Submission to Productivity Commission Disability Care and Support
Mary Nolan 19 August 2010

20 August 2010

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From Mary Nolan

Submission sent by email 21 August 2010.
Hard copy of Submission and Appendices sent 23 August 2010

1. Submission from Mary Nolan

2. CD Radio National documentary Street Stories *Locked in with Friends* producer Cath Dwyer. High commendation in media section of HREOC Human Rights Awards December 2005

3. DVD *'The Diving Bell and the Butterfly'* true story of Jean-Dominique Bauby who suffered a brain injury and dictated a book by blinking his eye. Best director in Cannes 2007. A moving look at the reality of living in a disabled body with an active mind and imagination.

4. Call to Action developed at Victorian Summit organized by the Victorian YPING Consortium July 2010

5. The book, *Acquired Brain Injury (ABI). A socio-medical model for the care of young people with severe acquired brain injury.* WDCW 2007 has been sent previously to accompany the WDCW submission.

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INTRODUCTION

This enquiry has the potential to be a once in a generation change for people with disability, and it is so important! I understand that all sorts of issues need to be considered. I am very grateful for the opportunity to make a submission and thank the Productivity Commission for taking on this work.

In this era of disillusionment and a certain emptiness and questioning about the consumer culture and the corporate world losing connection with people, I make a strong plea for you to consider firstly the humanity of people, their and our shared personhood.
Some years ago I stayed with a wise woman psychiatrist in Chicago who specialized in depression. She told me that that every human person needs **to f*eel* safe and to *feel* valued/loved. Not to be *told* we are safe and valued but to *experience* it -** which is quite different. That has been my reference point in these past years of the journey with our son Chris who has a very severe hypoxic ABI – reference point in relation to him and for all of us who journey with him. Like others who have experienced massive life change, he teaches us the difference between 'individualism' and 'personalism' which is the basis of the philosophy of partnership in care and what personhood and our common humanity is all about![1]

It's distinct from but complementary to the intent expressed*: Social inclusion is about ensuring that everyone is able to participate fully in Australian society. It is about people having the necessary opportunities, capabilities and resources to enable them to both contribute and to share the benefits of Australia's success as a nation. Being socially included means that people have the resources, opportunities and capabilities they need to: learn, work, engage and have a voice'* (Australian Social Inclusion Board, 2010:1)

Acquired Brain injury (ABI) can happen to anyone at any time. Very severe ABI is a comparatively newly recognized disability and neuroscience and new imaging techniques in the past decade now demonstrate that the brain *can* make new connections and that an enriched environment is a very significant factor in that happening. As well as the person, ABI has profound effects on the families/friends. My focus in this submission is on Chris and others like him with very severe ABI who are the most vulnerable and least known perhaps of any people with disability. While needs vary, principles for them can generally be applied to others with acquired disability.

THE STORY AND JOURNEY SINCE ABI 1996

This is a personal and communal story of 14 years of what I described early on as feeling like *Living in a Different World with No Road map*, encountering massive road blocks and identifying and *bridging or getting around gaps in the system to enable Chris to live life and to make a difference for Chris and others.*

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[1] The Philosophy of Partnership in Care is well developed in the WDCW book, *Acquired Brain Injury (ABI). A socio-medical model of care for young people with severe ABI. See 2.2 Personalism vs individualism page 24*

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I offer a brief overview of a big story in order to identify what has worked and why we believe this is important to:

1. the consideration of the Productivity Commission Disability care and support
2. what needs to happen in the short term before any outcome from the Commissions findings.

Chris Nolan is the son of John and Mary Nolan who have always been involved in local and wider community. He grew up on the family farm, with a great capacity for people and friendship and high achiever e.g. School Captain, sportsman, lawyer, and founder of the Meredith Music festival in 1991 which now is one of the most successful Australian festivals and still held on the farm www.mmf.com.au, www.goldenplains.com.au
While working in Hanoi in 1996, Chris suffered a multi organ collapse and catastrophic hypoxic acquired brain injury (ABI). Airlifted to Singapore for 3 weeks on life support then to St Vincent's Melbourne where he was very ill and 6 months in coma. He 'woke up' in November 1996 laughing at a joke.
Significant

1. Mary was a health professional and the family had a very wide and diverse friendship network, and experience of local and wider community involvement. Parents insisted that friends be enabled to continue involvement with Chris and set up strategies and communication means to facilitate that from the beginning. Friends came in droves.

2. His parents formed a group of 4 (John and Mary and 2 close friends of Chris (Lawyer and doctor) to make decisions for Chris including withholding treatment. Reason for friends' involvement was because while Chris and parents were very close, friends have a different aspect of Chris's 'voice' and desire was to be authentic to Chris.

3. Since Chris emerged from coma, friends have been invaluable in establishing that Chris is 'there' and trapped in a profoundly disabled body and communication system. In the late 1990's, this understanding was in direct opposition to the prevailing view of the brain (held by almost everyone we met) as incapable of recovery and hypoxic ABI was even more hopeless.[2]

4. The decision to keep Chris in inner city Melbourne (rather than take him to Ballarat or Geelong closer to the farm) was made because there seemed to be professionals who knew ABI and *also he was central and accessible to friend*s. He was very frail and not really expected to live long. That decision has meant that Mary has lived most of the time in inner Melbourne while John continues to run the farm. From the beginning, Chris demonstrated his tremendous will to live life against all odds and traversing 3 countries.

In December, 1996, Chris moved to an aged care nursing home (HMcCH) in North Fitzroy and one of the first to be funded by the Victorian Acquired Brain Injury: Slow to Recover (ABI:STR) program.

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[2] Appendix 2 *The Diving Bell and the Butterfly* is the film based on the book of the same name written by Jean Dominique Bauby who suffered a stroke in December 1995, and was locked in.

There was no model to work from and based on the strong Philosophy and Practice of Partnership in care at HMcCH, the Director of Nursing (DON), Rosalie Hudson, and Chris's mother, Mary (a health professional), worked with therapists, staff and friends and family to try to help Chris. The 'Model' developed with Chris was adapted for 8 other young people over 9 years at HMcCH.[3]

In 1999, Mary was a member of a reference group for Melbourne Citymission (MCM) Study into the *Accommodation Needs for Young People requiring Nursing Home Level of Care*. Mary wrote the *'Case Study: Christopher Nolan'* for the MCM Study outlining the "Model" for the first time. This was a turning point as it was the first articulation of how we were working with Chris, approved by the therapy/care team, and it gave Mary 'voice' and some sense of worth and credibility and a way forward in this 'different world'

In 2000, MCM employed Mary Nolan to follow up that study with a project, '*Accommodation Unit for Young People with an Acquired brain injury at Harold McCracken House,'* December 2000. Change in leadership at MCM meant that the proposed Unit was not taken further.

In 2001, a group of young volunteers who knew Chris, in response to his Yes, formed to build and organize a float in the Melbourne Federation Day Parade in May to highlight the issue of YPINH with ABI. Moved by the plight of the YP they met, that group later became incorporated as Inability Possability Inc www.inabilitypossability.org.au See Inability Possability inc submission to this enquiry. That group continues and now supports a YP, Families and Friends Association of about 80 members.

In 2001, Mary and others met to discuss *how we can work better together* for young people in nursing homes. That group formed the YPINH Consortium and ran a National Summit in 2002 and National Conference in 2003 - out of which the YPINH National Alliance was born. The YPINH Consortium remains the Victorian branch of the Alliance and recently ran a Victorian Summit to develop a Call for Action at year 4 of the 5 year COAG Young People in Residential Aged Care (YPIRAC) program.

In 2002, Mary was awarded a high commendation in the community section of the HREOC Human Rights Awards for her '*Ground breaking and pioneering work in bringing the issue of young people in aged care to public attention*'. In 2005 Cath Dwyer ABC Radio National received a similar award in the media section for her 30 min radio documentary Street Stories, *'Locked in with Friends'*, on Chris and friends[4].

Around 2004, there were rumors that HMcCH NH may close. Despite all that had happened on the wider level, there was still no option other than aged care for Chris with

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[3] The nine stories of those young people are recorded as Appendix 1 in the book, '*Acquired Brain Injury (ABI). A socio-medical model for the care for young people with severe ABI*' published by the What does Chris Want (WDCW) 2007 and launched by Hon Bill Shorten in December 2008.

[4] Appendix 2 CD will be sent by mail. It gives the impressions and experiences of Chris's friends

his high medical needs and social network. It was obvious that Chris was hearing and understanding but unable to speak or move or see much. He was communicating with facial expressions and a long blink for yes, and responding appropriately and typically of the Chris we knew now trapped in his profoundly disabled body and communication system.

In June 2004, realizing they were unable to continue alone and with family and friends still very involved, his parents formed the What Does Chris Want (WDCW) group of about 16-18 friends and family with Chris. The aim was to define what Chris wants and needs and to work with him and others to secure appropriate accommodation, care and support. WDCW has met at least monthly since then with several sub groups working in between. It is an extraordinary and diverse group of people.

In late 2004 Mary wrote a Submission to Senate Inquiry into Aged Care under term of reference 3 – the appropriateness of young people with disability being placed in aged care. Mary Nolan Submission no 185
http://www.aph.gov.au/Senate/committee/clac_ctte/aged_care04/submissions/sublist.htm
I recommend this paper for your perusal – even from an historical point of view 2004 – 2010 it is of interest.
In 2005 April she appeared with two of Chris's friends at Melbourne Public Hearing of above Senate Inquiry.

2005 was a time of great anxiety with the NH where Chris lived closing, and he still had nowhere to go. There was intense political and media campaign by WDCW and the wider network to secure appropriate accommodation and support for Chris and others like him – including Federal and State governments. (See Hansard Federal and State). Media included: Jon Faine 774AM radio interview with Chris and friends – Jon said he changed from skeptic to believer in the course of that interview, and he 'ran' with the YPINH issue for 1 month. Print, television, radio was also used. WDCW was instrumental in lobbying strongly on State and Federal levels for the COAG agreement about YPIRAC. And on Victorian level for a 10 person place for Chris and others which would be a socio-medical model based on what had been developed with Chris. DHS agreed pending COAG.

In December 2005 HMcCH aged care NH closed and there was still no option for Chris. After several meetings and agreement to continue the partnership care and support approach (which included Chris's team of therapists and carers continuing with him) WDCW identified Boyne Russell House (BRH) aged care facility in Brunswick as an interim facility. BRH is a state aged care NH and only employs registered nurses. However with no vacancy, WDCW insisted that Chris remain where he was until he could move to BRH. 4 major agreements were signed involving the old and new service providers, Vic Disability Services and Commonwealth Aged Care. A service provider was contracted, Chris's therapy and carer team continued with the 'Model' and so he remained the only resident at HMcCH for 11 weeks. He made improvements during that time, especially in communication as carers had him as total focus, and so his non verbal communication was responded to and he also responded!

In March 2006, Chris moved to BRH with Vic Disability Services funding held by Melbourne Citymission case management service. Choice and decisions are made with Chris and the WDCW group and team:

- ABI:STR funding was continued
- Flexible funding package which enables him much greater community participation and support. This has been very significant for Chris.

The same model/approach was continued of slow and gentle movement involving Chris and enabling him to participate. The Integrated Approach incorporating procedural learning which incorporates all areas of Chris life and care and allows him maximum opportunity for participation and choice, and for the brain to make new connections. The same therapists and carers team continued.

Chris remains at BRH at this stage and continues to make gains (small by ‘well’ standards) but very significant for his quality of life at 14 years post catastrophic ABI.. Examples include:

- Progress demonstrated in video fluoroscopies:
    - 2001 where we were advised not to feed him. However with speech pathologist and team leading a program for carers, we proceeded slowly as we knew he wanted to eat
    - 2007 when the xray showed significant improvement and 2009 further improvement.

    Chris now eats lunch (of moist mince consistency) and is about to begin a 2nd meal and so replace a 2nd PEG feed (through his tube). It’s hard to imagine how good it is for him to be able to eat a range of foods, and his friends love it!
- Initially with his jaw so tight and his upper teeth embedded in his lower lip (a permanent mouth guard was fitted at St Vincent’s and remained for 2 years), then needing general anesthetic/hospital for dental examinations for many years, Chris is now able to go to dentist’s surgery like anyone else. He opens his mouth on command for clean and check.
- He won the footy tipping last year using his long blink for yes, and is leading this year – he is passionate about football and enjoys all sport.
- Under supervision of Prof Mark Cook neurologist, decrease of anti epilepsy medication over past 4 years (95 ml/day to 20ml/day)has meant Chris is so much more responsive and alert and is now vocalizing with occasional yeahs and nahs. It’s more a two way – as he is more responsive he and others give/engage more.

In 2006 in Victoria, the Department of Human Services (DHS) Disability services set up the *my future my choice* (mfmc) program for the roll out of the COAG YPIRAC and Mary became a member of the DHS mfmc Advisory group. WDCW presented the WDCW Model (see below) to the tender information session at DHS for the 10 person place.

Mary then became a member of the reference group for organization for the design and implementation of the 10 person place in what was initially agreed would be the WDCW socio-medical model.

In December 2008, ‘*Acquired Brain Injury (ABI). A socio-medical model for the care for young people with severe ABI*’ by the What does Chris Want (WDCW) group was launched by Hon Bill Shorten.
This book was written in collaboration with several others, including professionals, to document:

a. Our own experience and knowledge over several years of this group of young people with severe ABI.
b. How an Integrated Approach can assist a person with catastrophic to improve and live life fully as he is.
c. Chris is living evidence of what is working and we wanted to develop that further for him and others. He is often described as ‘*Nolesy, you are the best connected person I know*’ We used photos in the book to illustrate what words fail to communicate.
d. How the model had stood the test of adaptation and assisted others.
e. And respond to World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) of 2001, identifying the gap between the social and medical models and the need for them to come together.
f. The growing experience and understanding (still revealing itself) of the *huge chasm* philosophically and practically between health, disability, aged care and rehabilitation
g. Families of YP with very severe ABI universal complaint that they are excluded from decision making with and for their loved ones, and lamenting the isolation of their YP. Learned helplessness and powerlessness are rife.
h. In the absence of anything we could find written on the socio-medical model and to have a basis on which to develop a socio-medical model further.

Chris now has roles in society in which he participates, both giving and receiving. He finds purpose and meaning on making a difference for himself and others and still has his great capacity for people and friendship as a 42 year old (not the 28 year old of 1996).
Examples:

- Friend and confidant. Paul: *Nolesy if you ever get to talk you are sitting on a gold mine – we have told you so many of our secrets.* M: *he listens and I tell him things I don’t tell anyone else. He teaches me to listen to the non verbal.*
- About 3 years ago, St Patrick’s College Ballarat, where Chris was Captain in 1985, named end of semester academic awards after Chris in recognition of his achievements pre injury and also since in his and our works for him and others. Chris attends school Assemblies for the presentation of the Chris Nolan Awards and seems to inspire students. It certainly enables them to know life is possible after ABI.
- Chris is involved in planning meetings for MMF and since its beginning in 2006 has opened the 2nd festival Golden Plains www.goldenplains.com The ‘punters’ love him and come to tell him what the festival means to them, and how he inspires them through hard times in their own lives. Links to GP openings 2009 and 2007
http://www.youtube.com/watch?v=eRpAMCKvsPY&feature=related
http://www.youtube.com/watch?v=6M-B3rZU4Q0&feature=related
- In past 2 years, MMF has day tickets for people with severe disability with high needs supported by a medical centre and staff, and equipment e.g. hoist and bed for rest/change. Chris took part in planning and is delighted with this opportunity for YP

- Member of Inability Possability Inc and WDCW groups and attends meetings. He also attends YPINH Consortium events and forums.
- Chris is godfather to a friend's son and attends social occasions of the wider network of friends (old and new) and family – dinners, pubs, music events, weddings, etc.

WHAT HAS WORKED OVER THE YEARS – MOST OF WHICH HAS BEEN/CAN BE ADAPTED FOR OTHERS.

1. The Victorian ABI:Slow to Recover program is a very good individualized program for young people with very severe ABI, and given the limitations of funding it is responsive to changing needs. Chris has benefited greatly.
ABI:STR funding for therapy, attendant care and equipment is available to YP with ABI wherever they live – e.g. at home, in disability supported housing, residential aged care. A limitation has always been appropriate accommodation for those with very high needs**.**
ABI:STR also now has data on this group and need to be continued.

2. Partnership philosophy and practice and structures and socio-medical model incorporating the Integrated approach is essential and underpins all we are and do.[5] Communication means are vital as are people who are prepared to work in this way with Chris and one another. Examples:

- The only thing worse than being unable to actually speak for oneself would be to be constantly misinterpreted. If different people who know him ask Chris and share interpretations he is more likely to be read accurately.
- Decisions –. The way of proceeding of the group of 4 that Chris's parents set up at St Vincent's to make decisions with the medical team continues. The structure and people have changed but this way of proceeding over the years remains now with the What does Chris want (WDCW) group (who in 2006 developed an Advance Care Wishes with Chris). It is envisaged WDCW will continue beyond his parents.

Listening is one of the greatest needs in Australian society (Hugh McKay social researcher) Listening to Chris and others has been the 'lubricant' for all we have done. Of the many politicians, bureaucrats, managers, organizational heads, medicos, friends, the ones who have made a positive difference have been those who listen and dialogue – always prepared to have their own viewpoint modified.

3. Adapting the principle used with Chris since acute hospital of keeping family and friends connected from the beginning and situating Chris central and accessible to his social network is key. It encourages more natural social inclusion, reduces isolation and offers the person access to and involvement with those who know him/her best. Such people can assist the therapy team/carers/staff to know who the person was and is, and are generally attuned to the non verbal communication and can ensure the person's wishes become known and responded to. They also assist the person to widen his/her network. 'People keep people safe, not systems'.

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[5] *Acquired Brain Injury (ABI). A socio-medical model for the care of young people with severe acquired brain injury*. What does Chris want group 2008. This book has a comprehensive explanation and overview of the philosophy and practice of partnership in care and support.

When someone we love has a catastrophic ABI it shakes us to our core and is profoundly dislocating. Doctors at St V's said to the Nolans, *You are everyone's worst nightmare because it could be one of us or our son or daughter.* It has a ripple affect across families, friends and wider networks.

Based on our experience with Chris, when we strongly encouraged and facilitated the friends network, (and I was probably the main facilitator), and the way in which his friends have continued over 14 years, I believe strongly in being open to and keeping friends involved from the beginning at the acute stage. In the first 6 months led by Chris's physiotherapist friend, friends came daily to move his limbs thus minimizing contractures and giving him the comfort of touch and engagement.

If/when friends disconnect for whatever reason, and some have, we try to keep the door always open to reconnect – and many have. Sometime it is just too hard. As one said, *Mims, Nolesy was always the initiator in our conversation, and I find it so hard to take that role.* This is an example of how both friends can be 'paralysed' as it were - each with their own limitations.

It is not merely the social connection but these networks can be such a resource.
For YP with severe ABI (and often their families) isolation is a very common and difficult problem. I believe means need to be used to keep family and friends involved as far as possible from the beginning. The YP we know who are non verbal and have no friends or family maintaining become 'blank slates' with no-one who knows the person in his/her context and what he/she enjoyed. It is difficult to re-gain that sense of the person once lost.

Ideas to assist family and friends to remain involved:

- Someone at the acute stage who assist people to navigate the alien environment of the acute Intensive Care and hospital, someone who can facilitate and explain and interpret information, and assist in whatever way is needed.
- Smaller accommodation +/- rehabilitation facilities with a slow to recover rehabilitation focus located close to the YP's core community, so that contact is maintained. These could be units attached to NH or health facilities but distinct in their focus.

<u>4. Core and individualized funding - Choice and Flexibility at all levels.</u>

- **Funding –** basically we know that no control over the $ means no choice and over the years risks to Chris, so funding needs to have two components – core and individual.
    - Core (as in the aged care funding which is held by the provider)
    - Chris has two individualized funding sources administered by MCM case management and Chris and we choose how that is spent.
        - ABI:STR
        - Flexible individualized package
    - One organization as landlord, service provider and holder of Chris's funds is <u>not acceptable</u>

- **Flexibility as far as possible in therapy team to** work together and respond if needed e.g. when Chris had leg fracture at Christmas physiotherapist came to readjust positioning, transfers and immobilization etc

- **Choice of carers**. Because attendant care agencies have not been able to supply carers with sufficient basic skills to train for Chris, we advertise, interview and choose with Chris, then an agency employs. Chris's care team is a mix of RN2 nurses and personal carers. Their time with Chris varies from 5 months to 13 years, and they are well trained and educated by therapists and care coordinator and work as a team. They all work in other jobs and have an interesting mix of life experience and interests.

- **Flexibility in carer team to go with Chris** e.g. to the farm for weekends or longer connecting him with Meredith/Ballarat/Geelong area communities, social events, music and festivals, social occasions, hospital, etc. This enables Chris to participate more fully in society and community. Chris's life has some planned aspects but like all of us, unexpected events and invitations come and he needs flexibility in his carer team to respond. Carers become part of his wider network, and so get to know Chris with friends, they are valued and appreciated, hence his team is generally stable - times vary from 5 months to 13 years
- The benefit of this is that carers and friends get to know each other and this is also connective for Chris**. *Nolesy, you are still doing what you always did well – bringing people together*.**

<u>5. Disability funding in RAC.</u>

- My future my choice enhancement packages e.g. for community participation, equipment has made a difference in the lives of young people in nursing homes.
- ABI:STR funding in RAC with therapists and carers coming from outside also very helpful to YPINH with ABI.

If they are not eligible for such funding, YP in RAC are denied even basic equipment or community access funding. Disability and RAC each argue that the other is responsible. **In short term, in the absence of any appropriate options other than aged care, Disability Services should be responsible for supports for YP in RAC.**

<u>6. YPINH with lesser needs and with ability to speak or communicate are much more likely to be able to be placed in other living options.</u>

However the YPINH with severe ABI like Chris, high medical needs and mostly non verbal with narrow margin of health, are generally not able to be adequately supported without nursing care. This is identified in the Commonwealth *Mid Term Review of the Younger People in Residential Aged Care (YPIRAC) program June 2009.*
See Appendix 1 for quotes.

<u>7. Leadership not ‘content free’ management</u>. There is a critical difference **between management and leadership**. Few managers are leaders, but a leader is generally one who listens and hence manages in a very different way

I could write a book on managers we have encountered over the years. Suffice to say we have encountered the best and the worst. In this area of human services, leadership where the person responsible is ready to work in partnership, listen, engage in dialogue and learn, make decision and then review with all involved, is gift. On the other hand, a manager who is controlling and manipulative is hell.

WHAT HAS NOT WORKED

1. National Disability Standards do not have standards to cover health or rehabilitation. I hope this will be rectified in the current review. How do disability services measure/account for these needs?

2. Block funding with one organization holding funding and power as landlord and service provider with no individualized package is not in keeping with disability legislation, inhibits choice and is not acceptable to us.

3. **YP with severe ABI need disability, health, aged care and rehabilitation sectors to come together to meet their needs.**
   Over the past 14 years, we have experienced the philosophical and structural and attitudinal barriers and the CHASMS that exist to the detriment of the YP in this category. I am very disappointed that even after all that has been done, these barriers have not been overcome.. I and others have worked at all levels and seen minimal progress.

   Something needs to happen to override existing systems which are not working in collaboration with others and create a unified response for the best outcome for the YP.
   Is a Statutory body, to bring together disability/health/RAC/rehabilitation in a person centered approach an option?

4. **Attitudes to people with disability create barriers. For a YP with ABI who is non verbal *such attitudes are magnified many times over – they are regarded as ‘not there’ and non person, and treated accordingly.***
   Attitudes pessimism, exclusion, not believing people are there are endemic in all sectors and people. Decisions are made accordingly and ***YP and their families become powerless and helpless.***

   <u>One way of bridging the gap</u>!
   When people see Chris interacting with friends/family they change (seeing is believing!). I use photos (sometimes sequence) to demonstrate his engagement and responsiveness in different social situations, and display photos in his room.

> A doctor said to me recently, the brain is the new frontier of medicine. The old view of the brain as incapable of recovery has been overturned with the knowledge now that the brain has neuroplasticity, and can make new connections. New imaging techniques demonstrate people previously considered vegetative are actually functioning. Across sectors however, the dominant view remains that people with ABI who are non verbal are not there and they are treated accordingly as non persons. Those who are isolated are really at risk.

WHERE TO FROM HERE?

We all know the current system is not working or resourced adequately. We need a social insurance scheme so that people with severe and profound disability are treated as persons and citizens, and enabled to live life giving and receiving. Care and support over a life time.

LONG TERM CARE AND SUPPORT, BUT WHAT IN MEANTIME?

Structures have to change for YP with ABI and high medical needs who need skilled care to survive and thrive. How is it that Chris is assessed at highest level of care in a NH, with a narrow margin of health one day, and proposed that he move to a disability house with a much lower level of care?

I understand that nursing homes were initially set up for those with complex care needs and end of life care – now aged care. YP with ABI and high needs are higher than most aged residents. **Those with very severe ABI and high medical needs need nursing care but in an age appropriate environment**. Why should this basic care need be denied them? Without that basic care need met, e.g. if a person is in pain or unwell or is uncomfortable, it is very difficult for the person to interact, socialize or get out.

What is required is are smaller facilities/homes that provide a level of nursing support equal to that of the NH but with a socio-medical rehabilitative focus and expertise. The culture and philosophy are critical and the WDCW Model describes this. We have worked many years for it and now find ourselves back where we were in 2005 but with much more knowledge and clarity/

One option is a rehab and long term care Unit/home attached to a RAC/health facility in geographic location of person's choice (close to core community, family, friends) and so greater possibility of retaining and expanding existing networks and minimizing isolation of person who is non verbal. It seems that once a person is removed from existing networks it is very hard to re-establish.
The home would need to be distinct from the RAC

The building would need to have larger bed sit type rooms, ample space for equipment, communal spaces, age appropriate decor and be close to community facilities.(as described in the WDCW book)

I suggest that aged care standards and disability standards and rehabilitation competency standards (as developed and written by the Australian Rehabilitation Nurses Association) be used as none are adequate in isolation. It could be a good exercise to bring the relevant sectors together to combine and draft specific standards for such a Unit!

Staff be recruited, trained and inducted in social medical rehabilitative model. Registered nurses Division 1 from existing RAC facility could be used for Unit, which otherwise would have its own core staff + attendant carers coming in for therapy and community access.

Funding – 2 components

- Core - RAC fund bed at whatever level person is assessed
- Individualized - Disability personalized funding for rehabilitation, social, equipment, etc, held by a case management agency or like, with control given to the YP/family/friend/team.

YP with severe ABI need disability, health, aged care and rehabilitation sectors to come together to meet their needs.

Over the past 14 years, we have experienced the philosophical and structural and attitudinal barriers and the CHASMS that exist to the detriment of the YP in this category. I am very disappointed that even after all that has been done, these barriers have not been overcome at all. I and others have worked at all levels and seen minimal progress.

Something needs to happen to override existing systems which are not working in collaboration with others and create a unified response for the best outcome for the YP.
Is a Statutory body, to bring together disability/health/RAC/rehabilitation in a person centered approach an option?

YPIRAC my future my choice – young people with different levels of need and different outcomes

During the first 4 years 2006 – 2010 of the COAG YPIRAC mfmc initiative in Victoria, several young people with lesser needs have moved very happily from RAC and we rejoice in that. They are much better off.

Some young people with severe ABI have moved to a 10 person place for those with higher needs. Originally this is what we worked so hard for. However it seems that Chris will be worse off with a lesser level of care than what he has now and no/little continuation of all we know that has worked over this past 14 years.

Chris and others are the hard ones, very high needs, and little known. This is the group the Mid Term Review mentions as needing the various sectors health, aged care, rehabilitation, housing and community services to come together to create person/family/friends centered options.
The mid term review of the YPIRAC has some relevant sections (see Appendix 1 below)

Decision makers need to know the people they are making decisions for. In the world of today decision makers are often very far removed with several layers of bureaucracy/service providers between them and the people they make decisions for. In our experience, meeting and conversation with politicians and advisors and bureaucrats who meet Chris and us and engage brings mutual benefit.

FINAL WORDS

After 14 years and what I have outlined, we feel very disappointed that Chris may be facing yet another NH closing and relocation (rumors are there), and that despite all we have done, he is still in an environment that is not age appropriate and he is almost spilling out of his small room!

I do not want to demonize Aged care. We have met the best and worst of staff and some amazing older people whose lives are inspirational.
Chris is probably one of the longest residents in aged care , but he is getting on with life in spite of that with the amazing support of family and friends and his tea and the RAC facility.

Chris is an amazing person with a zest for life that is infectious and a capacity for people and relationships that can be life changing. He has had many words written about him. Always with a socio-political stance, he continues to gain purpose and meaning in making a difference for himself and others.

The Human Rights Award words in my award of 2002, ‘Her ground breaking and pioneering work in bringing the issue of YPINH to public attention’ – it has been a like a multi marathon in a *different world* but we now have some *road maps.* We need to take this further for Chris and others like him who are unable to speak for themselves and have so much to give and receive as persons in our society.

We welcome any further contact or opportunity to engage further in this Enquiry.

Mary Nolan

Appendix 1 quotes from the Australian Government Mid Term Review, Younger People in Residential Aged Care (YPIRAC) program June 2009:

p31: 'However, despite the Program meeting the target, a significant demand for services for YPIRAC will remain. This is particularly the case for clients with very high needs and for those living in rural and remote locations'

p 41: Clients in the Program have varying levels of support needs. Some jurisdictions when forecasting Program costs for example, made assumptions that the client group would be evenly split across the four levels of support – low, medium, high and very high. In reality the majority of clients have either high or very high support needs.

p43: Foster et al (2007, 314) argue that supporting people with ABI requires harnessing the interface between health, rehabilitation and disability support services and identifies this as a key challenge for the YPIRAC Program. They argue that the YPIRAC Program should place people with ABI and their families inside of and with clear access to the health and rehabilitation systems and specialist frameworks that have been designed to promote recovery for this population. Rehabilitation is currently outside the scope of the YPIRAC Program.

The next bit is vague in the first instance - it's about quality as important rather than just quantity:

p44: As with all government programs, there are demands on jurisdictions to report quantitative achievements and data on clients to enable confidence in program achievements and expectations about efficiency and accountability. Reporting by governments is therefore less likely to include qualitative information that may be available regarding programs, including information which demonstrates the texture and the challenges of program implementation. However, it is acknowledged that the opportunity to consider qualitative outcomes will be addressed in formal program evaluations and reviews.

It is a bit clearer later on:

Section 5.5 on Short-term implications for the YPIRAC program
p54:
5.5.4 Analysing the rich narratives and stories that have been collected
While the AIHW NMDS reports provide a useful insight into the characteristics, clinical information and background of clients, the limited qualitative focus is inhibiting the ability to understand at a national Program level:
The complexity of the Program's interface between the health, aged care, housing and community services sectors.
The significant narratives and positive quality of life outcomes for individuals involved in the Program.
(*The point here is that we have provided this in detail regarding Chris' circumstances, so it is significant that these quality aspects have not been addressed so far)*

p55: 'Jurisdictions have expressed concern that the relocation of YPIRAC Program clients from RAC (PO1) and at times diversions from hospitals as part of PO2, because the client is assessed as being 'at risk' of entering RAC, removes clients with ABI prematurely from structured environments that have been established to support their ongoing rehabilitation.