



We're Mad as Hell

We're not taking it anymore - and there are millions of us

www.australiansmadashell.com.au

CONTENTS

**About Australians Mad as Hell
Recommendations
What people want**

1 About Australians Mad as Hell

Despite all the money poured into the disability sector, so little reaches the people who need it. Hundreds of thousands of people with disabilities and their families have for decades been marginalised and hurt by the systems which are supposed to support their inclusion in life. And no one seemed to listen, care or change the system. So Mad as Hell was born, founded by two mothers of boys with severe physical disabilities, supported by a small group of parents of children with disabilities of various ages and by adults with disabilities and driven, as one person who contacted Mad as Hell described herself "by an internal ball of fury."

Australians Mad as Hell (MaH) is a grass-roots, online lobby group with the single goal of making all political parties understand that urgent reform of Australia's dysfunctional disability support system is critically important to millions of voters; that is 1.4 million people with serious disabilities and their 700,000 family carers. We also think the rest of Australia would be badly shocked to realise that if they become disabled in the future, the system will let them down as well, except for a fortunate few covered by vehicle or workplace insurance.

Mad as Hell is not an organisation or a charity; it receives no government support or funding other than small private donations. Mad as Hell seems to have captured the imagination of a wide range of people across Australia who have heard about the campaign through family, friends, networks, colleagues and national newspaper, magazine and radio coverage. It has ignited a barely suppressed rage among the hundreds and thousands of people with severe disabilities and their families in Australia, who will no longer tolerate being treated so contemptuously by governments, bureaucracies and many disability sector organisations.

By mid July 2010 nearly 25,000 people have taken the Mad as Hell Pledge of Voting Intent (reproduced below), signalling their intent to vote in the 2010 federal election for the party/ies that commits to introducing a National Disability Insurance Scheme (NDIS) and individualised funding. Disability dominates our lives – or rather the failure of the system to deliver the supports people with severe disabilities and their families need to take our place within our affluent, democratic nation. We have become disability refugees in our own country.

Because disability dominates our lives, it will dominate how we vote.

Mad as Hell Pledge

We're mad as hell

We are **not** going to take it anymore
And there are millions of us

- I pledge that in the next Federal and State elections, I will vote for a political party which publicly promises to transform Australia's broken, inefficient, crisis-driven disability support system by:
- Introducing and supporting a **[national disability insurance scheme](#)** (NDIS) immediately after the Productivity Commission study, due July 2011
- Ensuring people with a disability and their family or nominated representative decide the best ways to use funding received to meet individual needs

2 Recommendations

Based on the feedback Mad as Hell has received, we believe the following recommendations are crucial to a successful, sustainable disability support system in Australia:

1. **Simplicity** - A single, electronic, secure administrative and information gathering system so that people with disabilities and their families do not waste their lives completing forms with the same information over and over. A national database can virtually eliminate the repetitious layers of national, state, local and agency administration which eats away at any funding received currently. This national database could be developed and used according to individual and local needs, for example an individual or their nominated representative could research the database to find relevant services or equipment which met specific needs now, or plan for future needs. User feedback could form part of a continuous review process to help providers provide and plan to provide the services consumers need.
2. **Flexibility** - a system which enables the person with a disability, their family or nominated representative to receive the funds on an annual basis, decide the most effective use of the funds in the short-term and plan for medium and long term. The system will also have the capacity for those who do not wish to take such direct responsibility to have access to transparent, accountable mechanisms to manage the funds on their behalf, and teach them how to increasingly take ownership of their funds management, if they wish. Many submissions to the inquiry refer to effective overseas planning models.

3. **Consumer-driven, like the rest of the Australian economy** - The switch from directing funds from service providers to consumers will increase the availability of quality goods and services and stimulate competition amongst service and equipment suppliers, who will need to demonstrate value for money to this consumer market. This will be a significant cultural and change program that needs to be well-managed. Customer-oriented service providers will prosper and grow if they meet consumer demand, the same way other industries operate in Australia's market economy.
4. **Proactive** - Aligned with other western nations, the move towards individualised funding and self-managed funding should begin now, before the Productivity Commission reports in July 2011, to enable service providers to begin a planning and transition process to develop the capacity and mindset to direct funds available to individuals, and to expand this process as soon as a scheme is finalised.
5. **Outcome-based** – Audits, reviews, assessments must have as their focus the quality of outcomes for people with a disability, not processes or systems of delivery. This process must report directly to the federal minister responsible for the disability portfolio. This should be a senior ministerial role.
6. **Dream big** – People with a disability and families/nominated representatives should be offered training and support in how to envision, plan, create, change and sustain the supports needed for them to take part in ordinary life. Many people will not need this; they already know how to and long to take control of their lives but are squashed by a system that ignores their knowledge and skills and assumes external service providers and professionals always know better. Often they do not.
7. **Respectful relationships** - Understanding that a revitalised, efficient disability system comprises not just forward planning, rigorous accountability, targeted service delivery and efficient equipment supply, but also strong relationships. Open, trusting, respectful relationships between people offering or supplying services and those who receive them are critical, particularly those involving children with disabilities and their families or adults with disabilities who may not have capacity to make informed decisions and are reliant on family, close friends or a nominated representative to assess what best meets their needs, not other agendas.
8. **Draw on community knowledge** – just about any parent of a child with a disability will tell you they receive most useful information, guidance, support and informal "counselling" from other parents in online or personal networks. What can the "disability industry" learn from that? How can this informal knowledge base be captured and used more effectively from the day of diagnosis/injury throughout a person's life?
9. **Supporting self-funded expenditure** – a tax-payer funded NDIS must prioritise support to people with severe physical, intellectual and mental health disabilities which affect their core activities and restrict their capacity for independent, age-appropriate activity in everyday life. To promote private funding *where possible*, there should be consideration of how to create a two tier system – of NDIS funding for those severe disabilities and non means-

tested, 100% tax deductibility of privately funded equipment/services for those with mild-moderate disabilities which do not limit core activities or age-appropriate activities or community participation.

10. **Integration of NDIS with external services and infrastructure** - The NDIS is not a universal panacea. It cannot and should not replace the community's economic and social need for integrated, planned design for inclusion in everyday life, for which elected governments are ultimately responsible. For example, there is no point an NDIS ensuring children with disabilities receive the therapy and equipment they need to maximise their health and capacity to contribute and learn, if the education systems still apply legally-accepted practices and funding models which discriminate between students with disabilities educated in the government system, the independent system, mainstream schools and special education schools/classes. Or students with disabilities graduate from school, TAFE and university but can't get to work because of inaccessible transport, or buildings, or workplaces, or employer attitudes.
11. **Convincing the rest of Australia of the need for an NDIS** – this requires a positive, solutions-based, sustained education campaign by the federal government as soon as the Productivity Commission's report is released in July 2011. There is no time to waste. Just as we learned about and accepted the need for seatbelts as a safety measure in cars, Australians will understand the need for an NDIS if the facts are communicated clearly and with multi-partisan credibility by a diverse range of people with disabilities, or those who speak naturally for them, such as their families. Australians without disability need to understand that disability can and does happen to them – to anyone, anytime, and that the current shambolic system wastes money and helps too few. We stress the need for extensive, meaningful consultation about a proposed education campaign with a wide variety of **real people directly affected by disability** – not just professionals, funded advocacy groups, service providers, consultants or public servants.

3 What people want

It humbles – but does not surprise us – that thousands of people have told Mad as Hell their stories. The fact that a no-frills, unadvertised, grass-roots electoral campaign run by parents in their "free" time with a simple, strong message received over 2,200 emails, letters, comments and phone calls in under 4 months shows the deep anger and resentment felt by so many disenfranchised Australians who are marginalised simply because they have some form of severe disability. In 2010, in a wealthy democracy, that is inexcusable.

A sample of emails and comments sent to Mad as Hell during the last 4 months is listed on the following pages, showing simply, eloquently and unarguably that Australia's welfare-based, ineffective disability system must be utterly transformed, with the greatest possible speed. Feedback is reproduced as we received it, although some initials are changed to protect identities. To the Productivity Commission: the hopes and dreams of hundreds of thousands of Australians hang in the balance of your findings.

Feedback received by Australians Mad as Hell 28 March – 14 July 2010

1. I am an Australian Occupational Therapist currently working in the UK within social services. A recent and ongoing change in the direction of Social Care policy in this country demands that 'service users' and their carers have choice and control over the support they receive. Personal budgets are offered to allow people to manage their own care, in the way they see fit. The personalisation agenda is having a major impact on the reduction of disability across the country. There is also a legislated consideration of the role of carers in this equation. The change has been staggering. Good luck in achieving similar outcomes in Australia. Frankly, anything short of that is an embarrassment. BM
2. Thank God there is finally some momentum being created around this issue! I will vote for anyone who promises to bring in this reform as it will literally give me a life and my disabled son the dignity he deserves. Good on you, people!! AH
3. I blame the system or lack of system. We received very little respite and then we needed it the most we lost all our respite altogether. I am angry and ashamed that I live in a first world country that treats people with disabilities as charity cases who have to beg for everything they get...this is WRONG!
4. My son may never live whatever adult life he can have independently, but it would be wonderful if he could have some of the equipment he will need in the future which is not on the Medical Subsidy Scheme.... Thank you for what you are doing...today in a meeting with Senator McLucas, I drew her attention to your website - I wonder have you promoted the existence of your pledge with all politicians?
5. THANK YOU, THANK YOU, THANK YOU!!! I've sent this website to everyone I know! I have a child with multiple disabilities (autism, down syndrome and hearing loss) and even though the facilities in Perth are fairly good, the costs are astronomical! Thank you again for addressing this. SB
6. A physiotherapist epal in Belgium wrote to me today about their system. This is what he said: First, the Belgian social system is so extended that handicapped people >21yrs old receive a disability pension (Å± 1600/month AU\$) that may be enough to live with their parents without working. In addition they receive a budget to live assisted by carers at home (Å± 3000/month AU\$). With this money, they may hire carers 24h/24. They lose this budget when they work, naturally. DR
7. we have been waiting for 3 years for a bed, my son has severe epilepsy and is peg fed and he has to sleep on the floor so he doesnt get hurt. we have a second hand wheelchair that still hasnt been adjusted to fit him properly. we r not asking for luxuries just quality of life that our kids deserve JA
8. Saw the 7.30 Report a few weeks back and was wondering whether there will be candidates standing (in the Senate?) at the upcoming State (NSW)and federal Elections. I am the father of an 11 year old boy with severe physical and intellectual disabilities. I am very keen to give my vote to anyone who is fighting for the disability sector. Any info you can supply would be gratefully received. GW, NSW

9. Met with NSW Ombudsman today - they're getting feedback on families with kids with disabilities. Gave them a lot of feedback - including a blast on how difficult it is to get funding, find information and why a great organisation like Lifestart is forced to beg to survive when the state government wastes so much valuable money. Behind you 100%. Nice work. MG, NSW
10. I would like to help in any way I can! I plan to make others aware of the existence of your, no our campagne to let those in power know we will no longer accept their pathetic excuses. I am, as always, Mad as Hell!!! RR, QLD
11. THANK YOU for this wonderful website. I'm another parent who is MAD AS HELL with lack of services in Tassie. WN, TAS
12. They have suggested We relinquish care so that we can get the right support for our child. its terrible how the mental health and disability system works here in aust my little boy falls right through the cracks!!!
13. Hi, my husband is currently in a rehab hospital after suffering a C4 complete SCI in Jan. WE have 2 small children aged 3 and 2. I am also living with all the issues that you have outlined so well and i 100% support the cause. I am also a physiotherapist and have worked in disability services in Australia, the UK and South Africa. Thank you for all your efforts, you are an inspiration. KP, NSW
14. Who in their right mind would want to have their house modified or filled with aids and appliances if they didn't NEED them. AB
15. When my child was 18 yrs I became unwell. I care for him alone. DSQ's only solution was to put him in a respite home even though he has been living in his own home all his ife. They refused any offer of support to him within her own home. FP
16. I'm a carer of now 3 people with various disability issues, none of which quaify for government help no housing/health care/disability services etc. The only help I am offered are anti depressants. Would love to see a Nation wide carers strike. (oh thats right we dont qualify for representation from the unions cos Carers arent workers. JG
17. Again I say thankyou to the founders of Mad as Hell. You are managing to get very good publicity for people with disabilities and their carers which has never been done before, and you are doing it very well. Now the rest of us need to take action and get things moving in each and every local area in Australia so the politicians realise that we are not going away....we are not going to back down until there is major reform in the funding of disability services. NH
18. Contacted disibility services to day got the run around again GB
19. I saw your story on Stateline today & agree with your suggested model. I think it's outrageous that these government organisations can muck it up so badly, how can they not see that it's better to provide prevention than spend loads more fixing up problems later? The bottom line should be about the people. I have immense admiration for those of you in this

situation and I really hope your National Disability Insurance Scheme gets through. FM

20. Waiting a year for a wheelchair is equivalent to restraining an able bodied person for a year. AB
21. When my son was getting a new wheelchair i looked at websites in the UK ...i could get the wheelchair he already had shipped to australia for approx \$400.00 so why did his first wheelchair cost us over \$4000.00....hmmm someone is making a huge amount of money from people with disabilities.. JS
22. So the SA government has found an extra \$85 mill for the footy / cricket stadium. Added on to \$454 mill already outlayed. How many services for people with disabilities would that pay for..how many wheelchairs, respite hours, needed pieces of equipment etc!!!! CO
23. Can someone tell the ALP they are in government and have the power to fix the disability system if they really wanted to. AB
24. The only way to get help, we were told, was to relinquish our little girl to DoCS (community services). Eventually we could not cope and found ourselves in a world where authorities find it hard to distinguish loving parents from those who abuse their child. It was wrong. We fought back.
25. My son waited for three and a half years for his first wheelchair. He only had a stroller that didn't support his head so he had to lie back at 45 degrees and he couldn't see the board- or the teacher or his classmates- at school. He was in year three when he finally got the chair and only then because I had written many letters and made many phone calls....and generally exhausted myself. As for a walker/stander- well don't get me started.And I still have to wash him on a towel on the floor because we can't get bathroom mods .And despite being assessed for home help I've never actually managed to get a worker who will do the tasks they're paid for. NSW Disability services SUCK. SR
26. As a working parent carer I am very frustrated with all the systems, which only put further stress on you and make it much harder to maintain employment. Nobody cares about the demise of your child or your family. Nobody cares about the stress or the lack of funds to pay for bloody everything. SO THANK YOU FOR YOUR REPRESENTATION/ ADVOCACY of our carers and their children. I am very very supportive of this campaign. KJ
27. I'm a carer of two kids with disabilities my family is treated as though we are invisible until the government comes along to take something else away from us as though we do not matter . Thanks to Kerrie-anne's show for getting the message out and getting me here, I'm behind you 100%. KW
28. Congratulations on doing what my husband and I have been threatening for years. We have a 19 year old daughter with Cerebral Palsy Spastic Quadriplegia. She completed a mainstream education, and is now studying at TAFE. This is through sheer dogged persistence, aggressive lobbying and many, many tears. She is totally physically dependent and mobilises in a motorised wheelchair. We could tell you some seriously

hair raising stories that support every single word each of you uttered in the Stateline NSW interview. She is about to move into his own unit, after more seriously aggressive lobbying, ministerials, and legal threats. We don't have a 'package' due to his apparent 'ableness'...that is she can speak, and can study. We have done the whole 'Circle of Friends' thing (read that as a bunch of people who barely know you providing 24/7 UNPAID support), and it fell apart before he could even move in. We are now back to lobbying for a package, and have been told we will only access one if we go into crisis or relinquish care. I used to wonder how parents could do that, but I see it's the only option. We have been dehumanised and our family basically terrorised by threats from the disability department. RP

29. I am one of those parents who are sick of having to jump through hoops and justify my kids disabilities at every turn. We live in Australia yet when one moves interstate we have to go through all the processes again - this is not America , why can't information for disabilities be accessed throughout the states as is Centre link.I have recently moved interstate and the disability services are not that informed to be helpful with the process of accessing post school services. DS
30. I have a 3 & a half yr old daughter who is Globally/Mentally delayed, who is extremely physically & mentally challenged,who cannot support herself at all not even communicate with us,& who of course needs 24/7 care which has predominantly been supported by me alone.
31. I have another (older) sibling to (disabled child), & my union with my husband & other fellow family members relationships are only hanging by a thread. I am Mad as hell that ADHC nsw (Aged disability & home care),solution to my "carer role to disabled child" is too hard, then my ONLY other option is to give my child up to a foster family who they assure me, will be more than happy to take him as their own! How disgusting are these people? are they even humans? do they even know what it feels like to watch your own child suffering let alone have any sort of disability?, how dare they say that to anyone facing this sort of challenge. SB, NSW
32. For the last 2 years we have used the "We are Mad as Hell" quote so many times out of frustration because of the overall lack of support and funding from the government. What we are dealing with is not only the way the government treats the families with children and adults with disabilities, but we are also dealing with a rare disease. ME, NSW
33. My husband has C4 quadriplegia due to a motorbike accident in 2004, and although we are "fortunate" enough to be funded by TAC - I can sympathise regarding accessibility and the fact that this can happen to anyone (as it did to us). SM, VIC
34. Why do programs such as "making a difference" actually differ from part of Victoria to the other? Why do some people have to climb through hoops to get support? why do some "support services" actually seem to working against you? What makes me even madder, When your child turn 18, All support is taken from you. He no longer qualifies for paediatric doctors and is forced into the care of doctors who nothing about him or his health issues. SK, VIC

35. As a teacher who works with children with disabilities, I support the introduction of a national insurance scheme. It is shocking that families have to beg for support. CK,QLD
36. Hi, I am the mother of a 27 year old son with a physical and intellectual disability. Myself and the mother of a Down Syndrome young man have started the long road of setting our sons up into independent living. I have read the reports on your website and cried. We are living all of these stories. How do I go about joining your organisation and being part of the fight for better support for people with disabilities and their families. CM
37. You are doing a great job. I have a 7 year old daughter with Cri du Chat (severe learning disability and low tone). I have emailed your info to everyone I know. How can I help your campaign? NA, NSW
38. I have been a carer to 3 of my family members for years.2 years ago i lost my husband now i have 2 adult kids that im caring for.Why do we have to really fight for everything,im tired,doing my best. what support i have is not enough,we have to make do as there are not enough carers we need to stand together and fight this government. GS
39. Thank you so much. Our family has been battling with all these problems over the last 18 years and YES we are MAD AS HELL -we will support any changes for the better. JK
40. As a mother of a disabled son, please keep me informed of your activities, what can I do to help? CM
41. I saw the piece on Stateline last night and it's such a relief to see that our family is not the only ones who feel so totally frustrated with the lack of basic support in this country. Our 6 year old daughter has Muscular Dystrophy, and since moving back to Australia from Ireland last year we have been appalled at the uncaring attitude of the government agencies. Everything you said on the Stateline interview rang so true with us.
42. An organisation like yours is the only way that things will change, but it will be a long and hard struggle. I would like to find out more about how I can help with your campaigns, or if there are any organised events (e.g. protest marches) that I can help with or participate in. MB, NSW
43. I have made my pledge. My son has an aquired brain injury due to a 'hit and run' car accident. Luckily we are covered by TAC, still a lot of caring to do though. I really feel for those poor people who have no support at all SH, VIC
44. Thank you for setting up this campaign and this web site. It is true as a carer that on 1 level I am mad as hell, but I am usually too busy and too tired and too filled with disbelief at my situation and that of many others to feel the rage. Thanks for putting it into words with the phrase Mad as Hell, HU, ACT
45. Thankyou for taking up the fight, some of us don't have the strength left to do. as i sit here in tears at almost 4 in the morning... a DADHC case mgr told me about you. i've finally looked at the site. thanks, more than you know, you've given me enough to get up tomorrow and do it all again. DB, NSW

46. I am a 21 year old full time university student who is currently studying social and community studies. I have worked hard to attain my grades and my position in the student community and one day I hope to aspire to become a social worker.
47. I am one of the many Gen Ys who has a disabled sibling. There are hundreds of us. You take every single family and there will be a child or children in that family who have no disability, but have it by association. They live with the tantrums, the staring, the knowledge that their brother or sister is not quite like the others. They face the ultimate depression and acceptance of having a sibling with a disability. Most importantly, they see their parents, their tired parents who have had to give up careers, dreams and in some cases marriages in order to care for their disabled sibling so that in some instances, their other child does not have too. They have seen their parents fight for basic services, such as wheelchairs, inclusion at the local school, a mobile bed, a van to fit a wheelchair or respite, so that the family can have a break from caring for a little while. Siblings have been described as the silent army, this is accurate as we do this along with our parents everyday and we too are mad as hell. We are mad as hell that we have to see our parents care for our brothers and sisters with little support and assistance from any government and we are mad as hell that we should have to take this over this care from our parents once they cannot provide care if they pass away or they themselves become ill. Caring about, and caring for are two different things which are worlds apart. I will never stop caring about my brother, my role as his sister and his advocate and friend will continue for the rest of my life. But I do not see that I should have to care for him. I dont want to be faced with that burden of care. And I am as mad as hell that at 21 years of age, a budding professional should be faced with that road ahead but unless things in this country change, I and the hundreds like me will be faced with that choice of caring for our brothers and sisters. I am a sibling of a person with a disability and I am as mad as hell. i just wanted to give a siblings voice to mad as hell. I think the both of you are doing an amazing job capturing the mood of every family in Australia in this situation. Lets hope that we can make as much change as we can! Keep up the good work, LP, ACT
48. My son is 15 and severely autistic. My husband and I are broken, poor and tired. When is enough enough? KB
49. I'm part of a couple of organisations supporting parents with Angelman Syndrome (one being www.angelmansyndromeqld.org). Just wanted to congratulate you on a wonderful campaign. We have drafted a letter for our members to send to their local members (both state and federal) reiterating the need for reform, and its importance at the next election. If there is anything in the future we can do to assist, please let us know. JK, QLD
50. As the single mother of a severely high-functioning autistic child who has been fighting- yes, literally fighting - for a "formal" diagnosis for just on five years, for a condition that all his teachers and carers knew about, due to their anecdotal (but alas- not "professional"- experience) and for him to finally being recognised as a disabled child, I am as mad as hell too. With myself not being able to work due to his being suspended from numerous schools at a moments' notice, and STILL not receiving a carers pension (though we do receive a paltry \$49 a week disability allowance),

it makes me madder still. I have been forced to sell our home for medical/diagnostic expenses. Count me in for whatever tacit publicity that you may need. (we still need our exact privacy respected, due to his condition, and the fact that he may not be accepted into certain gov't schools). KM

51. I am mother and carer to my son who who has a fairly severe disability. I want to commend you for the great work you are doing in getting the message out. I also want to offer my services to you, if you need them. I am on unpaid leave. My job was largely preparing letters, briefings and memos for MPs and senior public servants. I am familiar with the system, familiar with the language, and willing to help in any way that I can. Please do not hesitate to let me know if you require any assistance at all with your campaign. FS, VIC
52. My wife and I have a 24yr old daughter who suffers from Rett syndrome, disabled mentally and physically from early childhood we have battled over the years just to get basic needs for our girl. I am 61 and my wife is 54. Who will look after our girl when we go? Maybe we can have her stay with the people that say we are wingers. . . no I don't think they have got what it takes! RD
53. My wife & I are aging parents of a 38 y.o. Down Syndrome daughter and need to have a future plan for our beloved girl to keep her safe and secure JV
54. I have been sole carer for my severely physically disabled wife for 10 years. At 50 we need suitable respite accommodation for her age group. I refuse to send her to a nursing home for a couple of weeks. RP NSW
55. I'm a mother and carer of a young man with Aspergers Syndrome and also suffers from Anxiety and Depression and has been suicidal twice in his young life already. The support we are offered is extremely minimal. We have even had our travel allowance removed now because he attends a private school compared to a state school. We struggle financially to enable him to attend so he can receive the best care possible. Thank you for standing up for the less fortunate. I admire your strength. You are making a difference. SJ
56. I am a mother and full time carer to my daughter who is nearly 9. She has arthrogryposis, is wheelchair confined, tube fed, with numerous other issues. It's about time the government stood up and realised just how bloody hard it is to do our job! I'm sick of having to struggle for the littlest of help, also making my job as a mother a little less enjoyable actually, I can't wait for the day when things may be just a little easier! We all do our best to love, care and support our children/family members to our best of our ability, maybe the government should realise and appreciate just how much money we are actually saving them! We keep our daughter with us because we love her, but I don't have the luxury to be able to employ someone to help with the duties at home, so we do it all, and just trying to get the equipment she needs is a constant struggle! It's a national disgrace if you ask me! About time these issues were given more attention by the media and our politicians! Good job you all for working on behalf of all carers and the disabled in our society! Thank you LH

57. I am 29yrs old and i am a full time carer to my brother who is 27 yrs old who has cerebal palsy and is confined to a wheelchair. I had to give up my job to take care of him. Just wanted to add my name to the signatures and add another voice of a person who is very much sick of the governments attitude towards people with a disability, but will gladly give women money to have children which is often a choice people who have a disability don't get that choice. My wish for the government is to pay and take care of us like any other job because whether they won't to believe it or not this is a job 24/7 by the way no hoildays no sick days.
BM
58. This is a fantastic website and the NDIS is a fantastic idea. It is entirely discriminatory that if my daughter's multiple and severe disabilities had happened in a car accident, she would have the 24/7 care along with all of the expensive equipment she needs...but because she was born with these disabilities, we have to beg and plead for any assistance, and we have had to sacrifice everything as a family to care for her, and there are no long term guarantees for her care. hopefully the government will soon see the wisdom in streamlining and consolidating and investing in all those who are disabled AND THEIR CARERS from the very start, rather than waiting for a crisis driven, fragmented, inefficient, virtually non-existent "system" to keep putting bandaids on problems that need major surgery. Keep up the good work. RZ
59. And thank you for the support. I have a severely intellectually disabled daughter of 24 who's luckily using the fantastic services of Windgap in Sydney. I'm very scared for the future and with you all the way DP, NSW
60. Hi, I am mad as hell. I am a new mum with a 22mth old with Cp, Seizures and blind. I am appalled at the system, I hardly understand it. I am sent to so many different agencies, no one tells you the basic infomation. I feel like I am tripping over my own feet and also coping with the grief of the life my child has been given. I do not want to give up work but feel that is my only option to care for my son. A life of welfare and that is not fair. I want to help you in anyway I can. I do not know if I can but I am mad as hell and I have only started on this journey of disabilities. I have a long road to go with my son and I want the best for him. JS VIC
61. Power to be taken from the Care Providers and given to the person with a disability and their parents. The Care Providers becoming administrative bodies suppling Care Workers The ability of those with disabilities to be able to reside anywhere within Australia. The rights of those with disabilities to be enshrined in legislation. Group Homes to be controlled by the residents and their parents. The problem I have with the NDIS is that it is not due back until middle 2011, then the Government goes though it and shall only implement the portions it wants, somewhere around 2013, which is too long and shall probably still leave those with disabilities in a bad situation. Furthermore, Bill Shorten has admitted that it may never occur. So to ask those with disabilities to wait three years for something that may never occur, is unacceptable. For over four years we have attended seminars regarding the mess that the Disability sector is in, so as far as we are concerned the time is up.
SM

62. My son was due for a new wheelchair, because he had grown, and also to help address his severe and worsening scoliosis. We applied for him to be fitted with a new one. We got an appointment 18 months after we requested it. Unfortunately, his scoliosis affected his breathing and he developed pneumonia as a consequence of H1N1 (swine flu). He died in hospital--two hours before his appointment. A timely new wheelchair wouldn't have saved his life, but it would have made his last 18 months a lot more comfortable. FP
63. I am a mother of 4 children 2 of whom are disabled, one with ASD who is 14 and one with a myriad of disabilities who is 7. I have been unable to work for a very long time. I am now 39yrs old unskilled and even a menial job I cant do because of the care of my daughter before and after school. My husband has just lost his job, no one wants to employ him he is 48 yrs old. I am an extremely intelligent woman capable of achieving anything but because of how Australia works I cant even get the opportunity to go to UNI gain a degree and then go to work. Somedays lately I start to wonder what is the point of my life then I look at A. She is my point of life, no matter how hard, monotonous, isolating or saddening, she is my point and I will never stop fighting for her. Maybe if a few of these politicians were unexpectadly thrown into our positions we could start to get some change. Its 2010, Australia, how shameful. JC
64. We are just another family in a common boat. 65 & 63 years old. 30 year old son with intellectual disabilites. Retired from work early to help my wife. Activities are mostly based around our son. Other siblings don't get the same attention. Earnings restricted for the past 20 years. What happens when we are not available to care for our son? This is not a sook because we do have a good life but we continue to look for long term solution. RA
65. Heard you on radio this morning I am a full time carer for my son at 19 surfing accident brain aneurism and near drowning... he can't speak and can't move at all. I am one of those you mentioned that in one phone call, all changed. what can I do to help I am mad too with the govt. They seem to lack common sense and waste heaps on so called help for the carer. SR
66. I have three boys with special needs. My two older boys have mild to moderate Asperger's syndrome, anxiety and learning difficulties. My youngest son has mild cerebral palsy, autism, is non verbal and at almost nine is still in nappies. He has a intellectual disability and has a mental age of about 2 years.
67. My husband and I had to make a terrible decision and that was to give up our youngest son to foster care. We have little family support, and my marriage was breaking down and was close to breaking up. I will never forgive myself and feel that I am a terrible mother and it is something that has broken my heart. I feel that we as a family had no other choice my two other sons were suffering and were having severe issues, my husband was ready to walk away and I became severly depressed.
68. I am a mother of a 12yr old daughter with severe Autism. I am a Social Worker for a Govt Dept, my partner is a nurse and we struggle to work and care for our child. we are met with apathy by the child care (OOSH - Vacation care services - special transport - and the school services) We

are sooo tired of fighting with buffoons, we are overwhelmed, our child is violent toward herself and others. We took a drastic step of trying to hand her over to DoC's NSW to get a voice and some assistance as we were in crisis only to be met with blame and accusations. THIS SYSTEM IS ABHORRENT. KH

69. I am a physiotherapist and I have worked with children and adults with disability for about 40 years. The provision of services has deteriorated significantly over the past 10 years . It was never great but is now at an all time low. I would like to know what you have in mind to galvanize the politicians and engage the community apart from this initiative CG, VIC
70. How can I help? Have disabled young son with CP, intellectual disabilities, autism etc. I feel so disenfranchised and have loathing for this system we have. Good to find others who feel the same. PB
71. Just wanted to say that I believe there needs to be massive change! I am an early intervention teacher and have been for 10 yrs...it is a nightmare for families to access services for their children. I currently work with families who have children under 6...mostly with autism...the autism package has been the first really useful initiative since I started with EI...should be for all families.. in this way a family has some control some say and at least get some support. The hoops to jump through are extreme for parents and I can say for us as govt paid services a nightmare...the time spent trying to resource some equipment/transport support/respite....knowing that the paper work will take me away from face to face teaching and really meaningful service...in order for some other bureaucratic paper shuffling department to cross the t's a thousand times before deciding that this person is a priority over that.the whole area and processes are a complete nightmare.... I support any system which will provide meaning ful and streamlined support to families who have child/adult with disabilities!!!! SH
72. We need a national no-fault accident and injury compensation scheme. But it mustn't be funded through yet another levy, which is simply a flat-rate tax and therefore inequitable - poor people pay a greater proportion of their income than rich people. Funding should come from general taxation revenue - if we need to increase tax, then do it as part of the stepped-rate income tax, not the flat-rate medicare levy. JM
73. I am the mother of a 22 yo disabled son who has now also developed a mental health illness. We need to know how to provide for our son before we are too elderly to cope. SB
74. As a Mum who has had to fight the system tooth and nail to get appropriate care for my adult autistic son, please add my name if it can help any other family avoid the disgraceful system that is currently in place. WM
75. Good on you all. I care for my 15yr old son with down syndrome and I am totally frustrated by the messup of education provision for him. He is part haome schooled, part private school, and we struggle to educate teachers about inclusion and his rights to a reasonable education. So my work suffers, and I get wrung out by all the fighting needed to get him what he needs. So yes, I am Mad as hell!!!! JM

76. I am so glad to see that this cohesive political approach has been taken by so many. CZ
77. I work in the early childhood sector and am appalled at the lack of funding to support children with needs. These children fall through the cracks and it's the families and dedicated staff who are left to pick up the pieces with no or little support from the government at all. What a disgrace Australia. TA
78. It is quite shocking that so many people are angry and upset about the Australian disability system. It is also great to see a website like this where people can share their ideas and we can advocate for change. I am an Occupational Therapist and I am fed up with the system of equipment provision, the funding and rules. I am constantly trying my best to help my clients and am always apologising to them for the waiting periods, the lack of funding etc.... I am the face of the system which is not meeting the needs of the people and I feel somewhat powerless to change it. I had client today who received a chair from XXXX. The chair was prescribed 6 months ago and now it is no longer suitable as she has a new diagnosis. The supplier won't take it back and XXX won't take it and won't fund another chair which meets her changed needs. These are the issues I am seeing and it is very upsetting for client and clinicians. FG
79. Hello and congratulations on your campaign. I'd not heard before of the proposal for a Disability Insurance scheme - what a great idea- it makes so much sense. Our 30 yo daughter has a mild Intellectual Disability, but more recently had developed treatment resistant schizophrenia and has been hospitalised. We cannot find suitable accommodation for her when she is discharged (probably tomorrow). MP
80. Congratulations! I am a single mother who is mad as hell that my family constantly faces destitution because my daughter is disabled. Why can't I use my super to buy a house so we don't become homeless again? Why does Child Support not take into account the cost of disability in calculating child support? Why are we even debating whether new houses should be disability accessible? Why do we have to wait for funding for a wheelchair? Why are there only 6 rehab beds for children in the whole of Victoria? I am happy to help your campaign in any way I can. If you need volunteers to stuff envelopes, tell stories, whatever - count me in! NA
81. Thankyou for this. It is really impressive. Our daughter is about to turn 10. In my naivety I had assumed that when the time comes there will be whatever support we need, when we need it, but sadly that isn't true. We have a young family, but as our other children get older the 'normal' demands that get placed on a family will be greater for us. We qualify for the carer payment but as soon as my husband earns more we don't get it anymore. I find that a bit frustrating. We are still 'caring' just a much, and my husband is working even longer hours. There is very little recognition of what we are dealing with. Plus it is all extremely tiring. Anyway, go for it. I will be listening carefully at election time. AM
82. I hope to see a lot more coverage on "Madashell" I'd like to see Govt. Dept's actively engage with parents & families of people with a disability to identify suitable solutions & outcomes. This is certainly not apparent at present & is a great concern to my wife & I. MW

83. You have made a magnificent case for major change in both government and community attitudes to this most distressing problem. We will do what we can though our ages (78 & 75) preclude much active work. MM
84. I'm mad as hell too!. Still trying to get council approval to build DPU for adult ID son! If it takes much longer I'll be needing it! Bureaucracy, red tape and petty LGA officials make an already stressed life even more so! You have my full support. CP
85. MY son is twenty. He has Down syndrome, autism and severe delay. What irks me is the secrecy and run around when trying to access support programs that have been allotted to my child. I was informed funds were allocated at the workers' discretion (at their mercy). Fantastic. So they virtually control me and my son. 1 (Am I worthy) 2 Do i beg enough 3 am i pleasant to her (hell no) 4 Do i play the game Id rather do without. yes im mad as hell, SA
86. Congratulations - we are parents of a 24 year old daughter who is profoundly disabled. She is now in a CRU - we are lucky - but the process we had to go through to get it was demeaning, distressing and unnecessary - and took years... This initiative of yours could be the right thing at the right time to make a difference - good luck. By the way the struggle continues when a CRU place is given - it's a daily battle for safe care with poorly trained, and a never ending rotation of staff - but it is the right thing to do. BK
87. As a carer of two people with disabilities (my son and husband), I concur with these views. I'm tired, dispirited and above all very angry there needs to be an urgent change of government priorities in the disability sector. HH
88. I am a special needs teacher, have worked within the Norwegian Ministry of Science and Education for some years, being part of making Sign Language legalized as a first language in Norway together with the Norwegian and Sami language, creating a full equalized curriculum for them within school, with all obligations for the community legalized. I am so disappointed in the politics for disabled in Australia, or the lack of such. Is this a country that does not care ? It is time to compare where Australia stands on this matters compared with other countries. And publicize the numbers. Which means we need the accurate numbers, which I believe the Australian government never cared to gather. Australia is a member of OECD, and it is possible to use the OECD country comparisons as a source where one can start to prove how far behind Australia stands. It is not only about the disabled, the education of sufficiently qualified professionals and teachers who are there to help needs to be questioned, compared and publicized as well. having worked at a special school in Melbourne as a volunteer for a year, I question what a special needs teacher is in Australia. One needs teachers who are well enough qualified to fight for the rights of disabled. AC
89. I have one leg and a prosthesis. Is there somewhere I could stand on one leg, with a t-shirt saying 'the government doesn't have a leg to stand on on disability support' and hand out copies of the pledge with the website at the bottom or something? I'm not severely disabled but disgusts me that the government doesn't do more for those who are. My partner and I will have kids soon, and what will I do if they are severely

disabled? Or if someone in my family or my partner suddenly became severely disabled and I had to care for them? People need to realise how easily they could end up in that situation. JH

90. I am in full support of what you are doing, as a carer and mother of a 14 year old with a disability I am thrilled to add my pledge. SZ
91. Hi, I think that another thing that should be addressed is the way in which Centrelink treats DSP's and their Carers. Our treatment from one particular office was disgraceful! We were conned by a staff member into signing a document declaring my fiancée/carer and I were living together in a de-facto relationship which was not true! We proved we did not live together, had no joint bills or assets etc. I think Centrelink needs to be held more accountable for the way in which DSP' and Carers are treated! We deserve to be treated fairly and allowed our dignity, not treated as though we are robbing the system like a dole bludger. I suffer from Hydrocephalus with arachnoid cyst, epilepsy, asthma, necrosis of both hips, osteo-arthritis and yet treated like a common bludger! politicians need to address this issue MB
92. This campaign is well overdue and I look forward to the battle. I have taken the pledge - but how else can I contribute? WS
93. I am so pleased you are taking the lead in this issue. Our local organisation supports 140 families including my own. We have tried 5 times to replace our old white ant ridden facility where we offer Therapy and Respite and training opportunities and we missed out every time. The government prefers to spend its money glorifying the labor movement with a dead tree. Your website is great. Thanks for taking the initiative. FM
94. Thank You for this website and for organising the pledge. I have a 6yr old son with cerebral palsy and - I'm mad as hell (that sums up my feelings perfectly). There always seems to be plenty of money to pay public servants who work in the disability sector but none for equipment or services for families. Too many people are being paid to tell families that there is no funding. SN
95. Good on you for trying to effect some real change and improve the situation for people with a disability. You have our wholehearted support! Please let me know what I can do to help. JC
96. THANK YOU FOR YOUR WEBSITE AND FOR OFFERING PEOPLE AN EASY WAY TO ['TAKE THE PLEDGE'](#). I AM THE MUM OF A 14 YEAR OLD SON WITH PROFOUND MULTIPLE DISABILITIES FROM BIRTH AND A 10 YEAR OLD DAUGHTER WITH SEVERE HEARING LOSS IN HER LEFT EAR...I ALSO HAVE A 16 YEAR OLD SON AND HUSBAND WHO NEED ME TOO...OH AND THEN THERE'S ME.. JG
97. Thank you so much for being mad as hell and staying mad long enough to do something about it. I'm new to this world where disability features largely. I'm so glad that there are others with an internal ball of fury that have done something about it. Thank you. ER
98. Thank you all for your time and effort in highlighting the plight of carers and their loved ones with a disability. I am a mum of a beautiful 10 year old daughter who has autism and it has certainly been a strain finding

and providing the services she needs. It has been difficult financially, emotionally and has tested our marriage. We are fortunate that we are still "hanging in there" together but without a scheme such as the disability insurance scheme all of our futures seem so uncertain. I applaud you for taking on this advocacy role as I know how busy you would be in just taking care of your families. If there is anything I can do in some small way please don't hesitate to contact me. YK

99. Congratulations on this fantastic, positive initiative. I wish you every success. I have already written to the PM and will sign your pledge and ask others to do so. AC
100. Hi Mad as Hell team, Fantastic campaign. I'm really pleased to see a disability based campaign hit the political air-waves - it's about time there was a stronger push for coverage for this group of society. Congratulations. Will be great to see how the campaign progresses throughout the year. NE
101. I was so excited to read the article in this weekends paper. 100% support. I have written endless letters to state and federal ministers with pathetic responses. My son has Cri du Chat syndrome and being rare he receives no extra funding than a carers allowance. Any help/support you need I am very keen to help. SA
102. Love the high quality of the website and that you are getting your message out. I know the story from both sides - working in a disability agency and being driven mad in with the energy spend in depriving people of services through red tape, endless reports meetings etc. I also have a son with a disability and have a disability myself which is making life hard as i get older! CO
103. Thanks for getting this movement going and I will tell all the other parents at S Special School CH
104. Just wanted to congratulate you all on your mighty effort. DS
105. Congratulations on a great site. I am the proud mother of two beautiful boys with Autism. I would love to help you kick butt to get what our families need. GF
106. I am a full time carer of two siblings with Fragile X Syndrome and a 17 year old nephew with Autism. I love them to bits but am appalled at the Government for the same reason as everyone else. The lack of funding, the lack of appropriate accomodation and the lack of recognition. People with disabilities deserve much much better than what little they get. I have joined the pledge and would love to speak to someone about what we can do to ensure a decent future for people with disabilities and their carers. AT
107. I support any initiative which seeks to improve care for disabled people. I also consider that very little will be done as long as unpaid carers continue to carry the load. What we need is a national carers strike. Say 24 hours when every carer takes their disabled person to the federal politicians office and leaves them there. If I took my son he might last 15 minutes before the staff were screaming for help. JL

108. I heard about your website a few minutes ago. It's wonderful! I LOVE the "Mad As Hell" theme. Your journalistic prowess shows through. CH
109. I can't believe that I live in the lucky country and that I was driven through lack of adequate funding and support to have to give up my child. What will it take for any government Labour or Liberal to get off their butts and instead of just talking actually passing legislation and fixing the system once and for all. LH