

## Who is Mad as Hell?

**We all are.** We are a cross-section of ordinary Australians who have one thing in common – unwavering commitment to changing the dysfunctional Australian disability support system to provide genuine, entitlement-based support to people with disabilities of all ages based on their individual needs. Delivering targeted, timely services to people with disabilities will help them to be part of everyday Australian life and support the families who care for them.

**Fiona Porter** BA, M Bus has two teenage children; her son has a severe physical disability due to a brain injury of unknown cause. His family helps him with all daily support. Fiona and her family moved from Sydney to Brisbane as “disability refugees” to reduce the debt they accumulated over 13 years paying for therapy and disability equipment. Fiona is a board member of Queensland Parents for People with Disability (QPPD), belongs to several web family, education and design forums and blogs about her experiences trying to build an accessible home <http://inclusivehome.blogspot.com/>. Using skills from her employment background in corporate and not-for-profit communications she runs a communications consultancy. Fiona is mad as hell about the inaccurate way disability is viewed as a cost. She wants to change the mindset by showing how an NDIS linked to self-directed funding will invest in people with disability, maximising their capacity to live a valued, productive life, benefiting themselves, their community and the nation.

**Sue O’Reilly** BA is a mother of three adult children; her younger son has a severe disability resulting from cerebral palsy and needs 24/7 support. Sue has worked as a journalist in Sydney, Perth and the Canberra parliamentary press gallery. She has also worked as a press secretary to a NSW Minister for Health, as communications director in two federal government departments and as a senior account manager for a leading public relations company. In London she worked as a feature writer on a Fleet St newspaper when she and her husband David moved to the UK in 1995 as “disability exiles”, to access high-quality educational and therapy services for their son. Since returning from the UK following the death of her husband, Sue has become mad as hell about the dire state of Australia’s disability support system and inflexible nature of support services, compared with the government-funded, self-directed funding models which operate successfully all over the UK.

**Trevor Harrison** is a successful South Australian consultant, loving husband, a doting step-grandfather and has cerebral palsy. He had a happy childhood and school life – with access to therapies that are unheard of for today’s children with CP. He credits his parents with “ingenious” ways of helping him enjoy physical sport and play that children with disabilities yearn to join in with. Trevor believes the greatest benefit he gained from school was inclusion in a variety of activities which helped him develop self-confidence and personal initiative – qualities which have stood him in good stead as an adult. Trevor has been invited to join numerous Boards and Committees and various positions stemming from Ministerial appointments. Trevor wants to help other people with disabilities enjoy similar opportunities for personal growth and believes a grass-roots Mad as Hell campaign will help achieve this with the introduction of an NDIS and self-directed funding.

**Anne Murphy** PhD is a Melbourne mother of two boys, aged 9 and 7 years old. Her younger son has Angelman Syndrome, a neuro-developmental disorder characterized by global developmental delays and severe speech impairment. He is non-verbal, has epilepsy, needs assistance with feeding, dressing and toileting and needs to be watched at all times. He is unlikely to be able to live independently. He is also a happy boy who fills his family house with laughter and wins the hearts of everyone. The family’s main challenges have been finding and keeping support for his needs. They have waded through the maze of accessing services, endured waiting lists, filled out endless forms with the same information and lobbied unsuccessfully to keep their son’s special developmental school open. Anne is mad as hell that their son’s future is so uncertain because of the dysfunctional disability system. She wants an NDIS and self-directed funding to help people with disabilities and their families have an ordinary life, like other Australians.

**Patrick White** B Sc (Pharm) MPS is a Canberra father of three children; his 19 year old son has low-functioning autism and epilepsy. Patrick's son cannot live independently and has been recognised by Disability ACT as requiring 'sustained support for life' including full residential care. Patrick enthusiastically supports an NDIS, which would underpin an 'entitlement based' system and along with self-directed funding would allow improved innovation and more options to best manage the current and future needs of people with a disability. Patrick has expanded upon his pharmaceutical career and now focuses on consulting and social project work. He is a committee member of the Pharmacy Guild of the ACT; member of the Quality Use of Medicines Pharmacy Advisory Group ACT; facilitator of the Quality Use of Medicines Project for Aboriginal & Torres Strait Islander people in the ACT; Vice-President 'Community Living Project' which focuses on a holistic approach to care; Ambassador of the Heart Foundation.

### **Website**

**Valentina Maniacco** B App Sc is a mother of two teenagers without disabilities and has a background in IT, sales, marketing and more recently web design. Like most Australians she has several friends who have a family member with a disability. Valentina's son attended school with Fiona Porter's son (who has a disability) giving Valentina the opportunity to observe for many years the 24/7 commitment the Porter family makes to try and give their son "a normal life". Valentina was delighted to volunteer her services to create the Mad as Hell website because it enabled her help make a difference and support the "voiceless people", who cannot go on anymore because their families are at breaking point.