

To: Hon. Kerry Finch Submissions: The New Disability Services ACT
Administration: Secretary Joint Standing Committee on
Community Development, Parliament House

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From: Patrick Eadington & Megan Donnelly- Consumer of Disability Services

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Introduction

This submission is being formally written in response to years of frustration, disillusionment & anger over a lack of transparency & accountability within the Tasmanian State Disability Services. As a consumer of Tasmanian State Disability Services my personal experiences represent hundreds of other individual cases who experience similar situations with the service who develop temporary band aid solution to various complex & involved issues which only perpetuate the unmet needs for the lives of people with disabilities.

Background

Historically people with disabilities & their carers have relied on various disability services to provide specialist services essential to sustaining a quality of life for people living with a disability. However through a lack of adequate funding, communication breakdown between Department Health Human Services, its operational component, Tasmanian State Disability Services and Community Service Providers – in my instance Community Based Support, we are once again left outside of decision making processes. A severe neglect from the State-Commonwealth Governments to sustain existing & new funding, to adequately inject new resources, provide adequate staffing to existing programs including ISP packages & residential accommodation further erodes the quality of life for people with disabilities.

Unmet Needs

Tasmanian State Disability Services have not always adequately assessed individual needs. Over the past five years the quality of service & responses to identifying & resolving unmet needs have completely diminished to a point where band aid solutions, severe frustration & occasional anger from both clients & service providers unable to resolve differences due to a lack of adequate funding. This has both a direct detrimental impact on families, parents, carers who are caring for a person with disability – and the consumer.

Financially one of the major problems to delivering disability services can be identified in the distribution of funding from the State Treasury Department – which delivers Disability Services. In any one financial year the bulk of annual funding contributes to four residential houses that Disability Services currently maintains. Also distribution of the treasury budget includes funding all the wages for the employees at Tasmania State Disability Services.

This same agency expects existing service providers to provide the income sources to address the unmet needs gap – which is ever increasing for the 23% of Tasmanians living with a disability. This was already identified in a personal letter to Tasmanian state politicians & others regarding ISP's in 2005 (see *Appendix 1*). Service providers themselves are claiming they are already under resourced, under budget & over stretched by the demand clients are placing on services to address their individual unmet needs .

At fault are both the current Tasmanian State Disability Service, and, my instance, Community Based Support. Instead of actively mentoring, guiding, supporting and teaching the person with a disability to build self confidence and levels of independence in the community. The burden is placed back on families & parents to become full time carers to the person with a disability. This in turn leads to financial, emotional & environmental breakdown which has a detrimental impact on the family unit.

DHHS Service Provisions

Currently the core function of the Tasmanian State Disability Services, under the DHHS is a 'one stop shop' to provide specialised services directly to clients with a disability, their parents & families and support advocates. However even these services will no longer be maintained after July 2009 – as they will be outsourced to private providers, to the detriment of all consumers. As a guideline any one of the following services are provided to individuals like me who live with a disability:

- Case Management
- Residential Accommodation Needs
- Commonwealth Independent Support Package, ISP
- Respite Care Services
- Community Rehabilitation Services
- Community Equipment Scheme
- Community Options – Referrals to Service Providers

Removal of services

Removal of these Commonwealth/State services from the above and handed over to private community organisations will leave **all** consumers without an independent watchdog in the provision of disability services. My current service provider is Community Based Support, and, the situation already, prior to July 2009 is becoming increasingly focused on corporate agency driven outcomes without real concern for us as consumers in the longer term. From my understanding talking to other agency representatives there appears to be a similar ideology & approach to delivering current and definitely post July 2009 disability services. The focus is on administrative & financial structures to the detriment of all consumers – who are not included in real decision making regarding unmet needs.

Yours sincerely

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Appendix 1: Disability Services Ailing Health – 2005

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I am writing to all politicians and political parties in a desperate plea on behalf of people with disabilities who rely heavily on parents, case managers, support agencies & workers, & the Tasmanian State Disability Services. All of these support networks are at their "wits end and at breaking point" where Disability Services has been neglected, unfunded, under resourced and under staff.

I really feel that people with disabilities are second class citizens whilst we are suffering the consequences of the "Ailing Disability Services" which the government of the day has so far ignored and have turned their backs on the most venerable group of people within our society.

During political campaigning the wider community hears all the mainstream popular vote winning issues which come pouring out like a raging torrent and yet the "life issues" that severely impacts on the daily lives of people with disabilities are surprise, surprise once again neglected. This Labour government thought in October/November in its wisdom to establish a premier cabinet disability committee in order to stem the flow of criticism and barrage over the neglect of the state of Disability Services through under funded and un-resource programs, packages etc.

To all those politicians and political parties I ask you, people with disabilities are your constituents please don't provide us with lip service or another empty premier cabinet disability committee in the hopes that Disability Services crisis will evaluate into thin air. Well I got news for you, until your party start listening and providing guaranteed long-term initiatives, funding, resources into Disability Services its programs, packages, day care centres, respite services and other vital services will on longer be able to support people with disabilities who heavily rely multiple service providers throughout our lives.

This following issue is my personal situation which will either improve or deteriorate depending how your party or the Government of the day value people with disabilities as equal citizens of Tasmania: I am a young man with a physical disability who is trying to live independently within the community with constant support from my parents and support workers, without these support I simply could not maintain my independence.

In order for me to maintain my independence I rely heavily on my parents as well as my support workers. I get terribly depressed and irritable knowing at 30 years of aged I shouldn't have to be constant burdens on my only family I have are my aging parents.

Because I have been on the "Never-ending waiting list" for a ISP (Independent Support Package) for three and half almost four years and during this time my physical health has deteriorated, due to my sudden deterioration I have been provided with emergency Short Term Support to met my every day basic needs in order to supplement my pre-existing HACC support which is totally and utterly unsustainable for me to become totally independent if I don't have a minimum of sixteen hours a week, which that the moment the Short Term Support is providing temporary relieve to myself and my aging parents who carry the burden, stress and responsibility of caring for my everyday personal needs.

This Short Term Support was meant to be a stop-gap measure until I receive the ISP, which would provide me with sixteen hours a week on a permanent basis. Disability Services said told me in no uncertain terms that they can no longer guarantee the continuation to provide me with the Short Term Support as temporary support whilst waiting for the ISP which is also no guarantee that I will receive the ISP which after three and half all most four years of waiting with no light at the end of the tunnel.

If the waiting game continues for an ISP "a quality of life", my aging parents will be responsible for caring for my personal everyday needs. This isn't being independent or having self determination over my adult life, this is humiliating knowing that Disability Services can no longer guarantee my STS let alone the ISP for my long term future whilst my aging parents carry the burden and responsible of caring for my personal unmet needs.

Appendix 2: Disability Information Resource Centre-Tasmania, DIRCT - Discussion Paper – January 2005

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Introduction
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2. Potential Stakeholders- DIRCT
3. Primary Objectives
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Introduction

As a young person (aged 29) living with a physical disability in Tasmania, also very active volunteer within in the disability sector including Anglicare Disability Employment Services, Hobart Access Advisory Committee and Tasmanians With Disabilities. In South Australia a non-government service provider, Disability Information & Resource Centre, DIRC that provides disability resource information direct to consumers, carers, families of people living with a disability and community service providers.

Whilst researching the background for this draft discussion I have also considered the services of Disability Action Inc, SA who provide extensive disability advocacy for both systemic & individual support. These include social justice issues, which influence the lives of all people living with a disability in that state. This paper considers the future development of establishing a similar disability resource centre in Tasmania, which incorporates both the above agencies formal & informal structures. The following discussion paper identifies an unmet need for effective support of information, peer based support, well being & systemic issues responses to effectively provide real choices for people of all ages living with a disability in Tasmania.

Background

Historically people with disabilities & their carers have relied on services which are either most visible, or those recommended by key agency personnel (e.g. frontline workers at Service Tasmania, Centrelink and other similar agencies). These processes have often failed to acknowledge an individual personal options & choices towards establishing a sustainable quality of life & well-being for a person living with a disability. Disability services have not always adequately assessed individual needs & this has often promoted frustration & occasional anger from both clients & service providers.

The Disability Information & Resource Centre, DIRC based in South Australia have been providing information and resources for people with disabilities, parents, carers, newly assisted migrants & former refugees and other members of the community. DIRC provides general information about the types of services available & resources on various types of disabilities. They provide a complete library of written and audio materials that process information about various services, which are readily available to all people with disabilities. DIRC has a comprehensive website [<http://www.dircsa.org.au/home.html>] That can be accessible information & linkages to relevant local, national & international disability organizations & services. DIRC only assists people without the skills to find appropriate information suited to their needs.

However, unlike Disability Action Inc, SA, DA, DIRC does not provide or address systemic disability issues, or provide individual advocacy on behalf of all people living with a disability in that state. Disability Action Inc provides extensively support for consumers in addressing key disability issues both from an individual & systemic advocacy level. Within Disability Action a high representation of people with a disability are employed, and at least 75% of all board members are living with a disability.

In establishing a formal structure for a ***Disability Information Resource Centre-Tasmania, DIRCT***, the south Australian models can be used as starting point. DIRCT would need to be readily accessible to community service providers, parents & carers, school, TAFE, university students or support workers and most importantly individuals living with a disability in Tasmania. Ownership of the centre would combine volunteer peer support, extensive member participation and community workers.

1. Identifying Unmet Disability Needs

Over 3.6 million people or 19% of Australia's population have a disability. Tasmania has the second highest population of people living with disability in Australia **with 105,100, 22.3%, of the population**. This is followed by South Australia with 67,200, 26% of their total population.

There are also 15,600 primary carers who on a daily basis provide significant support for family and friends who because of ageing or/and disability are involved with primary care. However, there is still an undisclosed amount of people with disabilities still not receiving or seeking the appropriate support services, for which they are entitled. According to the Australian Bureau of Statistics, ABS, -Disability, and Ageing & Carers 1998.Vol1 1301.6.... there are:

- 6.1% of carers felt they could provide better care.
- 5.7% primary carers feel an emotional obligation to provide personal assistance to the person with a disability.
- 8.1% of family felt a certain responsibility to provide care to their loved ones.
- 4.5% of families have no family or friends available to help assist in providing emotional & personal support.
- 7.0% of Families, parents & carers have on choice or alternative support services are unavailable to their unmet needs and requirements.

According to 2003 ABS Census on Tasmania's population, people aged 65 + will rapidly increase to 33.8% of the state's total population by the year 2051. These figures would then make Tasmania's ageing population the highest in Australia. The impact would also result in far greater numbers of Tasmanians living with a disability, and as a consequence, disability service providers would be under far greater stress in delivering existing & future programs & services. As a result primary carers in Tasmania will potentially continue to shoulder the emotional, physical & financial burden along with a responsibility of providing personal assistance and support to the person living with a disability.

2. Potential Stakeholders- DIRCT,

In considering the establishment of DIRCT, and remaining completely autonomous as an independent resource centre from the community service providers then it is important that collectively all stakeholders recognize that while working collaboratively DIRCT would need to operate completely autonomously. Interested stakeholders could involve any of the following:

- Community Service Providers
- Educational & Training institutions
- Multicultural Organizations
- Tasmanians With Disabilities
- Carers Association
- Metropolitan & regional Councils
- Regional Disability Organizations
- Disability Services
- Advocacy Tasmania
- Cerebral Palsy Association
- Brain Injury Association Tasmania
- Families of people with a disability

3.0 Primary Objectives

One of the primary goals of DIRCT is to respond directly to the needs of people of all ages living with a disability, their carers, support workers, & families through providing appropriate resource information, which enable them to make clear and effective choices towards meeting their independent needs. In achieving this aim DIRCT would provide a gateway to the 'disability sector' by making a smooth transition between existing service provisions, future community disability services and related programs - based on their own individual needs and therefore:

- 3.1 To provide a clear & proactive advocacy role in communicating the needs of members of the organization, people with disabilities, and the general public towards identifying individual and systemic issues impacting on the lives of all people living with a disability.
- 3.2 Assist in alleviating the issues of disability, facing families, carers, & people with disabilities when trying to access community & health services.
- 3.3 To develop both a hard copy of available literature resources, including Braille, audio, & caption materials, and to establish a newsletter that informs people with disabilities, carers & parents of the changes and entitlements the State/Federal Government have implemented. What service providers are available and any other relevant information relating to community services.
- 3.4 Offer opportunities to participate in peer support activities & social well being programs.
- 3.5 Create a resource base of information to really help improve the benchmark for quality of community services, support and choices for people with disabilities in Tasmania.
- 3.6 Provide peer & formal educational training, social & well being programs
- 3.7 Develop a Mentoring for both genders & related self-development opportunities for people with disabilities.
- 3.8 Development for people non-English speaking backgrounds to meet, socialize, participate in the centre's activities and access interpreter services.

4.0 Discussion points

The following points for discussion summarize the key essential focal elements requiring a response, and would need to be considered before finalizing your own written comments at the end of this document.

- 4.1 Strategies for establishing formal consultations & expressions of interest from interested disability agencies, organisations, and interested consumers throughout Tasmania.
- 4.2 Development of a pilot research project within the wider community & disability sector and clearly identify the unmet needs that exist with people with disabilities and the essential need of the establishing a Disability Information Resource Centre – Tasmania, DIRCT.
- 4.3 To establish interim discussion groups amongst other people living with a disability towards identifying key needs and requirements for the Disability Information Resource Centre - Tasmania, DIRCT.