

SUBMISSION BASED ON DRAFT INQUIRY REPORT: *DISABILITY CARE AND SUPPORT* APRIL 2011 BY Ursula Smith (from an Autism perspective)

a)p6 The Overview and Recommendations document states: "...underservicing in one area-such as not enough access to respite and home modifications- results in costly additional servicing in another less appropriate area...such as someone staying in hospital because their home has not been modified fails to capture the more serious issue of children with autism. In Victoria for examples since 7/12/07 4 autistic children have absconded(wandered away) from private and respite homes due to a lack of property modifications and died, and 1 child absconded from a non-fenced playground and died. This is a preventable death rate of 1 child per 8 months:

- 1)7/12/'07-7y.o.absconded from home.. run over by train Strathmore Train station.,
- 2)14/6/'09-14y.o.(neurologically 3y.o.)absconded at playground.. drowned Yarra River
- 3)30/10/'09-3 y.o. absconded from home and drowned in Yarra River,
- 4)10/5/'10-9y.o.absconded from unfenced respite home..run over by 3 cars Kyneton,
- 5)30/4/11-6.y.o.absconded from home..run over by train Corio.

As noted on page 44 despite this unacceptably high preventable death rate, families with autistic absconders are not considered one of the most disadvantaged target groups.

Could the Productivity Commission please consider this serious issue in regard to private home modifications, respite home modifications and a percentage of public housing stock being fitted with secure fencing, gates, deadlocks on door and windows. Also, tie this request in with Draft Recommendation 17.3.."..In the period leading up until the full introduction of the NDIS, the Australian Government should supplement funding under the National Disability Agreement to reduce some of the worst rationing of support services..."

b)p21 in Overview and Recommendations: 1)In *Aids and Appliances* there is a need for suitable GPS tracking device to keep track of absconders and be included

2)p21 in *Respite*...for many families who have a family member with core limitations the household income is often limited so funding to enable the family to have a holiday together would really benefit some families and create positive memories,

3)p21 in *Therapies*...Speech Therapy is vital for people who have communication disorders. Currently only 5 subsidised sessions through EPC Medicare plan are available per calendar year. Being able to communicate is really a basic HUMAN right and needs funding through NDIS.

Also, Some well accepted biomedical therapies used overseas successfully such as oxytocin for socialisation in Autistic persons (and currently trialled at Monash University Melb), need to be considered for funding through NDIS if based on evidence-based research from Australia or overseas. (reference to Draft Recommendation 4.4)

4) p21 in *Community Access Supports* states that supports would include supervision and physical care. There needs to be clarity about what ratio of support this would involve. Currently there is a misguided belief that the Commonwealth funded Inclusion Support Agencies support ALL children with disabilities to access mainstream outside school hours services. This however is not the case.

Inclusion Support Agencies provide funding for an additional staff member to attend a mainstream programme that a child with a disability wishes to attend. However, the additional staff member and no ordinary staff member are “attached” to any particular child. Therefore the children who are not allowed to attend the services due to OHS regulations for fear of risk to the child with a disability, staff or other children are those with the following nuances:

Absconding, pattern of behaviour of aggression towards themselves, others or property, those requiring 1:1 assistance with feeding or toileting.

There is no service currently available to enable full inclusion into mainstream services so if the NDIS has “supervision” as a community access support can that be 1:1?? This would enable an improvement in lower income levels and employment participation rates of certain carers referred to in Draft Report 2.5, and decrease the social isolation of people with Disabilities and their carers referred to in Draft report 2.3.

High Support needs 1:1 outside school hours services are currently underfunded, demand outstrips supply in current services or services are non existent (particularly high needs before and after school care)

Draft Report 2.11 states “..Beyond school..many people with disability who would like to work feel constrained by the lack of employment supports...) Therefore, would “supervision” as referred to in the Draft Report extend to support for a person with a communication/socialisation/sensory processing disorder such as autism so that a mentor/support person could be called upon in times of “need”?..eg) dispute resolution? communication assistance where required??

c) With reference to *Assessment of Support Needs*, the **International Classification of Functioning, Disability and Health (ICF)** framework fails to encapsulate autism-related impairments of body functions such as:

motor dyspraxia,

obsessions,

absconding,

sensory processing disorder,

self injurious behaviour,

pattern of injury to others or property,

hearing..indifference to stimuli,

pain..abnormally high threshold,

perception of danger,

understanding of concepts of norms and mores,

communication as well as language disorder,

semantic language disorder,

metabolic dysfunction involving temperature perception and regulation.

ICF's Activity Limitations and Participation Restriction categories fail to

incorporate semantic language disorder in the communication category or absconding, motor dyspraxia or motor planning disorder in the mobility category. Also obsessions and compulsions in the "other activity" category.

ICF's Environmental factors need to incorporate Sensory Overload as a barrier.

ASSESSMENT TOOLS: The most widely accepted assessment tools for Autism Spectrum Disorders are DSM-IV-TR and ICD-10.