teacher, and significant improvements in the child’s overall level of health over a six-month period. In addition, young people in this program had increased educational attainment, as well as improved employment (e.g. 87% went on to full-time employment) and functional outcomes relative to a national cohort study of

other children in care. Finally, a recent inspection report awarded the program as outstanding.

The Croft Child and Family Unit Cambridge. This is an intensive therapeutic program for children aged 0-12 years old with developmental disorders, co morbid emotional and behaviour problems, and their family including siblings. In the residential program, children and their families stay in the ward during the week and return home on weekends. There is also a day program and an integrated educational program. The typical placement is 6 weeks. The program involves both assessment and a variety of treatment programs including family therapy, group therapy, education curriculum, attachment therapies, cognitive behavioural therapy, music therapy, medication and re-feeding for severe eating disorders. The program has a multidisciplinary approach including psychiatrists, psychologists, nurses, teachers, social workers, music therapists and dietician.

Kisimul. This is a residential treatment and educational program for children with autism or learning disabilities and challenging behaviours. The program has a thirty-year history, and offers two types of schools including one for 8 to 19 years old, and one specifically for boys with Asperger's syndrome, challenging behaviours and ADHD or ADD. An individualised, structured program is designed for each child, and there is a high staff to child ratio of at least 1:1. Kisimul also offers post-school placements in small adult homes for individuals aged eighteen and over. The program has twice won the Teacher of the Year Award (Excellence in Special Needs Teaching – East Midlands Region). Their latest published report in 2007 was an overall outstanding rating.

Pegasus School. The Pegasus school offers an educational and therapeutic program for individuals aged 8-19 years with autism, challenging behaviours and communication and learning difficulties. The program is offered as a day or residential program. The residential program is either for full-time for 52 weeks, school terms only or between 39-51 weeks. The multi-disciplinary team includes teachers, therapists and support staff. The program makes their yearly inspection reports publically available on their website and their latest rating was good, which indicates a high quality standard overall. The program has also been awarded a British health and safety council 5 star award.

Ridgeview Children's Home Inc. This residential staff-run group home is designed for children aged 3-12 years old with complex mental health difficulties, and co-morbid developmental disabilities. Therapeutic services are offered and the home has links with local schools.

Young Foundations. This program offers three residential homes in Scotland, North-East England and the midlands for children with complex needs. The program has a 12 week assessment period with psychologists, psychiatrists and residential staff. The team develops an individual treatment plan which includes monitoring emotional and

behavioural well-being as well as psychological therapy. Psychologists and psychiatrists provide ongoing support to residential staff.

Canada

Better Behaviour Services (BBS) at the Centre for Addiction and Mental Health (CAMH). This program offers an evidence-based outpatient program for disruptive child behaviours. It consists of the 15-week Incredible Years Parenting program (Reid, Webster-Stratton & Hammond, 2003) to increase positive behaviour, reduce parenting stress and decrease problematic behaviours. In conjunction, the Dinosaur Skills Program is run for 6-8 years old. The service also runs a CATCH classroom which is a 10-month educational day program for 6-8 years who receive individualised treatment plans.

Peel Children's Centre. This is a community outreach program for complex cases with multiple family stressors, limited coping strategies, and risk of family breakdown which haven't responded to standard models of care. The program uses a "wraparound process" which is a strengths-based approach pioneered by VanDenBerg and Grealish (1996) that capitalizes and builds on existing social and community supports to the family. Peel's Children's Centre also offers other services such as respite care, a day program, a residential program, and psychological and psychiatric services.

Web sites for Clinical Care Models

Alternate Family Care, Inc. in Florida, United States

<http://www.altfam.com/>

Better Behaviour Services (BBS) at the Centre for Addiction and Mental Health (CAMH), Canada

http://www.camh.ca/en/hospital/care_program_and_services/child_youth_and_family_program/Pages/better_behaviours_science.aspx

Coral Tree Family Service, NSW, Australia

<http://www.nscchealth.nsw.gov.au/services/coraltree/index.shtml>

Child Behaviour Research Clinic, NSW, Australia

<http://cbrc.psy.unsw.edu.au/>

Childhood First: Healing hurt minds, United Kingdom

<http://childhoodfirst.org.uk/our-services/residential-care/greenfields/>

Croft Child and Family Unit Cambridge

<http://www.cpft.nhs.uk/training/the-croft-child-and-family-unit-cambridge.htm>

Peel Children's Centre, Canada

<http://www.peelcc.org/en/services-for-professionals/prof-peel-wraparound>

Pegasus School, UK

<http://www.senadgroup.com/pegasus/>

Mercy Family Services, QLD, Australia

<http://www.mercyfamilyservices.org.au/our-programs/out-of-home-care/therapeutic-residential-care/>

University of Miami Parent-Child Interaction Therapy Program, Miami, US

<http://pediatrics.med.miami.edu/mailman-center/clinical-services/developmental-behavioral-pediatrics/parent-child-interaction-therapy/>

Rivendell Child, Adolescent and Family Unit, NSW, Australia

<http://www.sswahs.nsw.gov.au/services/PTN/rivendell.html>

Ridgeview Children's Home Inc. UK

<http://www.oarty.net/default.asp?id=1532&orgid=44>

Young Foundations, UK

<http://www.youngfoundations.com/Clinical-Support-2-42.html>

Appendix B: People with Intellectual Disability and Co-morbid Mental Health Issues: an environmental scan of Australia

This appendix lists the policies, frameworks and services relating to intellectual disability and mental health issues for each state and territory in Australia.

Australia/ New Zealand

Intellectual disability mental illness is an unmet need (media release, 1 June 2011) – The Royal Australian and New Zealand College of Psychiatrists (RANZCP)

RANZCP released a statement in 2011 “calling for better recognition, services and funding for people who have both an intellectual disability and mental illness” in Australia and New Zealand. In this release, RANZCP made mention of their endorsement of the NSW Councils for Intellectual Disability position statement *The place of people with intellectual disability in mental health reform*.

The media release can be accessed on

http://www.nswcid.org.au/images/pdfs/Intellectual_disability_and_mental_illness_June_2011.pdf

Intellectual disability and mental illness (briefing paper, October 2012) – The Royal Australian and New Zealand College of Psychiatrists (RANZCP)

In 2012, RANZCP provided a briefing paper to The Hon Mark Butler, former Minister for Mental Health giving a range of recommendations in the policy, services, and training and education context to achieve “better recognition, services and funding for people who have both an intellectual disability and mental illness” (p. 1). In this briefing, RANZCP points out that “the RANZCP recommendations for improved services, expertise and quality of care are in line with Australia’s obligations under the United Convention on the Rights of Persons with Disabilities” (p. 5).

It can be accessed at

https://www.ranzcp.org/getattachment/Policy-and-advocacy/Social-policy-and-health-inequality/Intellectual-Disability-and-Mental-Illness-briefing-paper-Oct-2012_final.pdf.aspx

New South Wales

Clinical Innovation and Governance at the NSW Department of Family and Community Services, Ageing, Disability and Home Care (ADHC)

Clinical Innovation and Governance was established to “provide leadership and coordination of services for people with complex needs and challenging behaviour” (ADHC, n.d.). It works with “a wide range of stakeholders providing specialist support in challenging and offending behavior”, including the following NSW Government agencies:

- Health
- Mental Health
- Corrective Services
- Community Services
- Housing
- Education
- Juvenile Justice
- Ombudsman
- Office of the Public Guardian
- Office for Children (Children’s Guardian)

Clinical Innovation and Governance consists of the Policy and Practice Team (PPT), Integrated Services Program (ISP) and Statewide Behaviour Intervention Service (SBIS). Clinical Innovation and Governance funds the Chair of Intellectual Disability and Mental Health at UNSW. The university chair “aims to improve support to people with an intellectual disability and mental illness through:

- teaching in the areas of mental health and intellectual disability to undergraduate and postgraduate medical students;
- engagement in and promotion of relevant research ;
- working with NSW Health to deliver psychiatric and clinical services to people with an intellectual disability; and
- the building of expertise in the diagnosis and treatment of people with an intellectual disability and mental illness”.

See more at:

http://www.adhc.nsw.gov.au/about_us/our_structure/clinical_innovation_and_governance#ppt

Intellectual Disability Mental Health e-Learning – Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Medicine

The Intellectual Disability Mental Health e-Learning tool is a free web based tool with the aim of strengthening health and disability professionals in supporting people with intellectual disability and mental health issues. The tool has been developed by the Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Medicine and was funded by the NSW Government.

It is available at <http://www.idhealtheducation.edu.au/>.

Intellectual Disability Mental Health (IDMH) Data Linkage Project – Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Medicine

This project seeks to build an epidemiological profile on the health and mental health of persons with intellectual disability by linking existing administrative datasets from the NSW State Government agencies of NSW Department of Family & Community Services - Ageing, Disability & Home Care (ADHC) and the NSW Ministry of Health. The project will also link with NSW Mortality data maintained by the NSW Register of Births, Death and Marriages (RBDM) and the Australian Bureau of Statistics (ABS).

The analysis of linked health and disability service data has the aim to develop understanding on:

- the mental health profile of people with ID across the lifespan;
- the correlates of mental disorders and predictors of mental health outcomes;
- the intersections that people with ID have with the health sector;
- whether or not the current health and disability service systems are meeting these needs;
- identifying discernable patterns of service use with the view to improving those service pathways engaged;
- the impact of any funding initiatives, policy developments or staff education/ training programs targeting this population group.

See more at

<http://3dn.unsw.edu.au/project/intellectual-disability-mental-health-idmh-data-linkage-project>

Service Framework to Improve the Health Care of People with Intellectual Disability (July 2012) – NSW Ministry of Health

The service framework is NSW Health's response to "promote a broader understanding of the health needs of people with intellectual disability and their right to effective services and care and improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with intellectual disability" (p.1). This includes services in mental health as the framework recognises that "people with intellectual disability across all ages groups are more at risk of developing mental illness than the general population" (p. 8).

The framework is available at

http://www0.health.nsw.gov.au/pubs/2012/pdf/service_framework_2012.pdf

NSW Mental Health Research Framework (updated February 2012) – NSW Ministry of Health, Mental Health and Drug & Alcohol Office

The framework “has been written to improve collaboration and strengthen the research effort across the NSW Health Mental Health Program. The Framework applies to mental health research funded by MHDAD” (p. 3). This includes research in the area of intellectual disability and mental health.

It is available at

http://www0.health.nsw.gov.au/resources/mhdao/pdf/mental_health_framework.pdf.

Disability Action Plan 2009-2014 – NSW Ministry of Health

The Disability Action Plan (DAP) was developed by NSW Health to “meet its obligations under both State and Commonwealth legislation” (p. 6), namely under the UN Convention on the Rights of Persons with Disabilities (CRPD), the Disability Services Act 1993 (DSA) and the Australian Human Rights Commission (AHRC). It recognises the diverse health needs of people with disability, including people with intellectual disability. It lists current initiatives in the area of disability and health, as well as actions to be achieved by 2014.

The DAP can be accessed at

http://www0.health.nsw.gov.au/pubs/2010/pdf/disability_action_plan.pdf.

Behaviour Support: Policy and Practice Manual: Guidelines for the provision of behaviour support services for people with an intellectual disability (2009) – NSW Department of Family and Community Services, Ageing, Disability and Home Care (ADHC)

The guidelines alert behaviour support practitioners to the high prevalence of mental illness in the population of people with intellectual disability and stress the need for comprehensive assessment including psychiatric/paediatric assessment (p.55-56).

The manual can be accessed at

http://www.adhc.nsw.gov.au/_data/assets/file/0003/228360/341_Behaviour_Support_Policy_and_Practice_Manual_Part_1_web.pdf

Stronger Together 2: A new direction for disability services in NSW 2006–2016 (ST2) – NSW Department of Family and Community Services, Ageing Disability and Home Care (ADHC)

Under ST2, ADHC commits to establishing “a joint professorship with a university in NSW in disability and mental health to build the evidence base for good practice; \$0.7 million over five years” (p. 23).

http://www.adhc.nsw.gov.au/_data/assets/file/0004/227866/StrongerTogetherPlan_2.pdf

As a result, Clinical Innovation and Governance at ADHC funds the only university chair in intellectual disability mental health in Australia, held by Associate Professor Julian Trollor at the Department of Developmental Disability Neuropsychiatry, UNSW.

The Place of People with Intellectual Disability in Mental Health Reform (position paper) – National & NSW Councils for Intellectual Disability and Australian Association of Developmental Disability Medicine

The position paper calls for action in mental health reform as it applies to people with intellectual disability. The authors' proposition is:

People who have both an intellectual disability and a mental illness need to be included from the start in mental health reform. They currently have very poor access to appropriate mental health services.

Government needs to address this problem, in particular by funding specialised intellectual disability mental health psychiatrists and nurses who can act as a consultancy, training and research adjunct to mainstream mental health services. (p. 1)

It can be accessed at <http://www.nswcid.org.au/images/pdfs/idmh1011.pdf>.

NSW Mental Health Commission Act 2012

The Mental Health Commission Act was passed through NSW Parliament in 2012. It states in Section 12 (2b) that "in exercising its functions under this Act, the Commission is [...] to take into account co-morbid issues associated with mental illness, such as drug and alcohol use and disability" (Mental Health Commission Act 2012, p. 7). Mr Andrew Constance, former Minister for Ageing and former Minister for Disability Services said in the debate of the Mental Health Commission Bill 2011:

What is particularly pleasing about this bill—no doubt it will be universally supported—is that it is about trying to get those structures right. For too long the mental health system has been fragmented and poorly resourced. The outcomes have meant that all too often mental health caseworkers in the community do not have the capacity to meet the needs of those who are suffering. All too often people with a dual diagnosis of disability and mental health have fallen directly into the crack between mental health and the disability system. Usually in that situation the person with dual diagnosis issues has become stuck in the middle of an argument between mental health services and disability services as to who should take responsibility for that individual. (Parliament of NSW, 2012)

Victoria

Centre for Developmental Disability Health (CDDHV)

CDDHV is an academic unit

established by the Victorian State Government to improve health outcomes for people with developmental disabilities. The Centre works with mainstream healthcare providers to build professional level understanding in relation to the health and healthcare issues of people with disabilities. [The] aim is to build the capacity of mainstream health services to optimise health, function and wellbeing and therefore to enhance the quality of life for people with disabilities. (CDDH, n.d.)

The centre is involved in the areas of clinical services, education and training, research, and systemic advocacy and policy.

The following publications by the centre include information and guidance in the area of intellectual disability and mental health:

Health Assessments for People with an Intellectual Disability: making them work and making a difference 2011 (case studies)

<http://www.cddh.monash.org/assets/documents/health-assessments-case-studies-2011.pdf>

Accessing Mental Health Services for People with an Intellectual Disability (factsheet)

<http://www.cddh.monash.org/assets/documents/cddhv-health-services.pdf>.

Challenging behavior (factsheet)

<http://www.cddh.monash.org/assets/fs-challengbev.pdf>

Depression in Adults with Intellectual Disability – Checklist for Carers

<http://www.cddh.monash.org/research/depression/> (general information)

<http://www.cddh.monash.org/research/recent-projects/depression-dd.pdf> (study overview)

Victoria Department of Health

Victorian population health survey of people with an intellectual disability (factsheet, October 2011)

[http://docs.health.vic.gov.au/docs/doc/3CB1F60EE2C47605CA25791F00146743/\\$FILE/summary%20of%20findingsVPHS-ID%202009.pdf](http://docs.health.vic.gov.au/docs/doc/3CB1F60EE2C47605CA25791F00146743/$FILE/summary%20of%20findingsVPHS-ID%202009.pdf)

Depression and Victorians with an intellectual disability (factsheet, March 2011)

[http://docs.health.vic.gov.au/docs/doc/08CD4F94508603D2CA25791F001B215F/\\$FILE/Depression%20VPHS-ID%202009.pdf](http://docs.health.vic.gov.au/docs/doc/08CD4F94508603D2CA25791F001B215F/$FILE/Depression%20VPHS-ID%202009.pdf)

An introduction to Victoria's public clinical mental health services (January 2006) – Victoria Department of Human Services

This document lists specialist mental health services available in Victoria, including services for people with an intellectual disability. It recognises that "intellectual disability is

not a mental illness and requires very different specialist skills than those offered by mental health services. However people with intellectual disabilities can also suffer from a mental illness" (p. 41). It further recognises that children and adolescents with developmental or learning difficulties and/or an intellectual disability are at higher risk of developing a mental illness.

<http://www.health.vic.gov.au/mentalhealth/services/intro-mhservices.pdf>

South Australia

Department for Communities and Social Inclusion – Government of South Australia

The Department for Communities and Social Inclusion has developed a range of factsheets on the topic of intellectual disability and mental health issues, including information on symptoms, causes, treatment and where to get support:

Intellectual disability and mental illness (dual disability)

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/intellectual-disability-and-mental-illness-dual-disability.pdf>

Intellectual disability and schizophrenia

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/intellectual-disability-and-schizophrenia.pdf>

Intellectual disability and depression

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/intellectual-disability-and-depression.pdf>

Intellectual disability and bipolar disorder

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/intellectual-disability-and-bipolar-disorder.pdf>

Intellectual disability and anxiety disorders

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/intellectual-disability-and-anxiety-disorders.pdf>

Disability information factsheet

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/disability-contacts-and-locations.pdf>

Centre for Disability Health (CDH) – Department for Communities and Social Inclusion, Government of South Australia

The Centre for Disability Health (CDH) is a statewide, primary health care service for people with disability who are registered with Disability Services. It supports people in the areas of:

- Intellectual Disability
- Acquired Brain Injury
- Neurological Conditions
- Physical Disability
- Dual Diagnoses (intellectual disability and mental health conditions)

See more at

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/centre-for-disability-health.pdf>

GAP Service: child and youth mental health service – Department for Communities and Social Inclusion, Government of South Australia

The GAP Service is a mental health assessment service for young people between the ages of 8 and 21 years with developmental disabilities, emotional or behavioural problems. The GAP Service offers short-term mental health assessment from a developmental perspective. It provides the young person, family and service coordinator with practical and user-friendly advice on mental health management. The GAP Service links young people with other community services or agencies to help them access ongoing and sustainable support. The GAP Service is a short-term service and does not offer ongoing care or involvement.

See more at

<http://www.sa.gov.au/upload/franchise/Community%20support/Disability/information-sheets/gap-service.pdf>

Western Australia

Psychiatric morbidity and intellectual disability: a Western Australian record linkage study – Centre for Clinical Research in Neuropsychiatry (CCRN), Department of Health, Government of Western Australia

This study represents a population-based approach to the study of co-occurring intellectual disability and psychiatric illness. The study has linked two population-based registers maintained in separate administrative health jurisdictions in Western Australia, namely the Mental Health Information System and the Intellectual Disability Register, in order to build a research database for the study of co-occurring disorders. The aims of this study are:

- To estimate the prevalence of psychiatric disorders among persons with intellectual disability and, conversely, the prevalence of intellectual disability among persons with a psychiatric disorder
- To describe the disability and service utilisation profile of persons with a dual diagnosis
- To examine, in particular, schizophrenia and co-occurring intellectual disability

Morgan, V. A., Leonard, H., Bourke, J., & Jablensky, A. (2008). Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. *The British Journal of Psychiatry*, 193(5), 364-372.

See more at

<http://www.health.wa.gov.au/ccrn/research/morbidity.cfm>

Tasmania

A Healthy Tasmania: Setting new directions for health and wellbeing (2012) – Department of Health and Human Services

This report is the Tasmanian government's strategy in response to the *Fair and Healthy Tasmania Strategic Review* in 2010. The report acknowledges that "people living with disability, particularly intellectual disability, are [...] more likely to experience poorer health outcomes" (p. 14), including mental illness. It refers to the *National Disability Strategy 2010–2020* under which "the Council of Australian Governments is working to support people living with a disability to attain the highest possible health and wellbeing outcomes throughout their lives".

See more at

http://www.dhhs.tas.gov.au/_data/assets/pdf_file/0009/115200/Healthy_TAS_2012_Web.pdf

Northern Territory

No specific activities in relation to dual diagnosis found

Australian Capital Territory

Mental Health Service for People with Intellectual Disability – Mental Health ACT and Disability ACT

The Mental Health Service for People with Intellectual Disability is a cooperative initiative between Mental Health ACT and Disability ACT. It is a specialist, cross-agency, consultation liaison service providing comprehensive clinical assessment and psychiatric

treatment to people with an intellectual disability and a mental illness. The team is co-located with Disability ACT and provides mental health expertise, training and education to community professionals and carers assisting people with an intellectual disability and a mental illness. This multidisciplinary service collaborates with treating practitioners, families, carers and other relevant agencies.

See more at

<http://www.health.act.gov.au/c/health?a=sp&pid=1316133581&site=51117&servicecategory=12>

Queensland

Queensland Centre for Intellectual and Developmental Disability (QCIDD) Clinic – School of Medicine at the University of Queensland

QCIDD operates a clinic which provides the clinical services to adults with intellectual or developmental disability (17 years and older):

- Comprehensive health assessments
- A psychiatric assessment service
- Telephone/email consultation services, including behaviour support consultancy

See more at:

<http://www.som.uq.edu.au/media/279226/Clinical%20Information%20Brochure%20for%20WEB.pdf>

Queensland Centre for Intellectual and Developmental Disability (QCIDD) – School of Medicine at the University of Queensland

QCIDD is active in the areas of research, teaching and clinical activities in the area of intellectual disability. The centre is led by Professor Nicholas Lennox and is part of the School of Medicine at the University of Queensland. QCIDD has published work in the area of intellectual disability and mental illness (dual diagnosis).

Lessons from the Labyrinth: Views of Residential Care Officers on Barriers to Comprehensive Health Care for Adults with an Intellectual Disability

http://www.som.uq.edu.au/media/197676/lessons_from_labyrinth.pdf

Sand in Society

http://www.som.uq.edu.au/media/197709/sand_in_society.pdf

Not On The Same Page: Report on the dual diagnosis project

http://www.som.uq.edu.au/media/197694/not_on_the_same_page.pdf

Absolutely everybody: Enabling Queenslanders with a disability (Action plan 2011-2014) – Department of Communities, Disability and Community Care Services, Queensland Government

The Queensland Government “commits to the development of three, three-year action plans, and in the tenth year, a final year of consolidation” (p. 3); the 2011-2014 is the first out of these three actions plans and commences the delivery of *Absolutely everybody: enabling Queenslanders with a disability*. Whilst there are no specific actions that refer to providing support to people with dual diagnosis, the action plan does refer to agency actions in relation to mental health, namely,

1.2.2.5 Conduct a screening trial at selected Magistrates Courts to identify people with intellectual, cognitive or mental health impairments and link these people to any appropriate and available support services

4.2.1.3 Continue to offer ‘Managing cultural diversity in mental health’ training for future Local Health and Hospital Networks mental health clinicians, including training in working with interpreters

The action plan can be accessed on

<http://cabinet.qld.gov.au/documents/2011/sep/absolutely%20everybody/Attachments/Attachment%202%20-%20Absolutely%20everybody%20-%20Whole%20of%20Government%20action%20plan%202011-14.PDF>

Positive Futures (reform) – Department of Communities, Child Safety and Disability Services, Queensland Government

As “one of the most significant reforms ever undertaken in Queensland's disability sector” (Queensland Government, n.d.), this reform promotes a positive behaviour support approach for adults with an intellectual disability who exhibit challenging behaviours.

As part of this reform, the Specialist Response Service (SRS) works with disability service providers in Queensland to support adults in the development of positive behaviours and skills to improve their quality of life and enable them to participate actively in their communities.

According to the Queensland Government “this model is providing adults the best opportunity to have a positive future and greater involvement in their community” and “integrates disability and mental health service responses”.

The SRS has multi-disciplinary teams including psychologists, occupational therapists, speech and language pathologists and learning disability nurses who work with teams of specialist care officers, psychiatrists, neuropsychologists and general practitioners. SRS teams provide specialist clinical support and expert advice to disability service providers in

developing positive behaviour support plans and where possible, reducing or eliminating the use of restrictive practices.

The program is underpinned by active support, person centred and positive behaviour support approaches. The evidence base for the program development is provided by the Centre for Excellence for Behaviour Support, who leads research and provides specialist expertise and knowledge.

See more at

Positive futures

<http://www.communities.qld.gov.au/disability/key-projects/positive-futures>

Centre for Excellence for Behaviour Support

<http://www.communities.qld.gov.au/disability/key-projects/positive-futures/a-centre-of-excellence-for-behaviour-support>

Section 10: References

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