INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

COMMENTS FROM THE ASSOCIATION OF DOCTORS IN DEVELOPMENTAL DISABILITY (ADIDD)

TERMS OF REFERENCE	COMMENTS
a) The historical and current level of funding and extent of unmet need	**MENTAL HEALTH:** • **Lack of Resources:** – There is a serious paucity of mental health resources for the entire population. – Psychiatry of old age, of eating disorders, of personality disorder, of anxiety states and even child services are extremely limited. – Minority groups such as persons with intellectual disability (ID) and mental health problems miss out. – The mental wellbeing of people with ID is essential for sustained familial relationships and good quality of life. Result**:** – Currently, there is heavy reliance on Private Psychiatrists. Typically these services are difficult to access and afford for the disabled population. Solutions: – There is an urgent need for increased funding to improve the access to MH services for clients with an intellectual disability. – A representative from the Private Psychiatrists group should be on any planning committee. • **Shortage of Experienced Staff:** – There is limited expertise in mainstream MH of the health needs of people with ID and associated mental health issues. – There is a shortage of psychiatrists, nurses and allied health staff trained in intellectual disability and psychiatry. – 40% of people with intellectual disabilities have mental health problems. – The diagnosis and management of mental illness in the context of intellectual disability is a difficult and challenging field. Result: – Diagnostic over-shadowing is common; i.e. serious Axis I psychiatric diagnoses are misdiagnosed as “behavioural”. – There is an inadequate workforce in place to recognise early signs of mental illness and implement early intervention programs. – When the mental health problems have been diagnosed, the prescribed therapies are often not adhered to. – Presentation to Emergency Departments in crises which could have been avoided. – Further exacerbation of symptoms due to the traumatic nature of the whole experience.

- **Lack of Training:**

– There is a serious lack of training opportunities for Psychiatry Registrars, Allied Health and Nursing staff in the health needs of people with intellectual disability and mental health problems.
– Apart from the recently created psychiatry registrar position in IDMH by the SESIAHS Mental Health Service, there are essentially no training positions.
– There is limited exposure of medical students to intellectual disability within the medical curriculum.
– There are no training programs for nurses in the field of intellectual disability mental health.

Results:

– There is a misunderstanding of the needs of people with intellectual disability and mental health problems and there is a stigma associated with this field.
– Intellectual Disability is not considered by trainees as a career pathway.
– There is a limited workforce with experience in this field.

Solutions:

– There is an urgent need to improve the training in, and exposure of mainstream MH staff to intellectual disability.
– Medical Curricula should include training in intellectual disability to improve the understanding of the mental health problems in people with intellectual disabilities and to reduce the stigma of intellectual disability mental health.
– Consider adopting the UK model where intellectual disability mental health is a recognised sub speciality of psychiatry and is given the same importance and status as that of forensic psychiatry and child and adolescent psychiatry.
– The establishment of a **Chair of Intellectual Disability Mental Health** (IDMH) by ADHC has been a successful step in the improvement of the training in IDMH and the identification of specific career pathways for Psychiatrists in ID.
– Implement the recommendations of the NSW Health *Service Framework for the health care of people with intellectual disabilities* for the establishment of Tier 5 units:

  - **Tier 5 – NSW Health Service Framework:**
    - *The establishment of a **Clinical Network** [as part of the Agency for Clinical Innovation] to provide support and clinical leadership to health professionals working with people with intellectual disabilities, to coordinate the development of intellectual disability health services, and to provide input into research, education and training.*
    - *The establishment of **three professional chairs** of intellectual disability medicine in intellectual disability **medicine**, intellectual disability **nursing**, and intellectual disabailty **allied health**, linked to clinical services and faculties of medicine nursing and allied health at appropriate universities.*

- **Gaps in Services:**

– There are many gaps in services and pathways to care as well as inequity to access for clients with ID and MH problems.
– The ID population is a heterogeneous group with a wide range of clinical needs. The needs of a person with a borderline to mild ID are significantly different of a person with a severe to profound disability. Persons with multiple disabilities have a range of complex mental and physical needs.
– There is a lack in client focus and flexibility in services to meet their needs.
– The prevalence of Autistic Spectrum Disorders (ASD) is similar to that of schizophrenia and yet the funding for mental health services for people with ASD is significantly less.
– Mental Health services may refuse to assess ADHC clients or those with an IQ below 70, arguing that challenging behaviour is not a mental illness, as a device for compensating for a lack of resources.
– There are a group of clients with ID and challenging behaviours who are not eligible for mainstream MH services because they do not have an Axis I Disorder (DSM-IV diagnosis) such as schizophrenia and bipolar disorder. Yet they have extremely challenging behaviours associated with profoundly altered brain function, need the expertise of a psychiatrist and do benefit from psychotropic medication.
– There are particularly vulnerable groups that include those with:
  - Clients with mild ID and comorbid MH issues who fall in the gap between ADHC and MH services.
  - Clients with ID and severe challenging behaviours without a formal psychiatric diagnosis.
  - Youth transitioning form paediatric to adult services.
  - Autism Spectrum Disorder and particularly Asperger's syndrome.

<u>Example</u>:

– *Clients with Klein Levin syndrome have a compulsion to bite off their fingers as part of the behavioural phenotype*.

<u>Solutions</u>:

– There needs to be clear, transparent and consistent pathways and equity of access.
– There should be clear lines of departmental responsibilities across the spectrum of needs and funding allocated accordingly.
– Services should be flexible to cater for these different needs, with some services accessed directly via mainstream MH Health and others by a specialist Disability Health Team.
– There is a need for a greater public awareness of these issues and mainstreaming of services for this population.

Case Scenario:

- *Mr John Smith, aged 23 yrs, suffers from Asperger's syndrome and major Depression. He lives with parents and younger sister with ASD. John was bullied and victimised at school and eventually home-schooled. He spends life on computer developing "special" friendships which inevitably disappoint.*
- *He has had several recent severe episodes of depression including suicidality; he has slashed his throat with a knife in a shopping centre carpark. There have also been altercations with wildlife officers over a sick penguin. John is very prescriptive about justice and behaviour and will want to correct other road users. He presented several times to a MH inpatient unit suicidal.*
- *He seriously assaulted a nurse who insisted that he have his meal in a noisy cafeteria and charged by police. He got off on Section 32 Mental Health (Criminal Procedure) Act*.
- *He is very much at risk of further suicide attempts.*
- *He does not qualify for an ADHC funding package. There is no community participation, no support. He is desperately lonely.*
- *Mental Health support offered but only if he joins a group therapy programme, the prospect of which terrifies him.*

- **Shortage of Specialist Disability Teams:**

- Currently, there are only a few specialist Health Services and even fewer Mental Health Services across the state.
- These Mental Health Services are located in metropolitan areas and provide limited outreach clinics to regional and rural areas.
- There are significant areas in the state where there are no paediatric or adult assessment services.
- The existing assessment services are working at capacity and there are long waiting lists.

Solutions:

- In view of all of the above, there is an urgent need for additional funding to enhance and develop Specialist Disability Health Teams to address the gaps in services.
- Such enhancement funding should be recurrent and insulated from other demands from parent services.

Disability Health Teams (Tier 4 - NSW Health Service Framework):

- The provision of specialist clinical services for people with intellectual disability, particularly those with complex problems.

Mental Health Intellectual Disability Services:

- These specialist services would provide consultation, support and capacity building of mainstream MH services.

Partnerships and Networks:

- MoU between NSW Health, Mental Health and ADHC to clearly delineate responsibilities.

❖ **Disability Health Teams (Tier 4 - NSW Health Service Framework):**

– Implement the recommendations of the NSW Health *Service Framework for the health care of people with intellectual disabilities* for the establishment of Tier 4 Teams:
  - o *The establishment of Clinical Nurse Networks across Area Health Services.*
  - o *The establishment of small, specialised, multidisciplinary health teams across Area Health Services to provide specialised health services to people with intellectual disability, building on existing specialised services.*
  - o *The establishment of larger, specialised, multidisciplinary health teams across Area Health Services to provide comprehensive, specialised health services to children, adolescents and adults with intellectual disability, building on existing specialised services.*
– These multidisciplinary teams would consist of:
  - o Medical (incl. Paediatricians, Psychiatrists, Physicians and Registrars),
  - o Allied health (incl. Occupational Therapists, Physiotherapists, Speech Pathologists, Psychologists, Dietitians) and
  - o Nursing staff

❖ **Mental Health Intellectual Disability Services:**

– These specialised MH services for people with ID would provide support for, and up-skilling of mainstream MH units to enable clients to have equitable access to mainstream MH services.
– Ideally referrals to such teams would require an assessment by CAMHS/Community MH teams first. This has been shown to be important in familiarising those teams with ID presentations.
– The teams could comprise of a Psychiatrist, Psychologist, MH Nurse and hopefully a rotating training position for a Registrar.
– These services should be integrated with the Tier 4 Specialist Multidisciplinary Disability Health Teams. Access to a Physician is an essential component of any IDMH service.
– These specialised intellectual disability mental health services should work in partnership with mental health and ADHC.
– There are already pilot projects in SSW Area Health Service, in another successful form within SESIAHS, and such a partnership was showcased through the Rydalmere Intensive Support Programme before its demise.

❖ **Partnerships and Networks:**

– There is a great need for closer collaboration between ADHC and Mental Health services to allow for dialogue particularly over the management of difficult cases and to ensure that the delivery of services are efficient and cost-effective.
– There may be a strong case for NSW Health to assume responsibility for all ADHC clinical services in the interests of integration and streamlining of service delivery. This would conveniently subsume many of the following suggestions regarding closer cooperative ventures between services.
– There needs to be MoU between NSW Health, Mental Health and ADHC to clearly delineate responsibility and to cover the whole spectrum of client groups. In order for such a model to be successful, however, a number of management, resource and service delivery issues have to be addressed in the mental health arena.

ADHC CASEWORKERS:

- **Waiting lists:**

– There are long waiting lists for caseworkers and other services (e.g. behaviour management).
– Caseworker input should be available for each client, at least initially.
– Some ADHC funded services are only available if you have an ADHC case manager.
– Many require case management who do not attract ADHC funding because of cognitive capacities just outside threshold.

- **Ongoing support:**

– Currently ADHC case management is either on an occasion of service basis or task specific.
– In reality, this means that support is only available for crisis situations and there is often poor coordination of service delivery.

Solution:

– Provision of a designated case manager for ongoing support and coordination of services.
– In this way, there would be greater degree of consistency and efficiency and thereby, greater capacity to manage larger number of cases.

ADHC THERAPY INTERVENTIONS:

- **Waiting lists:**

– Notwithstanding the strong evidence for the importance of early intervention, there are cases of children waiting years for early intervention therapy. There is a huge level of unmet needs in therapy.

Case Scenario:

Child R was referred to early intervention services (ADHC) for speech therapy at age 6 months because of a severe communication disorder. Waiting for services, he only received 3 visits to "lunch" club for feeding difficulties and no speech therapy assessment. The parents had to access private therapy services at their expense. A "Transition to School" service funded by ADHC through an NGO service resulted in a pre school visit, one observation in a service facility and one meeting with the parent. At age 5 years and 9 months, they were referred to school age services in (ADHC) after receiving no service. They then went on to another waiting list.

- **Lack of Resources:**

– There is a lack of timely, comprehensive and effective prevention and early intervention services for people with disability.
– The chronic lack of resources for children with a disability or chronic illness has not only resulted in unacceptably long waiting times for assessment and treatment but has also limited the capacity of these services to provide early intervention and prevention.

Solution:

– Prevention and early intervention need a long term commitment that is too often forgotten in light of more acute problems and changes in management.

RESPITE AND ACCOMMODATION:

- **Waiting lists:**

– There are inadequate places for children and adults.
– Parents are not given a timeframe for when services may be available, they are not given options for other services, and they are not advised of the need to re-refer for ongoing needs.

- **Parents/ Siblings:**

– An inappropriate and inordinate expectation that parents/siblings will remain actively involved in the direct care/ management and coordination of services for the intellectually disabled until late in adult life.
– Parents and foster carers often burn out as they also need respite.

- **Infants with Complex Medical Problems:**

– There is a small but constant stream of infants with extremely high medical needs who require regular high quality out of home respite and this is not available in the public system.
– Much of the brokerage is done through very costly NGO's and obtaining clear information is very problematic.
– There is minimal planning for future needs.

- **Ageing Carers:**

– Young adults with severe / profound disabilities often have to rely on ageing carers because of the lack of resources.

- **Mental Health Co-morbidities:**

– Few services exist that can manage young people with intellectual disability and associated mental health problems and mainstream MH do not accept responsibility for people with intellectual disability.
– There is still no clear and orderly plan to accommodate people with high medical needs and those with severe challenging behaviour and/or dual diagnosis who have been often identified in childhood.

Result:

– It is tragic and demeaning for families to have to break down or "give up their child" to get a service in this civilised society in which we live!!

Solution:

– There is an urgent need for respite care and supported accommodation, particularly for people with intellectual disability and associated mental health problems.

TERMS OF REFERENCE	COMMENTS
b) Variations in service delivery, waiting lists and program quality between: ➢ services provided, or funded, by ADHC ➢ ADHC Regional Areas	**MENTAL HEALTH:** • **Artificial separation** of Disability and Health Sectors: – Result: fragmentation of delivery of care; disputes over who contributes what. – Solution: enhance fluidity between teams; develop and enhance joint forums (as per the ADHC/Mental Health MOU); cross secondment between Mental Health and Disability team. • **Lack of shared facility** for joint (ADHC & Health) triage and assessment of urgent cases: – Result: access to mental health services is poor; cases 'bounce' between services, with delays in assessment and treatment. – Solution: develop capacity within Health/ADHC for joint intake of complex cases. • **Lack of willingness of community MH teams** to take on patients with intellectual disability and mental disorder (mental services not funded and structured appropriately): – Result: ADHC services left dealing with both ID and mental health related issues with limited support, increased staff burnout. – Solution: funding for ID mental health teams at an Area Health Service Level. • **Lack of ownership** (between ADHC & Health) of responsibility for development of mental health services: – Result: failure of development of capacity to assess and manage mental disorders in people with ID. – Solution: single Government department to take primary responsibility for funding specialist ID mental health services. • **Limited resources** is a widespread problem: – Respite care and out-of-home care, behavioural support in the community, particularly deficient in the regional areas. • **Workforce Issues:** – There is variability in recruitment processes and professional development to ensure that ADHC and ADHC-funded staff have the necessary skill set to care for clients. Example: *A staff member may not speak English or may have limited capacity to understand or undertake the role of a carer.* • **Variations in Service Delivery:** – The above difficulties and lack of collaboration of services is highlighted in the following ***case scenario***.

CASE SCENARIO:

Background:

- *John Citizen is a 17 year old man with a rare congenital syndrome, moderate intellectual disability, transgender issues, behavioural problems and bipolar affective disorder.*
- *The parents of Mr Citizen are unable to care for him at home. After several attempts at placing him in a group home, he now resides in an ADHC owned 5-bedroom residence which has been modified to accommodate only him. He is attended by one carer 24 hours day and two carers during travel to day program/ leisure activities all provided by an NGO.*
- *Prior to the change in residence to single occupancy, Mr Citizen had numerous admissions to psychiatric facilities across the Sydney region. Following the diagnosis of Bipolar Affective Disorder, he was commenced on psychotropic medication and a comprehensive behavioural management plan was completed by the ADHC Psychologist.*

Issues:

- *A total of 35 incidences involving absconding from residence, day program or car during travel, ingestion of poisons, property damage or aggression towards family or staff have been reported since moving from the group home. Eleven of these involved either police or ambulance services and 9 of these resulted in hospitalisation.*
- *Nine staff members who have provided in home supervision have reported being physically assaulted. To address this, a "safe room" has been established where staff will shelter until Mr Citizen has either ceased being aggressive or their rostered shift has concluded. Suggestions regarding increasing the number of staff from 1:1 to 2:1 have been resisted due to the financial cost despite the ongoing occupational health and safety risks.*
- *Implementation of the behavioural plan has been difficult due to the itinerant nature and level of literacy of the staff employed; most of whom have rudimentary English as evidenced by poor report writing. None of the staff have any training in either intellectual disability, nursing or mental health.*
- *Mr Citizen's access to suitable leisure activities and educational programs has been severely affected by the difficulties in providing adequate numbers of staff to ensure safe transportation.*
- *Absconding, soliciting for male partners on the internet, ingesting poisons and large doses of prescribed psychotropic medications all pose a great risk to the safety of Mr Citizen. The inability of staff charged with care to prevent these occurrences constitutes a breach of duty of care.*

Conclusions:

- *The management and care of individuals with intellectual disability and mental health issues require unique skills and a thorough understanding of English and the ability to communicate clearly.*
- *ADHC and their partner agencies have a duty of care to both staff and clients to provide a safe and appropriate environment.*
- *The cost to NSW Health and the community of repeated use of ambulance and police services combined with Emergency Department and Hospital admissions would if spent on appropriate accommodation and staff be greatly reduced.*

ADHC FUNDED NGO SERVICES:

- **Consistency:**

– There is no consistency in terms of governance of NGOs. Potentially there would be significant variation in the quality of services provided by different NGOs.

Examples: *of lack of governance and dissatisfaction with the quality of care provided.*

- **Funding:**

– ADHC do not fund all the residents whom the NGOs accommodate.
– For adults, ADHC have in the last few years started to tender out ADHC group home residents to NGOs.
– NGOs are taking on more and more very disabled people with complex medical and mental health problems.
– There is no statutory funding for these clients. NGOs are not consulted or involved in the funding strategy. They have to compete with each other for ADHC funded clients.
– Too often, smaller amounts of interim funds are offered for a short term, to multiple agencies.
– NGOs are aware of their client group needs in their community but may not be able to meet those needs within the funding agreement.
– NGOs are then required to access additional resources via fundraising to meet demand outside of the funding arrangements.

Results:

– The results could be either under funding for the individual disabled person or tedious tendering process or lengthy negotiation of terms and conditions.
– Charitable organisations need to supplement their budget through fund raising and innovative enterprises.

Solution:

– Variations in the way that funding allocated to NGOs needs to be addressed.

- **Case Management Services**:

– The level of support is variable and hence the outcome may not be optimal.
– There is a lack of nursing positions provided by NGOs.
– There is greater demand on NGOs to negotiate with private or public health professionals: GPs, medical and surgical specialist and psychiatrists.

- **Internal Communication Systems:**

– Some NGOs may demonstrate poor internal communication systems.

Example: *an agency may not routinely refer to other programs within the same agency.*

NGO PARTNERSHIPS FOR PRE-SCHOOL EARLY INTERVENTION:

- **Services:**

– In some areas, the use of NGOs to provide early intervention therapy services has been successful.
– There are some longstanding collaborative partnerships with well established organisations that provide continuity and family centred practice for example, Learning Links, Lifestart, Pathways, Noah's Ark, Disability Services Australia to name a few.
– One of the strengths of this arrangement is that they see children to a finite age (0- 6), rather than closing the case once a goal is reached and then expecting the case to be re-referred for further therapy.

- **Funding:**

– Too often, smaller amounts of interim funds are offered for a short term, to multiple agencies.
– These often come and go; the NGO often experiences teething problems, offers a limited service to a lucky few who tend to be nearby and the services packs up or closes its books.
– The problems with this intermittent "bucket of money approach" include:
  - The brief to the NGO is too broad or over prescriptive, failing to meet unrealised needs.
  - NGOs are aware of their local needs but not necessarily the broader community long term planning.
  - Usually a first come, first serve basis - lacking priority to those most at need.
  - Families, by the time they hear positive news about the service end up missing out, feeling frustrated and have nowhere else to turn to.
  - Overly diverse availability and application of service within the same and different regions.
  - An incredibly complex array that confuses not only vulnerable families but also therapists, clinicians, those within NGOs and ADHC themselves including ADHC Case Managers.
  - This diversity does not create a network web but instead a paralysing entanglement.
  - Little opportunity or mechanism for key stakeholders to give feedback to ADHC.

<u>Examples</u>:

– *Applied Behavioural Intervention (ABI) is a quality Autism therapy, with only limited places. There is confusion with clinicians and ADHC themselves about availability, eligibility, priorities. Some regions were not aware that children only needed an Autism diagnosis for referral in spite of the referral needing to go through ADHC intake.*
– *The Transition to School Therapy Program run by the Spastic Centre has similar problems.*
– *In some areas, Early Start Autism Support was run at the NGOs discretion and not in collaborative with established stakeholders.*

<u>Suggestions</u>:

– Continue funding NGOs that show evidence of good practice and client satisfaction.
– Reduce the complexity, greater transparency, clearer sharing of information and plans.
– Promote consistent longstanding partnerships with shared responsibility and involve other stakeholders in planning.
– Clearer focus on equity and priorities.

ADHC INTAKE:

- **Intake Processes:**

– Different regions may have different intake processes. For example, some regions are happy to email an intake form to the referring agent to complete. Other ADHC regions want to speak to the referring agent - inconsistency amongst ADHC regions.
– There is a long wait for processing of referrals. There is a further long wait for the family to receive a needs assessment.
– This has clearly become worse over time, with a greater community consciousness for intervention coupled with more obstructive processes.
– There are different eligibility criteria for the under 6's and school aged children.
– Many families are asked to organise a psychometric assessment even though the person has been a "client" for many years. These assessments are costly and resource intensive and there is a long waiting list in the public system.

Results:

– This process is extraordinarily complex and often has to be done repeatedly for any one client.
– The capacity of the intake system falls far short of meeting the needs of client families and referring professionals.
– The current ADHC intake system disadvantages families from a CALD background.
– Delays in processing the referral by the allocation panel as they do not act on referral until the detailed reports/scores are sent.
– There is excessive reassessment, time wasted, duplication, loss of information, lack of co-operative partnerships and confusion which essentially results in the attrition of needy families.

Solutions:

– There is a need for a different intake model where clients are not discharged but can be reactivated. The client family should remain with the same case manager wherever possible.
– A needs assessment by ADHC should not really be necessary when the referring agent such a Diagnosis and Assessment Team has provided a comprehensive multidisciplinary assessment and report of both child and families needs.
– The complexity of ADHC intake processes should be reduced.

- **Feedback to Client Families and Referring Agencies:**

– There can be a long gap between a referral to intake and someone from ADHC contacting the family.
– There is often no feedback to the referring agent whether the request was accepted by ADHC and what is happening next.
– If a referring agent emails intake information, the intake officer only occasionally sends a return email to the referring agent to acknowledge receipt of the information.
– The referring agent is also often not informed of when some ADHC funded services (such as Therapy Transition Program) are accepting referrals.
– ADHC does not routinely pass on information about their funded services.
– A family or referring agent may need to call intake on a number of occasions. They rarely get to speak to the intake officer on the first call, often leaving numerous messages for the intake officer to call back. This is time consuming.

Results:

- The entire system of intake/ referral/ management/ service coordination is hugely complex.
- There is an unfair expectation that parents will be capable of navigating this system.

Examples:

- *A referral was made 3 times by the referring agent and still ADHC did not act on the referral request nor inform the referring agent why there has been no action.*
- *There are examples of referrals being made to ADHC and the referral being lost by ADHC.*
- *Families and referring agencies may not be aware of when vacancies are being considered. A child may miss out on being considered for a service because the application goes in after the intake has closed. For example, Therapy Transition Program has to be referred to ADHC intake during set allocation periods.*

Solutions:

- Greater transparency of allocation process, clearer sharing of information and feedback to referring agencies/services.
- There needs to be a more transparent and co-ordinated system of prioritising referrals.
- Overhaul of the intake system with input from client families and carers as well as clinicians and others who regularly refer and ADHC staff themselves (i.e. not by consultants).
- Seamless mechanisms for re-referral back to therapists etc. at time of need.

ADHC CASEWORKERS:

- **Quality Assurance:**

- There are inconsistencies in the type and quality of services provided by caseworkers.
- There is often a lack of understanding of the health needs of clients.
- The person responsible for clients is often unclear.
- In many ADHC areas, there is a distinct lack of high quality transition services from early intervention to school age and then onto to adult services.
- Some regional areas have demonstrated good local capacity to drive and foster innovation (e.g. Illawarra office – "learning about disabilities"/ early playgroups/ therapy groups).

- **Services:**

- Some ADHC funded services are only available if you have an ADHC case manager.
- Often behaviour management is required urgently by family and this could have a very lengthy wait.
- There are cases of children waiting years for early intervention therapy.

TRANSITION TO SCHOOL:

- **ADHC Programs:**

– There is a lack of flexibility in transition to school programs.
– Transition should be seamless.
– It needs clarity of purpose and is well done in some rural areas (such as Nowra).
– Families may not be aware of ADHC service that is being provided to the child at school.
– ADHC feedback to other services is minimal.
– ADHC often close cases even if the child and family have ongoing needs.
– There is a limited focus on working with the family in a holistic manner.
– The provision of intervention is not co-ordinated between therapists.
– Case management is not routinely offered or provided to families following transition.

Example:

– *In some areas, transition to school programs have been "out sourced" to the Spastic Centre. The Service provided may be the child's only ADHC-funded intervention. The Spastic Centre's core business is not intellectual disability, so therapists do not necessarily have expertise in this area. The Spastic Centre's premises may not be suitable for mobile children with developmental disabilities; for example, a child may access car park onto main road at the press of a button. There may be no toys to occupy an active child not confined to a wheelchair.*

Solutions:

– The intake process via ADHC for the Transition to School Therapy Program run by NGOs should be simplified.
– There is a need for better collaboration with Children's Diagnostic and Assessment Teams and ADHC intake processes for transition to school therapy programs.

	ADHC THERAPY SERVICES: • **School-aged clients:** – There is limited therapy intervention for school age clients. – There are constant changes in service delivery and limited consistency - families are not informed. – There is poor capacity for therapists to support clients with mild-moderate support needs; e.g. for speech pathology services there is a focus on clients with feeding and swallowing difficulties. – Once therapy intervention has been established, this is generally of limited scope - i.e. often less than 3-5 visits before the case is closed by ADHC. – There is often no plan for review or re-assessment. – The parents need to re-refer to ADHC for a service. – The parents may be unaware of system or too busy caring for child to follow this process. Examples: – *Parents may be provided with a standing frame but then no follow up to adjust it as child grows. Either the therapist has left or it considered by ADHC a new need.* – *Students with intellectual and physical disabilities at a local SSP require therapy intervention to access the school curriculum. The local ADHC office says they are not referred. They have had ADHC services in past. These children and young people will have ongoing therapy needs such as equipment adjustment and prescription (e.g. ill fitting walking frames needing adjustment).*

TERMS OF REFERENCE	COMMENTS
c) Flexibility in client funding arrangements and client focused service delivery	**MENTAL HEALTH:** • **Eligibility Criteria:** – There are inequities and inconsistencies between areas in terms of eligibility criteria for access to services, particularly in the area of mental health. Solution: – Include functionality as one of the criteria of eligibility; currently not adequately addressed in the ADHC intake criteria. **ADHC CASE MANAGERS:** • **Lack of Continuity:** – Opening and closing cases results in a lack of continuity and is disruptive to the provision of holistic services. – Families also frequently encounter different case workers due to their high turn over. Example: – *A number of therapy services are identified following ADHC's "need assessment". An individual professional (e.g. physiotherapist) is assigned as the case worker. A block of therapy (say 10 weeks) is offered. When the therapy is completed, the case is closed. It then takes a long time for the next therapist to take up the case again. In the mean time, the family is left with the notion that no more service is to be given by ADHC and the family seeks out private service through the enhanced health care plan. When the ADHC therapist eventually contacts the family and learns that the family is receiving private therapy, the case is then closed for good.* • **Transfer of Cases:** – Once a client is being allocated to a NGO to manage, it is difficult for the NGO to transfer the client back to ADHC when the client is too complex for the NGO to manage.

LACK OF CLIENT FOCUS:

- **Barriers:**
  - Lack of focus on the client families' needs by a system that is perceived as putting up barriers to limit access to services.

  Example:
  - A lady with a severe physical disability living in a family home needs the assistance of a paid carer with going to bed at night. The lady would like to go to bed in the evening but has to go to bed at 5.00pm because the carer would have to be paid overtime.

ACCOMMODATION:

- **Lack of long-term planning:**
  - Generally undertaken as an emergency rather than a planned process.
  - Generally, people plan for their retirement etc.
  - For this population, the ADHC processes do not allow for such long-term planning.

TERMS OF REFERENCE	COMMENTS
d) Compliance with Disability Service Standards	**DISABILITY SERVICES STANDARDS:** • **Standards:** – ADHC and especially NGOs may fall short with their compliance the Disability Standards. Examples: – Epilepsy management plans and psychiatric reviews for psychotropic medications. Solution: – All medical reviews should be supported by adequate documentation, medication charts, and behaviour and health logs and attended by a case manager or primary carer. • **Inconsistency in Policy Implementation:** – The policies from ADHC Central Office may not be reflected in the practices of the Regional Offices. – Inconsistency in the implementation of policies between Regional Offices may disrupt service delivery. Example: – A Group Home may not allow a resident with complex epilepsy to wear a safety helmet prescribed by a specialist neurologist on the grounds of restrictive practice but another may allow the resident to wear the safety helmet on medical grounds. • **Non-Compliance:** – There appears to be no transparent mechanism for managing agencies that are non-compliant with the Disability Standards. – Even if an agency is clearly non-compliant, the problem appears to go "unnoticed" by ADHC. Solutions: – Publically available documentation about compliance with the standards.

TERMS OF REFERENCE	COMMENTS
e) Adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services	**ADHC POLICIES & PROCEDURES:** – Many of the ADHC policies appear to be internal to the Department. – The processes for decision making for eligibility for services and equipment are not transparent or consistent. – It is difficult for consumers to complain about these processes because ADHC does not make these public. – It is difficult for ADHC-funded NGOs to provide a submission as this could jeopardise their funding. – ADHC make so many administrative demands on NGOs, such they may not be able to afford both administrative support and advocacy so that advocacy suffers. – ADHC does not keep any publicly available record of grievances. Solutions: – Factors fundamental to the wellbeing and health status such as choice and control, social participation and relationships, to be supported in government policy and program design. – Increase the representation of people with disability on advisory bodies. – Publically available documentation about grievances. **ADHC DEFINITION OF DISABILITY:** – ADHC is selective in which disabilities it tends to address. Historically, the focus has been on intellectual disability. – Although under Stronger Together, ADHC services are reputedly based on need, there is still a preference to treat people with intellectual disability as their primary target (even when people with ID have comorbid MH problems). – The target group of the Disability Services Act are people with a disability that is attributable to an intellectual, psychiatric, sensory, physical impairment or to a combination of such impairments. – The Disability Discrimination Act also has a broader definition. For instance, people with mental illness which results in substantial, adverse and long-term effect on their ability to carry out normal day-to-day activities are also likely to be covered by the DDA. – The Minimum Data Set (MDS) against which ADHC funded services report includes psychiatric disability. Example: – An NGO may continue to support people with psychiatric disability as this group is recognised by the DDA as 'people with disability' and the MDS against which ADHC funded services report includes psychiatric disability. Solutions: – The definition of disability in the relation to the eligibility for provision of services and human rights that underpins the new National Disability Strategy (2010 -2020) needs to be further addressed.

f) Internal and external program evaluation including program auditing and achievement of program performance indicators review	**MENTAL HEALTH:** • **Governance:** – Regionally, Mental Health services are often non-existent. – Usually governance is reasonable within the ADHC system with access to in-house Psychologists to perform functional analyses of behaviour. This is not the case within some NGO systems: Example: – NGOs that do not have ready access to ADHC Psychologists may employ a private consultant to conduct a functional analysis at significant cost with no check of compliance or subsequent support to implement the recommendations. • **Training of ADHC and NGO Staff:** – Lack of uniform/minimum training for ADHC staff in mental health & intellectual disability. – This is a problem given the substantial comorbidities. Solution: – Increased funding for development of generic and specific training modules for ADHC staff in IDMH. – Best coordinated by single centre; the Chair of IDMH could be funded to do this. • **Intellectual Disability Health Policy:** – Lack of coordinated, strategic, forward thinking development of health policy in this area. – Disability theory and practice, and social frameworks change rapidly. – This issue is being neglected and has the potential to improve access to, and quality of, health care for people with intellectual disability. Solution: – Establishment of a joint ADHC/NSW Health ID Health Policy Committee.

DEPROFESSIONALISATION:

- **Clinicians:**

– ADHC tends to recruit young graduates/ junior workers with limited experience and opportunities for professional supervision.
– These junior persons may be assigned as consultants to ADHC clients without providing hands-on intervention programs. This has caused confusion and dissatisfaction among client families.
– There is a lack of training and supervision and professional career paths.
– The only way of advancement in ADHC may to become a manager.

Result:

– ADHC clinicians tend move into managerial position to achieve promotions.

Solutions:

– Workplace satisfaction and professional development should be the focus with senior and very competent therapists or psychologists at the top of the salary tree.
– New positions such as dietitians, nurses and therapists who provide health services should be allocated to the Tier 4 multidisciplinary Disability Health Teams where there can receive adequate professional support and supervision.
– For the above issues and to avoid gaps in services, consideration should be given to subcontracting all ADHC clinical services to NSW Health.

- **Untrained Staff:**

– Trained carers with professional qualifications and experience are more expensive to employ than untrained staff with no professional qualifications or experience.
– ADHC and NGOs tend to employ untrained carers with inadequate skills to undertake the role of a carer.
– This leads to problems in the management of clients in residential care.

Example:

– *A resident in a group home was seen by psychiatrist for management of behaviour problems and a detailed report with interventions was written. As 80% of the group home staff could not read English, the interventions were not implemented. Within such group homes, medication errors may be a common event.*

Solutions:

– ADHC should retain some of their very experienced Registered Nurses.
– The employment of Clinical Nurse Consultants rather than untrained staff assists in the raising of professional standards.
– Funding should be allocated in line with the Stronger Together initiatives which recommend working in partnership with NSW Health to improve health outcomes.

TOO MANY MANAGERS:

- **ADHC Bureaucracy:**

– There are too many levels of management required for a decision to be made.
– There are multiple levels of managers rather than hands-on practitioners.
– There is a lack of transparency in the department.
– There is then a reluctance to admit a mistake and re-look.
– There is undue reliance on consultants to develop tools etc.
– The hands of ADHC caseworkers are tied by paperwork and multiple levels of management.
– The system is not user friendly.
– Where is the evidence base for much of what is done?

Examples:

– *In some ADHC offices, a manager must co-sign each document produced by clinicians (letters, reports) which delays important clinical information*.
– *ADHC Speech Pathologists are being trained in the Hanen program to help a child develop the best possible language, social, and literacy skills and yet the program is not being delivered to the client families.*
– *Physiotherapists are trained in the use of plaster casts for tendon stretching but ADHC does not provide them with the basic equipment to use this intervention.*

Results:

– There is no apparent accountability for decisions made by management.
– Many policies and documents are adopted and developed without consultation with those who will need to use, develop, train and implement them.

Solutions:

– ADHC practitioners should be empowered to deliver clinical programs in line with their professional training.
– Future staff training program should focus on the client's needs rather than an exercise governed by ADHC bureaucracy.
– The current system needs to be streamlined.
– This is an important issue that needs to be addressed by the current Inquiry into ADHC.

TERMS OF REFERENCE	COMMENTS
g) Other matters	**INTERAGENCY COLLABORATION:** • **Networks and Partnerships:** – People with developmental disabilities are likely to have a variety of educational, social and health needs during their life. – Clients, families and carers must often deal with a confusing array of professionals, therapy interventions and agencies to meet their needs. – Evidence shows that small multidisciplinary health teams provide the highest net benefit and cost effective model to improve health care and therapy services for students with developmental disabilities. – The benefits of early intervention and prevention to help them establish successful and independent adult lives as well as the associated cost savings to the Government is well supported by evidence. – In the current system, various government agencies including ADHC, NSW Health and NGOs are funded to provide services. <u>Result</u>: – There is confusion in responsibilities, significant variations and frequent changes in service criteria and intervention models, increased complexity for client families and carers navigating the system, inequity of access and gaps in services. <u>Solution</u>: – There is a need to improve interagency collaborations and partnerships in the provision of services with complex health and developmental conditions. – The existing best practice collaborative models could be expanded to other areas of the state and modified to meet the needs of the local communities. • **Examples of Good Collaboration:** – The following models are examples of good collaboration between ADHC and NSW Health. – These models outline the benefits of multidisciplinary health teams and the potential for significant cost savings through early intervention, diagnosis and assessment and ongoing management of health conditions related to their disabilities. o School Physical Disability Therapy Teams o Hospitalisation of Patients o Transition from School to Adult Services o Dysphagia and Nutrition Model (Westmead)

❖ SCHOOL PHYSICAL DISABILITY THERAPY TEAMS:

- **Issues:**

– Many parents report that the level of therapy intervention services declines dramatically once their child reaches school age.
– Many teachers highlight the long waiting lists for students with developmental disabilities - in some cases for up to two years - and the lack of continuity and responsiveness of ADHC and ADHC-funded therapy services.

- **School Therapy Physical Disability Team (SESIAHS Model):**

– NSW Health, in conjunction with ADHC, fund a limited number of multidisciplinary health teams which provide support to students with physical disabilities.
– Services are provided in the student's school environment and the multidisciplinary health team aims to improve the student's ability to carry out their roles in safely, with dignity and as independently as possible.
– Services are provided in a flexible interdisciplinary model in which each discipline provides their expertise but collaborates actively and frequently in intervention planning and implementation with school staff, health professionals and parents.
– Teachers are able to access student-specific advice, training, in-service or support as required.
– There are no complicated re-referral processes; each student is eligible based on their physical disability and remain with the service until graduation.
– The School Therapy Teams have links to their local Child Developmental Teams that provide paediatric clinics.
– ADHC therapists can refer to and attend Specialist Clinics held in schools to improve overall management and planning.
– The teams facilitate both the transitions from pre-school to school and from school to adult services.
– The table compares the potential or real impact of the team's intervention to the scenario where such a team does not exist.

School Therapy Health Team	No School Therapy Health Team
o Evidence based o Integrated services provided in schools o Multidisciplinary assessment and management o Coordinated communication between therapists, school support staff, teachers, clients, families and carers o Training for all stakeholders improves outcomes for students o Linked to other health developmental services	o Therapists working in isolation at multiple locations operate as a barrier to access services o Not holistic approach o Discontinuous service o Communication is fragmented o Discontinuous service o Limited upskilling of therapists and school staff

- **Conclusion:**

– Each Area Health Service should aim for the "gold standard" of a School Therapy Team/s. The development of these teams aligns with the *NSW Service Framework for the health care of people with intellectual disabilities*.

❖ HOSPITALISATION OF PATIENTS:

- **Issues:**

– When there is a crisis, ADHC usually does not have a set of fall-back protocols to manage out-of-control behaviour.

– This is often left to the Police who then fall back on Health, usually Hospital Emergency Departments and Mental Health.

– The Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals (Garling Report) highlighted the needs of adolescents, particularly with mental health problems.

- **SESIAHS (Kogarah) Model:**

– SESIAHS has piloted a Disability Consultancy Service of specialists and social work input at St George Hospital, particularly for adolescents and adults with challenging behaviours presenting for admission to hospital.

– The pilot has identified necessary improvements in services for patients, integrated admission and discharge planning, education of hospital staff and interagency co-operation.

– Protocols have been established to support ADHC in managing extremely challenging behaviours avoiding costly admissions or presentations to ED units.

– The existing local protocol also includes:

  - o An early intervention and prevention component: community clinics to address client's health needs in the community setting minimise the need for hospitalisation.
  - ~~o~~ An internal Social Work protocol in Emergency and the Wards: the Hospital Social Worker contacts the Social Worker in the Kogarah Disability Health Team to advise of the patient's presentation and to obtain information regarding known clients, Disability Support Agencies in the community and input from Medical and Allied Health specialists.
  - o Assistance in the interagency coordination and facilitation of services.
  - o A protocol for the best physical location of patients with disabilities and autism; e.g. a quiet sealed-off end of a ward for disturbed young people to minimise sensory stimuli rather than a standard adult ward - in line with Garling Report.
  - o Support for Gate Pass Leave to maintain links with community programs, to assist patients who find the hospital environment stressful and to facilitate early discharge from Hospital.
  - o Discharge CNC protocol: Discharge CNC contacts the Disability Social Worker to facilitate discharge planning and to put in place supports in the community to facilitate early discharge.

- **Conclusions:**

– The program requires integrated support/ participation and cooperation from ADHC and ADHC funded services, Health and other agencies where appropriate.

– ADHC staff can often manage if, despite inadequate training, they feel that MH is supporting them.

– Ongoing review and internal adaptations leads to improvements in patient care.

– The pilot identified significant cost savings from decreasing the length of hospital stays for mental health and social problems.

❖ TRANSITION TEAM:

- **Issues:**

– Youth with developmental disabilities are a disadvantaged group with complex health, educational and socio-economic needs that require services from a number of professionals and agencies.
– They are particularly vulnerable to the stresses of the transition period from paediatric to adult services including access to health services.
– Youth with an intellectual disability and mental health problems present significant difficulties when they attend hospital.
– The Agency for Clinical Innovation (ACI) Transition Care Network provides a state-wide approach to improving systems and process for young people with chronic illnesses arising in childhood including those with intellectual disability when they transition from paediatric to adult health services.
– A specific Network for Intellectual Disability across the Lifespan is currently being considered by the ACI, representatives of ADIDD and NSW Health.

- **SESIAHS/ ACI Transition Model:**

– The multidisciplinary health team based at Kogarah in conjunction with the ACI Transition Network (formerly GMCT) supports adolescents with complex needs in their transitions between health, disability and educational services.
– Many clinics are provided in collaboration with ADHC and DET and are conducted off-site, often in special schools such as Cairnsfoot.
– Regular interagency meetings support clients with complex needs and their families during transition.
– The aims of the transition team are to:
  - o Improve access to quality health care for adolescents with developmental disabilities during the transition period from paediatric to adult services.
  - o Reduce preventable presentations to ED and decrease prolonged hospital admissions for non-medical reasons. The significant cost savings that result from these reductions can be then be used to assist funding of preventative programs.
  - o Develop and establish policies and protocols for (a) access to hospital, (b) specialist multidisciplinary health services and (c) for Disability Action Plans.
  - o Facilitate the development of networks between teams and individual clinicians from the paediatric and adult health facilities. Such networks will assist in development of transition pathways for clients and families/ carers, in accordance with the 'Framework for Policy and Planning of Services for Children and Young People in New South Wales' (2008).
  - o Promote collocation / conjoint clinics between paediatric and adult services for young people in transition.
  - o Ensure interagency collaboration between ADHC, DET, Mental Health, Community Health, shared care with GPs, NGOs, Carers NSW, Police Department and Justice Health.
  - o Develop and establish ongoing programs for staff education and promote development of KPI's quality assurance projects and outcome based research activities.

	• **Conclusions:** The transition team continues to focus on: – Developing an integrated model of care that promotes interagency collaboration in the provision of services. – Providing opportunities for innovative (often cost-neutral) and client-focused services such as transition clinics in special schools that are responsive to the needs of local communities. – Providing opportunities for increased numbers of adolescents to access quality health care services. – Increasing the satisfaction of the target group in their ability to access quality health care.

The comments relating to the adolescent transition services have been collated with the collaboration of Lif O'Connor, Transition Care Coordinator, ACI Transition Care Network, and are supported by its Chief Executive, Dr Hunter Watt.

Dr Robert Leitner, Chairperson
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