

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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We are (PPSN Committee) are prepared to present our case to the committee in person.	

1. Brief Summary of our submission

Over the past 20 year waiting periods for clients and families to access and receive publicly funded services have grown dramatically.

Eligibility criteria to access agencies has become more restrictive.

Collaboration in practice as well as in policy statement needs to occur between agencies. Commitment by government is required to fund, recurrently, direct client services in Child Development and Disability services at primary secondary as well as the tertiary level of care.

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;

Our general view: No they are not because:

- 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 referral, initial assessment and commencement of intervention, therefore the children/families miss out on months of therapy during a critical time in their development. A review of the length of wait times should occur.
 - 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. Many clients, families that are or have become ineligible for publicly funded services are required to access private services. If eligible they may receive commonwealth support through the Medicare enhanced primary care program. If they are 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. Dot points 2 and 3 come into play. 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 community based services are, in the interim, referred to private services whilst they await the resumption of public funded services
 - 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
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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.

Our reasons/ experience:

Within our committee we have experienced paediatric physiotherapists who have worked in health and disability sector of Western Australia since the late 1970's. Enormous change has occurred from that time.

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
 3. Other medical innovations interventions e.g. Botox that creates further demand upon available AH resources for therapeutic follow up
 4. An informed consumer who has access to national global information re therapeutic intervention strategies service models and compares to what is available to 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".
 6. Consistent change of prioritisation of public spending based upon political philosophy
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Our recommendations:

- 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.
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- 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
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b) how to appropriately identify developmentally vulnerable children;

Our 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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Our reasons/ 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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Our 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
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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.

- 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;

Our general view:

- Research conducted by National Disability Services WA revealed that both families and service providers have expressed concern regarding the absence of any framework for the coordination of services to children and their families. Collaboration between health, disability and child care/ education sectors is required for effective identification and delivery of early intervention services. Additionally, its important this collaboration occurs among service providers to assist families in finding information and supports they need before its gets to crisis point within the family unit.
- 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, Memorandum of Understanding between DSC and Mental Health services.

Our reasons/ experience:

- 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 and agencies confidence that it will always be another agencies' responsibility.
- Sadly MOU are totally ignored as they are not binding

Our recommendations:

- Don't just talk about services. Agencies and government should be accountable for all spending and detail the spending.
 - Develop a plan strategy and commit to it for 10 years
 - Departments should remove egos and focus upon the client family
 - Agencies should have a moral responsibility towards their clients families, potential clients.
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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 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.
 - 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

Our reasons/ experience:

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- So meetings occur about collaboration without ever delivering collaborative services to the consumer

Our recommendations:

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- Agencies need to be accountable and clients, families, need to receive real services that meet their children’s needs
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- e) how to best prioritise the resources available for meeting the needs identified;

My general view:

It is very hard not to be biased and focused upon own area of paediatric developmental 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 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
 - Resource funding focus should be place upon the client and family not on the institutions
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Our recommendations:

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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 and actually receiving intervention services
 - 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.

Our reasons/experience:

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

Our 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
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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.
