Mrs Jacqueline Crouch

20/07/06

The Secretary
Senate Community Affairs Reference Committee
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Senate Community Affairs Reference Committee

Inquiry Into The Funding And Operation Of The Commonwealth State/Territory Disability Agreement.

Specifically addressing terms of reference: (b)
- the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels in unmet needs and, in particular, the unmet need for accommodation services and support;

Summary:

My son, Patrick, has been living independently for seven years, formally in South Australia now Tasmania. Whilst living independently, he has received entirely different levels of accommodation & living support services. Although a highly motivated individual who contributes significantly to his own wellbeing, and, in a voluntary capacity to the wider community he daily experiences *severe anomalies* in accessing, maintaining & sustaining appropriate long term services. Patrick, like 247 other Tasmanians living with a disability have to respond daily to the delivery of local support service provisions, State/Commonwealth directives & subsequent funding anomalies (see attachment 3); all of which adds additional unnecessary stresses to overall wellbeingness.

One commonwealth policy objective which identifiably assists individuals like Patrick to sustain a long term quality of life is an *Independent Support Packages*, ISP. Whilst meeting the necessary eligibility criteria, after four years he still remains on the waiting list – along with other Tasmanians. Outlined in the submission below, and more detailed in the attached documents, which includes a recent response from the Tasmanian State Health Minister, Lara Giddings, MHA, are the pertinent issues which impact on the daily lives of Patrick, my husband & myself.

<u>Attached documents</u>:

1. Original Unmet Disability Needs-ISP Package, Patrick Eadington
2. Additional Background
3. Response letter - Minister for Health & Human Services, Tasmania, Lara Giddings MHA,

Dear Committee Members,

My name is Jacqueline Crouch, and I am the proud mother of Patrick, aged 31, an Australian citizen living in Tasmania, who is in receipt of a disability pension for Cerebral Palsy.

In relation to consistently having to deal with bureaucracy on behalf of Patrick's needs, despite his own ability to remain fully independent (*see attachment 2)* I would like the committee to acknowledge the following pertinent statement. It is with utter disgust that it is necessary, as a 69 year old pensioner myself to be constantly corresponding with state & federal ministers (*frequently with the lack & courtesy of even a formal reply*) along with the media, community based service providers and others in seeking appropriate entitlements on behalf of Patrick.

As identified in formal, verbal & written correspondences with relevant NGO/Government services there are serious identifiable anomalies existing which diminish access to and provide entitlement for adequate daily needs support services towards sustaining Patrick's & other individual Tasmanians (247) independence – all this – *in this wealthy country*. In Patrick's individual case he is seeking to obtain, after 4 years of waiting, an Independent Support Packages, ISP (*see attachment 1 – Unmet Needs Package, ISP –Patrick Eadington).*

Further research indicates there is clear lack of national identifiable quality of care standards for people living with a disability; as these might currently exist, albeit appropriately, for Aged Care Services. People living with a disability receiving a range of services do not have any formal charter of rights beyond the *Disability Discrimination Act*, in which to address an inappropriate lack of service provision. Noticeably, in Tasmania, is that lack of transparency, democratic community leadership, open mechanisms for consumer to provider/administrative/government dialogue with relevant decision makers.

A recent report from the *Australian National Audit Office* into the Commonwealth State/Territory Disability Agreement, *CSTDA* comments that 'CSTDA may not actually be meeting it's own objectives' – no doubt this committee will also be in receipt of a formal copy of that report.

In a recent federal parliamentary debate a public inquiry into disability services was *'voted down'* by the 'political majority' in the house of representatives which only subsequently reinforces ineffective governance and the implementation of bad policy objectives on behalf of people living with a permanent disability. Added to this burden a total lack of uniformed assessment standards, inappropriate support worker training directives, and recognition by all tiers of government that this issue is a systemic human rights violation.

In closing, I would urge this Senate Committee to formally implement public hearings in the state of Tasmania to enable individuals, community representatives & others to more formally respond. Patrick fully supports this correspondence and would welcome the opportunity to formally address the committee. Finally may I take this opportunity of wishing the committee every possible success in it's findings, recommendations, and subsequent public outcomes that *finally address* a sustainable quality of life & independence for the long term for all people living with a disability in this wealthy country where a quality of life should be available to all members of the community – not the privileged few.

Yours sincerely
Jacqueline Crouch

1. Original Unmet Disability Needs-ISP Package

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Unmet Disability Needs – ISP Package [PP:1- 4]

Dear Hon Tony Abbott, MHR

My name is Jacqueline Crouch, and I am the proud mother of Patrick, aged 31, a citizen of Tasmania, who is in receipt of a disability pension for Cerebral Palsy. It is with utter disgust that it is necessary, as a 69 year old pensioner myself to be corresponding with you for what should be a Disability State/Federal Services responsibility, this being the delivery of an entitled Independent Support Package, ISP for Patrick.

Introduction:

[By way of introduction I draw the minister's attention to three key points:

1.Independent Support Packages, ISP,
2.Physical health deterioration
3.Current HACC disability support status
4. Appendix: 4.1 Additional Background, 4.2 Patrick's Community Contributions, 4.3 Riverview Surgery -Dr Andrew Vidor,

This correspondence also acknowledges an informal supportive meeting held on11/05/06 at Patrick's Unit inTasmania with Margaret Reynolds Executive director ACROD, Lisa Singh, ALP member for Dennison, Jacqueline & Philip Crouch, parents.]

1.1 Independent Support Package, ISP

Whilst accepting that State government distributed Independent Support Package ISP's are assessed on a priority of need basis, & acknowledging that emergency short term support STS has been delivered to Patrick in the past 12 months – sustaining long term disability support services remain totally inadequate. His *unmet needs* continue to significantly impact on his physical, mental & social wellbeing. Whilst meeting departmental eligibility criteria for an ISP package; and, after 4 years of continued deterioration of his physical, mental & social wellbeing ***he is till waiting***. At the time of writing, departmental guidelines, and delivery through Community Based Services provide a review of ISP & similar services once every six weeks. Despite discussions, evaluation & consultation with both Community Based Support, CBS & the Department of Disability has resulted in unsatisfactory outcomes. Administratively, and as an urgent priority the newly formed disability advisory committee within the state premier's cabinet should seriously address the ISP issue on behalf of Patrick & *other eligible citizens* of Tasmania who meet this criteria towards resolving this *unacceptable* dilemma.

Granting an ISP to Patrick would effectively ensure long-term sustainability for the delivery of 16 support hours per week … entitled services, as opposed to the current ad hoc basis of support. This would enable him to access independent support hours for grocery/clothes shopping, administrative tasks (form filling), taking him to the bus depot when travelling to Launceston, attending medical appointments & similarly related tasks as these arise. Most importantly, the package would provide an accrual of unused support worker hours. Currently there is considerable reliance on my partner & self to complete these tasks in enabling Patrick to retain an independent living status. In consideration of my age, 69, I won't always be here to ultimately support Patrick.

Patrick needs this package immediately to enable and sustain a totally independent quality of life…whilst continuing to contribute voluntarily to the community as a whole.

1.2 Physical health deterioration

It has been publicly documented that many individuals living with Cerebral Palsy experience physical deterioration during their lifetime, and in my son's case he is no exception. Over the last 7 seven to 10 years, despite being a *highly* motivated young man who makes a direct voluntary contribution to the local community, continues to experiences bouts of depression & irritability. In addition his physical mobility is *now* significantly restricted as outlined below:

- Osteopenia in the left hand, as a result of a *fall* in 2005 - and brittle bones density
- Osteoporosis and vitamin D deficiency
- Continued *falls* around his unit, (despite not reporting this to us or appropriate services) rendering him without assistance until support workers arrive on normal shifts
- National Emergency Medical/Police/Ambulance Alarm service – Medi aid alarm
- Inability to use the micro-wave to transfer meals & similar appliances due to restrictive hand control – *with the left hand almost physically useless*
- Needs to have a support worker in the unit whilst showering – in case of a fall,
- As already identified through CBS & Disability Services considerable in-house care needs, [note: there are no appropriate *residential* group housing arrangements for Patrick]
- Additional mobility aids including an in-house trolley, hip-pads, shower stool,
- Waiting for 48 hours before support services are available (beyond emergency STS)
- Completion of shopping lists, paying bills, bureaucratic form completion, and other issues as these arise in Patrick's life requires parental support – which is not successful or sustainable independent living

Federal & State health administrators, bureaucrats, and policy makers *need to seriously* address Patrick's & others unmet needs as ascribed to in this letter. The issues are of a personal, systemic, & human rights concern for all Australian citizens, requiring an appropriate immediate & serious response.

1.3 Current HACC disability support status

Current community service support worker provisions for Patrick are provided by Community Based Care, CBS, Hobart - which receives HACC funded monies. In June 2005 Patrick broke his left hand through a fall in his unit. Subsequently he spent six weeks convalescing at *our home* with my partner & self, and we assumed not unwillingly the full time role as support worker/care. However during this time, there was no administrative accrual of support worker hours forthcoming from CBS. The agency's response provided 16 hours of emergency Short Term Service, STS per week after Patrick returned to his own unit. Our short lived appreciation of these additional hours were once again shattered when Patrick informed me that his STS status had changed, and this provision has now subsequently expired. As of May06, despite meetings, discussions, & correspondence with Department of Disability Services & CBS alike, raising health & wellbeing concerns Patrick's support hours remain uncertain and generally consist of an inadequate ***8 hours per week***. What's next?

In closing….

When federal government spending include tax breaks for the 'wealthy', A$billion per armoured military vehicle, further, with the recent Federal budget revealing no new financial initiatives for individuals in Patrick's situation (*and others*), as citizens we need to seriously question *whose* needs are being served. Perhaps if departmental administrative bureaucrats, state/federal treasury officials, individual politicians from all parties including the Prime Minister & Premiers alike were to change places with Patrick for 6 months and experience how individuals like him live…or survive, there may actually arise some genuine social & human rights understanding, and appropriate supportive funding responses.

We await in great anticipation for any Tasmanian state government initiative through the delivery of it's 2006 budget directives towards addressing this most serious abuse of human rights, and eligible entitlements of an ISP package for Patrick

We await with dignity your replies.

Yours sincerely

Jacqueline Crouch

> **Note**: *This issue was raised in the Tasmanian State Parliament by leader of the Greens, Peg Putt, MHA. A Formal reply from the State Minister for Health, Lara Giddings, MHA, has indicated there are several issues raised in the above. At this state Patrick is not subjected to a monthly review of Short Term Support hours until December 2006. However, this in no way adequately addresses the long term support for Patrick, specifically that of an Independent Support Package, ISP. A recent Tasmanian State Budget Facts Sheet has not indicated any additional funding for disabilities. Again a lack of transparency in what funds have been distributed in relation to disabilities does not publicly appear available.*

2. Additional Background

The necessity of having to correspond with the minister for health appears as an ongoing saga which has been eventuating over the whole of Patrick's 31 years. As a 69 year old pensioner, and now with my partner of 18 years we have continuously held meetings with community agencies and various interested stakeholders on a regular basis towards improving Patrick's quality of life. At a time when both the Federal & State governments boast economic financial surpluses – people in Patrick's situation remain *consistently & continuously disadvantaged in the 'lucky country'.*

If both my partner & myself were to depart from this earth the sole responsibility of Patrick would remain with the State as there are no singularly extended family support members. Recently (2005) when Patrick broke his hand he had to return and live with my partner & self for 6 weeks -thereby diminishing his ability to remain independent. There was insufficient sustainable extensive support offered by his community service provider or other agencies.

Regular tasks carried out by me, as his mother, include shopping, medical appointments, paying bills, taking him to entertainment venues, more recently assisting with his court appearance as witness in a trial. My partner & self quality of life remains, not unwillingly for Patrick's sake constantly diminished whilst we assist him to retain a sustainable long term independent living – an ISP would significantly alleviate this necessity.

Despite the constant meetings with various administration personnel, advocates, disability services officers & others to improve Patrick's life there remains significant disadvantages even more restricted as there are no residential houses for people with Patrick's level of disability. Current allocation, as determined needs (?) are prioritised to those of high & multiple needs or for individuals with an intellectual disability.

As a public indicator to the community issue of insufficient policies of the State in providing an adequate support service to Patrick & others ACROD's executive officer Margaret Reynolds recently stated in the Hobart Mercury that

> ' …there are 247 people waiting for support packages. Short-term support has been frozen in the south, surprise surprise, because that's being used instead of the longer-term individual support packages. These are for people who might need someone to help them get up and

> shower, modifications to their home, with transport, money to allow them to live independently or semi-independent. ACROD called for a $5m boost, using an estimate of $20,000 a year for each person. It's not only from the human perspective, but from the Treasury point of view, it's a relatively small amount of money so they can avoid ploughing money into hospital beds or long-term accommodation’. (article, Hobart Mercury, 21/04/06).

2.1 Contribution to the community

Patrick is a highly motivated and intelligent young man who has continuously extended himself beyond his physical disability whilst making a vital contribution to the community’s social health & well being - a brief summary follows:

- gaining entrance into main stream schooling, from special education (before formal inclusiveness)- pioneering the way for other young people with disabilities,
- as a teenager & early 20’s snow skiing, ab sailing, (now unable to participate)
- board member of CARA, south Australia,
- *various* community committees & respective responsibilities in South Australia & Tasmania including Anglicare, Hobart Council Disability Access group, & Arts Action,
- academically, school certificate, Tafe -community services certificate & workplace assessment; as an invited guest speaker delivering his disability support worker training package to Tafe students & private health providers, development of a young men’s health & wellbeing program
- extensive recognition amongst peers & particularly community service organizations
- continuous interest & development in arts/drama/ life long learning
- ACROD award for a short essay on ‘Disability Services Ailing Health’,

The *above* information is a significant indicator of Patrick’s capabilities – *not disability*.ation is a significant indicator of Patrick’s capabilities – *not disability*.

3. Response -Minister for Health & Human Services, Tasmania, Lara Giddings MHA,

MINISTER for
HEALTH and
HUMAN SERVICES
Tasmania

2 8 JUN 2006

MTS No.: 30037

Mrs Jacqueline Crouch

Dear Mrs Crouch

Thank you for your letter of 12 May 2006 regarding the circumstances of your son Patrick.

The information that you provided was extremely comprehensive and provided a very clear picture of Patrick's physical disabilities and his support and funding arrangements.

Demand for the individual Support Program (ISP) offered by Disability Services continues to be strong and it is obviously necessary to avoid duplicating service support where a client is already receiving support through the Home>and Community Care program.

I understand that Patrick is currently receiving 11 hours of HACC and five hours of short term care support. I can also understand that the monthly review of the short term care funding is very stressful for both Patrick and yourself.

To alleviate this stress I am proposing that the five hours of short term funding be guaranteed without review for the next six months.

During this time I have asked that the guidelines for ISP funding and the Home and Community Care program be reviewed to see if some improvements to funding allocation processes involving these two programs can be made.

As HACC is a joint Commonwealth - State funded program the program is managed within the criteria established by national guidelines. For people who receive services through the program this can present as a lack of flexibility compared to the Individual Support Packages.

I sincerely hope that greater funding certainly can be provided for Patrick in the longer term.

In the meantime I suggest that you maintain contact with Alison Jacob (Deputy Secretary, Human Services and Housing), telephone 6233 8091 to receive updates on the review of funding mechanisms.

Yours sincerely

Lara Giddings, MHA
Minister for Health and Human Services

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Ps: Original document copy of above held by Jacqueline Crouch.