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SUMMARY OF KEY ISSUES FOR PARLIAMENTARY INQUIRY

❖ MENTAL HEALTH:

- Mental disorders are at least 2.5 times more common in people with ID than in the general population. Additional specific mental health needs are present in those with complex/severe disabilities, challenging behaviour and developmental disabilities such as Asperger's syndrome.
- Apart from behavioural support, the specific mental health needs of this population are almost entirely unmet by both ADHC and NSW Health, with neither Department having assumed responsibility for service provision. People with ID and mental disorders therefore experience major problems accessing appropriate mental health care.
- A major barrier to effective mental health care is a lack of staff skills in assessment and management of mental disorders in people with ID. Despite the high burden of mental disorders and complex presentation of problems, there are no minimum standards of training for ADHC, NSW Health or NGO sector staff in intellectual disability mental health. This contributes to under-recognition of mental disorders and delayed or absence of access to appropriate treatment.
- There has been a lack of coordinated and strategic Health Policy development in this area and in ID healthcare in general.

Solutions:

- Specific NSW Government funding should be designated for use by either NSW Health or ADHC, to develop and deliver effective mental health services which should include:
  - Funding for designated intellectual disability mental health teams within CAMHS and Adult Mental Health Services for each Health Network (as per Tier 3 - NSW Health Framework).
  - Funding of Specialist ID Mental Health Services as a component of Specialist Multidisciplinary Disability Health Teams (as per Tier 4 - NSW Health Service Framework). This would enable complex case review and adequate support for front line clinicians within mental health.
  - Development of a mandated shared triage capacity between ADHC and Mental Health for complex cases or where ID and mental disorder co-exist.
- A separately funded State based training and education centre of excellence should be developed. This could be hosted by a tertiary institution and would be in keeping with Tier 5 of the proposed NSW Health Service Framework.
- Mandated training in IDMH to minimum standards is recommended for front-line staff in ADHC, NSW Health and NGOs.
- Establishment of a joint ADHC/NSW Health ID Health Policy Committee with broad representation.

❖ ADHC INTAKE PROCESSES:

- There is a long wait for processing of referrals. There is a further long wait for the family to receive a needs assessment. There is an additional long wait for the family to receive an intervention.
- 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.
- The capacity of the intake system falls far short of meeting the needs of client families and referring professionals. There is an unfair expectation that parents will be capable of navigating the system.

Solutions:

- Overhaul of the intake model where clients are not discharged but can be reactivated. The client family should remain with the same case manager wherever possible. There should be seamless mechanisms for re-referral back to therapists etc. at time of need.
- 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 and related processes should be reduced.

❖ THERAPY SERVICES:

- There are long waiting lists for therapy services. Children may wait for more than 12 months for therapy services although there is strong evidence for the importance of early intervention. Once therapy intervention has been established, this is generally of limited scope before the case is closed by ADHC. A new referral needs to be made to ADHC Intake for another episode of care.
- There is confusion about who is responsible for providing therapy services for the under 6 year olds – Community Health if mild, ADHC if more delayed but in reality the ADHC service is often non-existent and so provided by NGOs or the private sector.
- Many parents report that the level of therapy intervention services declines dramatically once their child reaches school age. There is a huge level of unmet needs in therapy.
- ADHC tends to recruit young graduates with limited experience. There is a lack of training and supervision and professional career paths.

Solutions:

- Prevention and early intervention need a long term commitment that is too often forgotten in light of more acute problems and changes in management.
- The options to be considered should include the provision of all therapy services for children through NSW Health and/or NGOs to simplify the system and avoid waste of needs assessments and huge gaps and inconsistencies in services. New positions for therapists who provide health services should be allocated to the NSW Health Tier 4 multidisciplinary Disability Health Teams where there can receive adequate professional support and supervision.

❖ INTERAGENCY COLLABORATION:

- 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.
- In the current system, various government agencies including ADHC, NSW Health and NGOs are funded to provide services. 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.

Solutions:

- There is a need to improve interagency collaborations and partnerships in the provision of services with complex health and developmental conditions.
- Examples of good collaboration such as the Transition Model and Hospitalisation of ADHC patients are detailed in the submission. The existing best practice models could be expanded to other areas and modified to meet the needs of the local communities. These models outline the benefits of multidisciplinary teams and the potential for significant cost savings through early intervention, diagnosis, assessment and ongoing management of health conditions related to their disabilities.