

To
The Principal Research Officer
Community Development and Justice Standing Committee
Legislative Assembly
Parliament House
PERTH WA 6000

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Submission to the
Community Development and Justice Standing Committee
INQUIRY INTO THE ADEQUACY OF SERVICES TO MEET THE DEVELOPMENTAL NEEDS OF
WESTERN AUSTRALIA'S CHILDREN

Submitted by

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I am prepared to present my case to the committee in person.	

1. Brief Summary of my submission

Over the past 30 years the per capita funding for community based direct client services for children and families with developmental concerns or known disability has decreased.. It is much harder now for children and families to gain access into public funded service agencies and they receive much less services despite the availability of scientific evidence based research practice studies.

In an effort to reduce client wait lists public funded agencies have "cost shifted" services to the detriment of young children, their families and our society. They do this by constantly changing the eligibility criteria that governs the access to their service.

A positive development in the public sector has occurred in health where child development services have integrated in the metropolitan area, developed clinical pathways for its, clients 0-17 years, client prioritisation and key performance indicators for the service and Memorandums of Understanding between DSC and Mental Health Service to permit collaborative client care. However the funding required to implement these new integrated clinical services to clients and families has yet to be delivered.

2. We would like to comment on the following Terms of Reference

- a) whether existing government programs are adequately addressing the social and cognitive developmental needs of children, with particular reference to prenatal to 3 years;

My general view::

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- Families experience significant wait times, phases of waiting, to access community based early intervention EI services in WA and often encounter more than one wait in their journey between time of identification of disorder, potential for disorder, referral, initial assessment and commencement of intervention. These families experience enormous stress and frustration which sometimes can have devastating effects on the child, the parents or other members of the family. Most parents are desperate to provide the best nurturance and care possible for their child. When there are identified delays parents want to get an accurate, if possible, diagnosis and get started on therapy, intervention as soon as possible, they want to help their child. They want guidance and support. They want to be able to trust the knowledge and skills of the clinicians involved with their child. As parents they want to feel confident that their child is in a consistent, safe, secure and trustworthy environment and that the service values them and their child. As parents they want to be listened to and be able to have an active role in decision making about services for their child. Parents are cognisant that the early years 0-5 years are critical years for the development of their child's brain and their child's development as a social interactive member of their family and society as a whole.
 - The first wave of waiting is engaged in accessing a service provider. The criteria for client eligibility to access to services from the various government funded service providers consistently undergoes change, becoming more and more restrictive. This has been occurring over the past 2 decades. Families and referees experience enormous challenges and bureaucratic barriers when trying to gain access to the appropriate, or any, EI service provider for their child, clients. The diagnostic acceptance criteria change, the demographic acceptance criteria change, the perceived therapeutic need for the client/ family from the service provider change. Families and referees have no control over this process. Many clients, families that are or have become ineligible for publicly funded services are required to access private services. On a positive note are the recent commonwealth initiatives, Medicare enhanced primary care program for children with chronic disabilities- they can access a maximum of 5 Private Allied Health treatments per calendar year and the Helping Children with Autism package access to assessment and therapy intervention for children with autism. However if a child is not eligible for any government support and do not have financial, social, resources their infants, children will receive no service.
 - When eligibility criteria for service is met, for the majority of publicly funded services there becomes the second wave of long wait times for assessment and in some agencies the third wave of waiting for actual intervention therapy services. Some agencies will only take in new clients at set calendar dates. Young chronically disabled and developmentally delayed infants, children, and their families can wait 8-9 months to receive therapy services from public funded agencies. Many families will often access private EI services. This incurs considerable cost to the family but also involves the infant young child and family having to develop and redevelop new relationships with a variety of adult clinicians as well as the difficulty of having fragmented services and less efficient cohesive coordinated therapeutic management.
 - In the tertiary health sector, in particular KEMH & PMH access to services is less restrictive than in the community sector. This is primarily due to these services being funded to provide service to medically ill antenatal mothers and medically ill infants. Once within the hospital system referral to Allied Health services occurs more efficiently for children and families. However the difficulty occurs as these agencies try to refer clients, families, out into their own local community service, child development service area or to the agency that deals with particular disability, diagnostic, disorder. These tertiary facilities are designed to have a high flow through of clients however when community agencies have long wait times for actual service delivery the clients, families, that need continuation of therapeutic service but can not access them then impact upon other children families ability to access these acute and subacute services. Many of these families that have been referred to
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community based services are, in the interim, referred to private services whilst they await the resumption of public funded services. Again this involves the infant, young child and family having to develop and redevelop new relationships with a variety of adult clinicians as well as the difficulty of having fragmented services and less efficient cohesive coordinated therapeutic management.

- Since 2002 there has been a 24% increase in live births in the Perth metropolitan area, (22405 infants)*Midwives Notification System DOH August 2008. 6% of these infants were Low birth weight infants. 7.5% of these children have medically diagnosed movement disorders and 4.3% have been diagnosed medically with developmental delay* WA DOH Child Health Survey 2007. Despite the population growth and increased survival rate of Very Low Birth weight infants the Allied Health clinical staff levels has been static for 15 years in Child Development Services, KEMH, TCCP and DSC.

My reasons/my experience:

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- I have worked in community health services since my graduation in 1981. Enormous change has occurred from that time. As a therapist in the early eighties the generosity and value of public community based health services from the Whitlam years was still evident. There were no increases in staff but health services could accommodate the population growth. In my public funded practice where I also work, our current staffing level was granted to us in 1978 (1.8 physiotherapists). The department was originally funded to service 200 referrals per year. 40% of those referrals would be discharged within 12 months, 40% would require services for 1-4 years 15% would be diagnosed with a condition that required intensive services and transference to another agency and 5% of clients would require ongoing services for more than 5 years. There had been no change to my departments' staffing level until 2008 when we have receive temporary increase of a 0.5 physiotherapy position. Our referral rate is over 600 referrals per year and has been at this level for the past 3 years. The time need for intervention service is still as stated above.
 - However from the mid eighties onwards funding focus really shifted to the acute hospital based services especially those hospital services that needed Allied Health staff to support medical and nursing staff to discharge inpatients. In a political arena this meant more beds would be available. The media and reactive politics have an extremely narrow view that health is in patient beds. Rehabilitation and developmental therapy are not medically intensive nor critically life saving measures they are about quality of life maximising potential.
 - The other major issues over the past two decades have been
 1. The dramatic population growth of our state and the subsequent increase in the volume of children and families requiring therapeutic developmental services.
 - 2.. The increased survival of LBW & VLBW infants who are discharged from hospital with persistent co morbidity status. Once again inpatient services are funded around medical, nursing critical care but the allied health interventions that are required whilst getting ready to discharge home or the intervention required post discharge are not in place. Expectation is that community services will pick up these families.
 3. Other medical innovations interventions e.g. Botox that creates further demand upon available AH resources and expectations from medical practitioners for therapeutic follow up
 4. Parents are becoming informed consumers they access national global information re therapeutic intervention strategies service models and compare them to what is available for their child
 5. Constant review of services, changes of models of care service delivery by organisations. Change in actual physical service provision towards a consultative model of care and transference of therapeutic responsibility to the family and "community services". This has been a real problem. As agencies try to control their waiting list numbers they reduce the number of clients coming into their service by changing their eligibility criteria. This is done without consultation with other services. Families can loose eligibility status, they get too old whilst waiting for a service, the geographical boundaries of a service can change or a
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particular condition disorder is no longer being serviced by the agency. Families are told to access the “community” what ever that means.

6. Consistent change of prioritisation of public spending based upon political philosophy. This year it is a 3% cut. Enormous resources are going into finding ways of reducing services by 3%.

7. Human resources are constantly being shifted from direct clinical service provision into administrative tasks or the development of glossy information packages. There has been a dramatic shift from direct therapeutic service provision, hands on therapy, to a consultative model. telling the parents what to do. Thus the skill base of clinicians is reducing as well as there is a transfer of responsibility to the parents for therapeutic outcomes

8. It saddens me that many families are treated with little respect or compassion by the administrative process of many agencies. My classic story from a parent which helped become a private practitioner was the response she received from DSC re having to wait for services for her month old Down’s syndrome baby, “Don’t worry it doesn’t matter if they don’t receive intervention for awhile you only start to notice when they are 2 how far behind they are”

9. It is common that infants under 12 months of age who have been diagnosed with cerebral palsy or developmental delay are waiting an average of 8 – 12 months before they receive therapy intervention. These families are required to access private services unless the child has coexisting medical concerns and they can access PMH services. However if they are admitted as a private patient for medical issues they can not always access Allied health services as some departments will not treat private patients. The lack of uniformity and eligibility for service in the tertiary hospital system is frustrating. The same can be said for metropolitan child development services. However there is optimism that since the CDS review there will be equity of access for families in the metro area

My recommendations:

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- A concerted bipartisan agreement to adequately fund, recurrently, and quarantine that funding to children and families with developmental concerns. Funding of Infrastructure, operational goods and services and importantly fund the human resources clinicians that are trained and able to provide clinical services and human resources of clerical support to meet the Best practice models of therapeutic service and public accountability.
 - Transparent accountability for public funded agencies to be accountable for waiting periods. To have Key Performance Indicators of acceptable time frame from receipt of referral to actual service provision. Executive management of services to be accountable. To have national acceptable Client Clinician case load, work load, ratios for best service provision and executive management to value and support clinical therapy service provision. For a moratorium to be placed upon agencies so that they can not change client eligibility criteria without consultation with other agencies and tangible strategies in place for families subsequently denied access to services.
 - Agencies to have moral integrity for their administrative process to a neutral, positive, experience for families
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b) how to appropriately identify developmentally vulnerable children;

My general view:

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- The Child Development Services (CDS) review with Community nursing has set in place an excellent structure of identifying vulnerable children and families. Child Health Nurses use the PEDI and ASQ
 - GP's, Midwives, Obstetric medical practitioners, mental health practitioners, within the public and private sector, Department of Child Protection need to also identify potentially vulnerable children, families, during antenatal care and in the neonatal period at risk. And have the knowledge and ability to refer to the most appropriate service agency
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- Family support workers in day care environments need adequate training and skill in identifying vulnerable children families and have the ability knowledge to refer to GP, CHN, and CDS for further identification, assessment.
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- Clinicians working in private and public services who deal with young children or with parents of children need to be trained and have a knowledge base, or ease of access to information, of where to refer vulnerable children/families for further evaluation, identification.
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My reasons/my experience:

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- Identification of vulnerable children CHN staff, best beginning staff, GP's are capable and can be excellent at identifying vulnerable children, families. Medical and AH practitioners in the tertiary and secondary hospital system are also excellent at identifying vulnerable children. The difficulty is where to refer or how does the referee manage, support the client, family, whilst they travel the long journey of referral acceptance, waiting for intervention or the more arduous journey of ineligibility for service, finding some where else or there is no service.
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My recommendations:

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- Our country, state, needs to establish community based child health and parenting service centres. That are universal services, a national model of care, that supports the wholistic development and social well being of infants children and families and are located within the community. Within these centres families can access GP's CHN's Family Support Services, Daycare support services, Allied Health services, Dietetics, podiatry, Occupational Therapy Speech Pathology Physiotherapy Social Work Clinical Psychology, Pharmacy Pathology Services. Within these centres vulnerable children can be identified and receive local services or, if required, be referred to tertiary, secondary level of care services hospital based services, for further diagnostic evaluation, service intervention or agencies with specific service programs e.g. The Centre for Cerebral Palsy etc. Funding is required to support this model of care. Children with chronic disabilities, 0-3 years, could be serviced in these universal centres if the services are able to meet the child level of need.
 - However, a child should be funded for services, medical, allied health. Each child is to be allocated a base level of funding, based upon their diagnostic categorisation and prognosis of service intensity requirements, this funding travels with the child and permits the child, family, to access services. This is to prevent services being dominated by severely disabled or high service need clients, families, and permits moderate care needs clients families access to best practice intervention services.
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- c) which government agency or agencies should have coordinating and resourcing responsibility for the identification and delivery of assistance to 0–3 year old children;

My general view:

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- Achieving collaboration is an enormous task and when viewed from the consumers perspective agencies currently function as quite separate entities. Despite years of collaborative meetings occurring between agencies at senior and middle management levels Ideally a common link is required, for example, a project officer/ team dedicated to researching how each agency works and designing an approach whereby they can closely connect and provide an effective, time efficient early intervention service to families.
 - Importantly when developing collaborative networks and clinical service provision clinical resources need to be quarantined and not transferred into administration, project management.
 - When memorandums of understanding between agencies are developed for service to clients there needs to be an order of accountability and adherence to the MOU.
 - The Metropolitan Child Development Service Review has recently developed good clinical pathways and interagency policies
 - If there is a transference of service delivery responsibility funding, human resources, clinicians should go with that transfer.

My reasons/my experience:

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- The public sector spends an extraordinary amount of time, human resources and money developing recommendations, programs, MOU for coordinating and defining the resource responsibility, cost shifting, for service delivery for children and families. With the end result of less services are provided to the consumer but it will always be another agencies' responsibility.
 - When transference of services occurs the original agency responsible saves money whilst the new agency has to pick up the tab with in its own resources. This occurs when PMH transfers clients to the community and DSC ceases to provide services to its clients.

My recommendations:

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- Don't just talk about services. Agencies and government should be accountable for all spending.
 - Develop a plan strategy and commit to it for 10 years
 - Agencies should be less ego centric, more aware of other services and their resourced abilities, and be client family focussed in their services
 - If clients are transferred from an agency funding goes with the client to provide the therapeutic intervention
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- d) what is the best model to ensure interagency and intergovernmental integration of developmental programs delivered to 0–3 year old children;

My general view:

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- One that is actually funded to provide direct consumer services.
 - A model that values the child and family and respects the stress they may encounter as their child family develops. A model that values and respects its staff those with direct client contact as well as the staff that support the front line staff. A model that values, respects and supports the human element within itself. A model that has moral integrity built into its framework
 - A sharing of pre developed resources, educational fact sheets, web site links, to parent forums, educational programs to limit duplication of resources where possible.

Local communities would benefit from access to developmental screening from community therapy services prior to referral to the health system. This would reduce pressure and waiting times within the health system and ensure referrals are warranted. Once a child is identified “at risk” they could then be referred to the health system or if financially viable, to private therapy services for formal assessment and intervention.

My reasons/my experience:

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- The Metropolitan Child Development service Review has developed some excellent clinical pathways and models, MOU, for interagency collaboration service between DSC and Mental Health Services

My recommendations:

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- A model that values the child and family and respects the stress they may encounter as their child family develops. A model that values and respects its staff those with direct client contact as well as the staff that support the front line staff. A model that values, respects and supports the human element within itself. A model that has moral integrity built into its framework
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e) how to best prioritise the resources available for meeting the needs identified;

My general view:

Very hard not to be biased and focused upon own area of interest. The dilemma as a clinicians, managers working in health and the disability sectors is that you see the growth in the tertiary health sector, in budget and actual staffing levels, some departments have grown by 50% in the past 15 years. Whilst community based paediatric physiotherapy services have stagnated. The funding at the tertiary level is focussed upon medical and nursing intervention and the AH support needed to assist in those outcomes. Acute medical issues surgical advancement techniques, media attracting projects always get first priority, preventative health and rehabilitation are always listed as lower priorities in the funding stakes

- Priority 1a Known risk Preterm infants, disabled infants, parents identified with psychological stressors should be able to referred to services and in receipt of therapeutic intervention within 4- 6 weeks of identification of disorder if not receiving any therapy intervention service, within 12 weeks if a transfer of service to another agency.
- Priority 1b Vulnerable Infants children Prevention of disability, psycho social dysfunction occurring should be in receipt of services at local CDS centre within 4 weeks
- Resources should be transferred to where the clients receive their intervention services

My reasons/my experience:

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- The metropolitan Child Development service has recently developed prioritisation levels, coding, for clients and families with key performance indicators of acceptable wait ting period for assessment and service provision for children 0-17 years

My recommendations:

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- Resource funding focus should be place upon the client and family not on the institutions
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- Child Developmental services should not have to compete with acute life saving medical programs for funding. There should be different stream of funding for acute hospital based health needs and primary ,secondary health and development services.
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f) what is the most appropriate measure of program outcomes; and

My general view:

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- Evaluation of client Development, parent evaluation of child development, progress, and service delivery
 - Clients being discharged from acute service providers to community based, home based service settings
 - Clients, families, actually receiving clinical services not just brochures and consultancy advice
 - Transparent independent public report on agencies and their service provision
 - Politicians, senior managers, being accountable for cut backs to client services
 - Key Performance indicator measures for the complete referral process.

My reasons/my experience:

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- Programs are evaluated recommendations are made but unless they are cost neutral or save money, reduce services, nothing happens

My recommendations:

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- Stop the rhetoric and act on the recommendations that show positive outcomes, benefit the development of the child and family
 - Have services audited by independent organisations or by each other
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3. Any other Comments

The provision of clinical services to children and families with developmental needs costs money and needs human resourcing to provide the clinical service. Our society has a moral obligation and duty of care to support all its citizens no matter their physical, behavioural disorder, financial status, ethnic background, religious faith or political beliefs. Please let this Inquiry have tangible outcomes to our children and families in need.
