# Brief submissions received by the study

The following table includes all brief public submissions that were made directly to the Commission’s NDIS Costs study, or via the organisation *Every Australian Counts*, from 20 January 2017 to 7 June 2017.

### Brief submissions provided to the study by *Every Australian Counts*

| **Brief Submission**  | **Submitter Details** | **Submission** |
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| 1 | Christie Centre Inc | The Christie Centre Inc founded over 60 years ago by parents in the rural region of Mildura established a solution focused, place based service to meet the needs of their community. Christie Centre Inc continues to do this offering and providing person directed opportunities to meet the individual needs of people living with disability. Our experience and evidence shows that when people exercise choice and control over their lives the need to utilise tertiary service is reduced. Our decision making is informed by the feedback of people, their families, the community and other stakeholders that when people are encouraged to live their life as social, economic and participating citizens the whole community benefits. The NDIS is a vital and long awaited shift removing the inequity of rationed funding and ensuring that all eligible people are provided with the range of supports to live a good life, a productive life and one that is on par with the rest of Australian society we ask for no more and no less than what is equitable and fair. The challenges with the roll out and the uncertainty the political environment has been creating distract us from embracing the most fundamental shift in societal thinking about capability and citizenship and has the potential to derail the benefits for so many. People with a disability are not burdens on the tax payer they are citizens and with support to meet their needs contribute broadly to the fabric of Australian society. |
| 2 | Anne Hansen | As my role as a disability advocate, I have seen the life changes in people with disability who now have NDIS funding. They are now accessing community, having a good life and have hope for their futures. The burdens are off the family, some aged carers, and there is job creation. Broken wheelchairs are now being replaced and people who never had wheelchairs, now have and can access the community. I now see happy people. |
| 3 | Lorraine Rodrigues | The NDIS to me is knowing that my son will have a future of his own to look forward to if I am unable to care for him for whatever reason. It is his opportunity to live his life to the fullest without having to depend on me to take him out, access community services and events, be in the company of his own age peers and be his own voice. I would like to see that such an endeavour is not misused or grabbed at from a financial perspective but is held accountable to the highest standards of delivery so that our children truly benefit from it. |
| 4 | Ann Verran | I have twin Grandsons born premi with Special Needs. One Heart issues (two open heart surgeries) and the other Cerebral Palsy. My Daughter is a single Mum and relies on family support to a great extent. This we give willingly, but her extended family is aging and her son with CP need the be in a situation where he has outside support if anything happens to her. He has had extensive surgery last year and the extensive costs of rehabilitation are funded by my Daughter with funds raised in her community. My Grandson can live a fulfilled life if he is given assistance. His CP is physical and he is determined to do everything his Twin does. This includes playing soccer in his walker, swimming with the local Orca Swim Club and "running" his school Cross Country in his wheelchair. He participates in everything. The NDIS will allow him to plan his future and gain his independence and continue to be a valued member contributing to his community. He has the same rights as all other Australians and his dis-ABILITY should not hold him back. He is in mainstream at school and the best thing about his inclusion, is the attitude of the other children in the school. He have been an integral part of the school since Kinder and his classmates learned very early on that he does not do sympathy and is fiercely independent and competitive. His and other children with special needs inclusion in his school has opened the eyes of all the other children to those with a dis-ABILITY. They treat him as a friend, a competitor and the best thing, just another kid. They will help him if needed, but it is just a matter of course. It has opened the eyes of others to someone with Special Needs. He does not see himself with a dis-ABILITY. In his case it is definitely a ABILITY. The NDIS, properly funded and working would make a huge difference to his quality of life. |
| 5 | Wendy McAra | My one and only grandson, Leo, turns 12 this month. He is non-verbal, severely autistic, and can do very little for himself. His parents, devoted as they are, are exhausted, stressed and struggle to pay for carers to allow them to lead a vaguely normal life. You would understand that the financial as well as emotional strain is huge. This is not a responsibility or future any of us would choose for ourselves. Those of us who have escaped such a fate should surely open their hearts and contribute some support to turn what would be a living hell into a possible, if far from normal, life for his parents, and family, like me, his grandmother. I emigrated from South Africa hen my children were under five. I so admired the generosity of Medicare and Social Security and I have been, and remain, proud to be Australian. The NDIS is a fine and socially responsible, caring initiative and is another move to uphold the decency of The Lucky Country.Thank you for caring, and doing the right thing.Kindest regards,Wendy McAra |
| 6 | Claire Galea | I am very grateful to the NDIS for the increase in funding I have received for my Asperger's son - I cried. However, my euphoria soon turned to disappointment when I realised that I cannot spend it on anything meaningful or long-lasting in terms of therapies that can actually make a significant difference to his life. I cried again. If I want to pay a carer to take him to the zoo every day for a year, then that's absolutely fine - the funding's there for that... if he wanted to do it... which he doesn't. But clubs and groups that he actually wants to join? No. Therapies that can actually prevent him from getting into trouble in class at school? No. Therapies that can help him understand conversations and improve his social skills? No. Learning support that can give him the skills to cope at school. No. Asperger's IS a learning difficulty - it's not a consequence of - that's what it is. Short term memory issues, sequencing issues, organisational issues, processing issues, auditory issues, sensory issues, comprehension issues, inference issues. THAT IS ASPERGER'S. So how on earth can you not provide learning support for it - this affects their every day life. Asperger's kids are usually of above average intelligence but below average academically. Why is that? Many of them end up unemployed. Why is that? If you don't want them claiming unemployment benefit or disability allowance for the rest of their lives, then please, please, please let us put the funding now towards therapies and programs that can help them at school to reach their intellectual ability so they can go out and get an education/job and make a meaningful contribution to society. Even Einstein was expelled from school. |
| 7 | Alexandra Pankhurst | Hi!! I am a 64 year old Mother, on my own, I have a son with Down's Syndrome 20 years old, my last child. I do not receive any informal or family supports so I desperately need the NDIS due to my age so my son can continue to gain independence, learn more social and living skills for his future for when I am not around. Due to my age, I get very tired so the NDIS is desperately needed to set up transport so my son can access all the organizations and support that I have been very proactive in for him to participate without having to rely on me to do all his running around. More Community access is needed for him in a social group. My son is placid and is well adapted to accessing the wider community always with the need of a support worker so he will walk straight into the NDIS arrangement. I have been under the YLYC and been managing my own supports for my son with great success so this has given me the experience to cope with the NDIS. Can't wait. Thank you. |
| 8 | Erin McCrea | My ten year old son has a diagnosis of Autism and Hearing Impairment. I have sought support from Disability Services Queensland, the Local Area Coordinator for Disability Services in my local area and Deaf Services. I have been advised that there is currently no support available in my area, though my son can have 8 AUSLAN lessons for a reduced rate of just under $800. The advise I have received is that I need to self fund any therapies or services until the NDIS comes to our area (mid-2018). At the moment, it appears that those of us who are not yet in areas where the NDIS has rolled out, are at a significant disadvantage. This is further impacted by Centrelink rejecting an application for carer allowance, which I am in the process of appealing. |
| 9 | Mike Lawson | I care for my disabled wife 24 hrs a day 7 days a week. I know for a fact there are many other carers in a similar position - ie - working for an incredible amount of time doing the caring/nursing of their loved ones and getting a crap pittance (carers pension) for it. That is a joke, given the hours an average carer does in caring. I do get some respite breaks, but compared to the break 'normal' workers get, we carers mostly do not get that. We (carers collectively) save the government billions of dollars a year by caring/nursing our loved ones at home. As far as I concerned, we work for a pittance for the amount of time and effort we put into looking after our disabled loved ones. If, we as carers, dumped our loved ones on the steps of Parliament House and left them, the politicians would collectively s---- themselves. Having a better system whereby the carer and the disabled person is better looked after, is a must. |
| 10 | Michael Hessenthaler | I am the 66 years old father and carer for my daughter that is high level quadriplegic and we are to finally receive help from NDIS soon here on the mid-north coast of NSW. I have to say that our initial elation about what NDIS will mean for our lives is more and more replaced by anxiety and worry because we read and see many stories of short comings, restrictions and of course endless political games they play about funding. There will not be enough to go round, there will be more bureaucracy to overcome, there will not be the opportunities for my daughter that she never had, but hopes to achieve when she has more help. I worry I am running out of time and the NDIS will not deliver what originally was intended by some people inspired by humanity and common sense. Please don't allow political pressure to diminish the funding. Have a realistic look at the relief it's brought many people already and the worry and limitations that some, like us, are looking forward to. Life with severe disability is tough and funding sufficient support and equipment is the fair and decent thing to do. And providing it without bureaucratic and political obstacles.Thank you. |
| 11 | Brigitte Krstanoski | I am a mum of a very disable young man 33 yr old who needs all his needs met by me feeding changing showering all of his needs. The NDIS has made a huge difference in his life so far but i put the hard work into it with help from a very dear friend it took months to prepare for his turn and the outcome was great he now can enjoy the life that he deserves like normal young men of the same age but he needs a Carer to achieve his dream he goes to a day program 5 days a week out on Sat and Sundays which he loves he doesn’t like the idea being home with the oldies , he will be getting the wheelchair that he needs maybe a forearm walking frame he is very happy now, i get fair bit of help from Australian Unity 5 days a week morning and night as my health is going rapidly and i cant care for him like i was when i was younger as the load is huge i do worry about his review when it comes up what will happen not far from my brain but Planner and Support Coordinator have told me don’t worry but I’m a mum and hard not to. I’m sadden for a lot of Disable people and their families aren’t getting the help they need like yesterday and aren’t getting it or there plains don’t fund enough and i see the stress there parents go through i thought the NDIS was to make life better for all? Please don’t cut funding from other places to fund the NDIS that’s not fare and the so called normal families will get their backs up on our Disable people that’s wrong. Our loved ones deserve a life freedom like normal people do or do they? Thank you. |
| 12 | Dale Kennedy | My son Nicholas is 32, profoundly physically disabled but high functioning intellectually. He is treated like a child in that day program hours are school hours and his group home don't have the funds or the motivation to do anything with him other than take him out once a month for a 1:1. He constantly watches DVDs and listens to music when all he desperately wants to do is go out into the community. NDIS has changed his life this year. We have been able to negotiate his costs with his day program provider and have been able to spend the residual funding on community access outside of day program school hours. He has been to two disco's on a Friday night and is planning to go to every disco every month between now and Christmas and he is going out for a few hours every Saturday with carers he has chosen to destinations he has chosen. Whilst this is still not enough for a young man of 32 it is way better than the 'ground hog' existence he had up until receiving his NDIS package. It has not been an easy journey learning about NDIS and what we can and can't do but just to see the smile on my son's face while out with one of his carers that he has chosen at a time that is not dictated to him and a venue that he has had input into make everything we do on behalf of him so worthwhile. |
| 13 | Nancy Donaldson | Ndis is important to my daughters future and any child who has a parent that can’t live for ever.We need to know our children will be safe and housed for the rest of their lives .To Malcolm Turnbull our children are an inconvenience to the taxpayers as he gets his perks and cashes in on his investments he gets .We don’t choose for our kids to be born with a disability and we don't choose to ask for help but we need the help .As carers we choose to stay with our children as long as life will let us and we choose to give them as much dignity and teaching as we can .Looking after our children without help does take its toll and most parents especially ones only on a carers pension do it hard.We need to choose food and rent over luxury always ,other than two days away in a row we have had no holiday and the rare bit of money needs to go towards their disability .Our children can grow to be wonderful adults if given the chance and we need the help and peace of mind knowing they will be supported. |
| 14 | Kristine FitzGerald | This is my family, husband, blind, on blind pension and unable to work, son 30 yrs old Autistic, Intellectually impaired and epileptic..on DSP, daughter, 34, Aspergers, severe anxiety, depression cannot work. She has zero income because when she was on Newstart allowance she was expected to apply for 10 jobs a fortnight, she is in the last year of her PHD (PHD's are not study according to Centrelink so no study allowance for her)and has not time nor ability to apply for so many jobs, there are not 10 jobs to apply for in our rural region. I also have my elderly parents in a granny flat attached to our place, my father is 92 and mother 88 and she has Alzheimers disease. SO, this is my life, caring for 5 people, financially supporting my daughter and physically supporting everyone ( I also had cancer 10 years ago) No time to rest for me but I do work 3 days a week as a teacher aide for students with learning difficulties. We live from day to day with no savings at all and a mortgage, such a huge struggle. The way my daughter was treated at Centrelink was absolutely disgusting with statements like "you will just have to get a job DARLING" with no respect for her illness. No holiday for 8 years and no respite for my son. No NDIS in my region yet and the mental burden of not being able to make my son more independent and being able to live his life like other adults. No supported houses for people like Luke, only if you are rich and can afford to pay for support workers and accommodation. It is very very tough both physically and mentally. |
| 15 | Brenda Gillett | My adult son James (39 years old) who has an intellectual disability, lived at home until almost two years ago, when we then decided it was time for him to try to live as independently as possible without our total support - after all we are ageing, with hopefully 15-20 years left to get our 'boy' safe and settled: with a very small flexible respite fund, we received minimal support - support through a provider who was unreliable and who almost caused us to abandon the whole idea and experience. Our NDIS LAC heard our story, and we now receive substantial enough funding to help us in our quest for James' independent life without his parents, and with other's taking care of him. He requires 24/7 support, so we have a way to go yet. Support from service providers and us, his parents, is shared about 50:50 - but we are on our way at last. James just loves his own 'unit' and his new (and much loved) support person who is enabling James to become more independent each day; and is helping him to become more inclusive in his community. No more cajoling him to get on a bus with people he didn't choose to be with - and go on trips he couldn't really cope with, just so his dad and myself could have an overnight break. James also has used funding specifically set aside for a speech pathology assessment and is looking forward to catching up with the 21st century and the rest of his generation by buying an iPad with which to look at his photos and use a communication app to help him express his needs and wants. Thank you for the opportunity to share our story with you. It hasn't been an easy transition - especially for a couple of oldies like James' dad and myself. But James has taken to it all like a duck to water: which is a tremendous relief and joy. |
| 16 | Heather Batt | NDIS means freedom form the powers of money driven organisations who do not respect the personal needs of PWD nor the natural authority of the family. NDIS means the opportunity to have a good, ordinary life engaging in everyday activities like exercise, visiting family, enjoying things PWD specifically likes and engaging in income producing activities the PWD finds fulfilling and capable of doing. NDIS means family can be the most influential people in PWD lives again, encouraging and supporting PWD to embrace as full and rich a life as anyone in the community with support. NDIS means seeing the smiles on PWD faces again.NDIS means alot to me because l can get my own support worker and not through organisation |
| 17 | Merle Searle | Hi, My husband and i are carers of a young man with Spina Bifida and behaviour problems. In the past we have always had a struggle to access respite as he needs one on one support staff and his D.S.Q. funding did not cover the funds required for overnight stays or at best very limited. Thanks to N.D.I.S. he now has a funding package that allows much more support. This is very welcome to us as my husband has some health problems at present and we will need to be able to use respite during my husband’s treatment. We are very grateful that the worry associated with obtaining respite is now in the past. The N.D.I.S. has made such a huge difference to us and our young man on a day to day basis as we are in the older age bracket i.e. over 70 and now because of the extra funding he has support workers that can take him into the community . Please keep up the N.D.I.S. it is so appreciated in our household. We have been Troys carers for 31 plus years. Regards, Merle |
| 18 | Paul Clarke | I have A.B.I from motor vehicle accident. It has impacted my life greatly, I have short memory as I need help with that. I also cannot plan like I once did. I have anosima from head injury. I acquired a few fractured vertebrae and live with arthritis and pain. I can suffer headaches and migraines on daily basis.I attend Headway Illawarra for fellowship and support. I also use Illawarra Brain Injury Service to talk it through with a social worker which is a good thing because it helps me stay on track. |
| 19 | Sally Shackcloth | My adult daughter's life has improved in many ways since she was a member of the trial group in Tasmania. An occupational therapist found that her bed was unsafe both for her and for the support workers dressing her. The physio review recommended a hip x-ray because of increasing mobility problems. The result is she is now having preventative treatment so her condition doesn't deteriorate. She now has regular time set aside to stand alone in her new standing frame. Standing is very important for many reasons especially for people who spend most of their time sitting in a chair or a wheelchair. Very importantly, she is now participating in an ongoing speech pathology program with an expert speech pathologist as she needs a communication system tailored to her needs. Up to now she has no reliable way to communicate. My husband and I are thrilled with the NDIS. |
| 20 | Denise Maindonald | My 19 old son with DS was unable to access post-school funding as he did a School Based Traineeship. Bryden needed full support whilst working as he is Hearing Impaired and there is a marked lack of understanding of talking to deaf people in the workforce. Bryden is now deemed as being able to work as he passed the course but jobs are not available. At present he is doing courses to learn how to be independent. I am a single mum and work full time. These course require Bryden to travel by bus, trains and trams to get to the courses which then teach him how to travel and be independent. We have had our successes but have also had our failures which have resulted in him being lost somewhere on the Gold Coast with a flat phone (he had to sit and wait at the bus stop for 1and 1/2 hours till the people met so he listened to music). I am learning on the spot the things that my son does not know such as 'On bus' is not the same as 'On the bus station'. We do not have NDIS here on the Gold Coast yet and I do hope that the funding is better organised than at present. I am trying hard to make my son independent but there is a gap present between for those young adults that are not high functioning and not more impaired. There are few appropriate courses for Bryden and those that are in place put Bryden in situations that possibly dangerous and are extremely stressful for me. This results in Bryden being left at home for part of the week while I work resulting in phone calls that he has decided to catch a bus to the shops but it went the wrong way and me trying to locate him on 'Find my phone' and then talking him through the situation. I raised my son to be confident and with the aim to him being as independent as able. He knows he is Down Syndrome and Hearing Impaired and is a proud advocate. We just need help to get him there and once there he will cost the government markedly less than a child that needs full time care. |
| 21 | Julanne Sweeney  | When my granddaughter Isadora Sweeney was born with Down syndrome in 2002 , I left my beautiful home in Far North Queensland rainforest and my Innisfail High School teaching job and came to Adelaide to support my daughter and her husband who are wonderful parents with extremely busy lives in the theatre and Festival world.Because we used every Early Intervention strategy possible and had access to supportive Kindy and Primary School and exceptional role modelling from 4 years- older sister Lotte ( and another sister Beatrix 5 years later),Isi developed into a delightful person,confident for the all girls High School which suits her needs but requires driving every day.Her mother has survived aggressive breast cancer 2 years ago and is in a demanding childrens's creativity job. I'm 80 now (living independently and very fit and helping almost every day). Isadora's loving father often has late hours and some o/s travel due to his work.So NDIS comes as a boon to help with school pick-ups and sharing outings with other Down syndrome friends,as well as training Isi to use public transport and support her social awareness and love of swimming. The strain on our busy family would be almost unbearable without NDIS.It has meant we could allow Isi to participate in the Adelaide Festival 2017 Restless Dance INTIMATE SPACE ( sold out) by attending so many rehearsals and performances. With NDIS help she is learning skills to equip her for independent living and employment in the future . |
| 22 | Lisa Jackson |  I am 53 yrs old in 2011 I became physically disabled after severe Miller Fisher Variant Guillain Barre syndrome .I spent 2yrs in hospital at Robina QLD before having NO OPTION other than discharge to a NURSING HOME where I still reside today. Life goes on I have made great strides in my everyday independence. Living in a nursing home surrounded by elderly people with dementia Alzheimer’s and watching people slowly deteriorate and died around me is a mentally cruel way to live. Last August after 3 operations in 2016 I finally got rid of my tracheostomy-I am ready to move forward now to doing some hydrotherapy-Iam using the last of my Superannuation to fund this-As both myself and the Physiotherapist believe after 4 yrs with no rehab I can still regain my strength to stand up and eventually walk-I am currently using an electric wheelchair. My fingers are clawed due to nerve damage despite this I have found aids and devised ways to write legibly, independently feed myself, prepare sandwiches, open and heat microwave meals, clean my teeth, operate my computer and mobile phone and travel independently using wheelchair taxis the train and the g link tram. I aspire to making my present dreams a reality I want to cook my own meals do my own washing live my own life as independently as possible. My other goal this year is to work part time again using a computer .I am a people orientated person who enjoys helping others. I have done everything within my power to move forward onwards and upwards in my life-a nursing home setting has restricted my ability to move forward greatly-I ring disability services every 6 months but I remain waiting-I need a helping hand up to rejoin contribute and become a valuable member of my community again. THIS IS WHAT THE NDIS CAN DO FOR ME PERSONALLY AND THOUSANDS OF OTHER DESERVING AUSTRALIANS |
| 23 | Tegan Pinkard | I believe the NDIS can provide freedom and choice for people living with a disability. I have had MS for 10years, my disability is currently mild however has the potential to change someday in the near future. I am the mother to 2 children and I am doing my best to remain fit and healthy in order to care for them as best as possible. At times I fear the unknown of this disease and what impact it will have on both my life and my families. I hope that the NDIS will provide me with options and be able to self-manage my healthcare. |
| 24 | A.S | Our daughter suffered 2 surgeries to remove a brain tumour last November. Our lives have been turned upside down. Thank the Lord she is making a wonderful recovery. However, the amount of paperwork, consultation with dozens of medicos, attempting to negotiate Government agency requirements, has been distressing and exhausting. We can only hope that NDIS streamlines and facilitates the processes required, when faced with such an unexpected health situation. |
| 25 | Val Date | My 54 yearold daughter Michelle is a victim of the 1966 road toll; her head and leg were hit by a car when she was crossing a suburban street, 3 weeks before her 4th birthday. This formerly intelligent little girl has been intellectually and physically disabled every since. At 81 I have fears for her future care and continued access to family members and wish to ensure that all her needs will be adequately provided for during the remainder of her life. On paper NDIS offers this, nevertheless I wish to ensure all her entitled comforts and care are securely provided for during the remainder of her (and my) lifetime. How can I be assured this will happen please? |
| 26 | Linda Sayers | Although the NDIS isn't yet rolled out in my area, it is coming soon. After being registered with DSS for almost 4yrs & waiting on their register of need as long, I am hoping that finally my son & I will have choices for his support & needs. We may actually receive some support. For my family hopefully this will be a positive change. |
| 27 | Laura Bloom | My wonderful son was diagnosed with severe autism at 10 months old. He is now about to be twelve years old. In that time we have received almost no additional support outside of school, and while we are still a loving and committed family, without the prospect of the NDIS bringing financial, physical and emotional relief I don't know how we would still be hanging on. We cannot socialise without a carer which we cannot afford. Therapy, and after school care is all paid by us, which means that although we earn a good wage and pay significant tax, we are crumbling financially, physically and emotionally. We are isolated and exhausted and the worst of it is our son has so much to offer! Although he needs support to do so he loves to engage and participate. It's just so hard coming up against our own physical limits to support him to do that. With support he will adore scouts, footie and family barbecues and other social events. Without, we are so exhausted from the non stop two man marathon my husband and I are engaged in that we are doing well just to all be here, still solvent (barely) and in one piece. Without wishing to exaggerate we have been a family in crisis for a long time, and yet everyone would tell you what a wonderful family we are. Disability services have been useless to indifferent. With the ndis we hope to return to the flourishing productive family we were and know we can be once again, if our son can participate and grow the way he's capable of and meant to. Thank you, Laura Bloom |
| 28 | Nathan Dore | I have been doing yoga help more my body better having cerebral palsy it makes my body harder to move if I not move it on a day move why the Ndis see it as a high need I do not know but health and fitness are a nervous thing to me |
| 29 | John Dean | This is the real story of severe Autism written from the heart of a mother. This link says it all and why NDIS is critical.<http://www.autismawareness.com.au/news-events/the-autism-post/yours-severely/> |
| 30 | Peter Macpherson | At the age of 52 I was struck down with a Neurological disability that is progressively becoming more disabling. I now need to use a walking stick at all times and a scooter for any distance of more than 50 meters. I worked for more than 30 years and raised two children who are now in the workforce. As my disability will continue to worsen as I get older and I do not have have the finances to ensure that I at least retain my dignity, my quality of life is dependant on the NDIS happening. |
| 31 | Lorraine Tydeman | My son is the participant, I am ageing, in the over 60 group and with NDIS coming, my sons provider uses vans and picks up participants and takes them to the activities they attend free of charge. They have informed us that this service is going to stop unless they can come up with a viable alternative. I and a few others who are older that me, some in their eighties are going to have to transport our children to their activities as I live in rural NSW and his service provider is 20 ks away. some people live 40 to 60 ks away and some taxis refuse to drive that far in the evenings, because of wildlife on the road, esp kangaroos as if they hit one they lose their means of income. The mid north coast is a very popular area and people moved here when their child with a disability to have a good life and now this is whats happening |
| 32 | Gillian Devine | My son is Brain injured from a car accident in 1988. Since that time my husband and i looked after my son but 5yrs ago my husband passed so now its only me and I am 70 this year. The ndis will help a lot of disabled people and put families mind at ease unless you have been the same position you could never understand the worry and stress people go through. |
| 34 | Mark Purcell | My name is Mark Purcell. I am the father of Elise Purcell who has severe autism, moderate to severe intellectual disability and epilepsy. I am 62 and Elise is 28. We have lived together alone now for 12 years. I have never wanted her to live in a group home. The stress caused by her behaviours while growing up contributed to the breakdown of my marriage with her mother and to psychological problems her younger sister has. I was able to work part time up to a year ago but then due to needing to be "on call" constantly I left work late last year.We live in the Shoalhaven area so not in the NDIS as yet.However the NDIS has given me the hope I never had before that Elise can live as independently as possible in her own home should I cease to be able to care for her. From 2014 -2017 Elise moved out of day programmes to self-managed community participation funded through the NSW Disability Department. At the start of 2017 this was changed to the Living Life My Way programmed. Initially the NGO we were with essentially evicted Elise from day programmes due to "behaviours". They did us both the best favour ever as Elise has flourished in the self-managed model. Over the years we have increased our genuine self-management of Elise's day to day life [in resistance to disability NGOs who seem to find sharing management with parents difficult] and she has continued to flourish and her "behaviours" continued to diminish. This has increased my optimism about life under the NDIS. Though I think it is a total mistake to dismantle totally the NSW Disability Department, the self-managed and living life my way seem to be a glimpse into how positive life for Elise can be under the NDIS. I remember reading that the role of a career is made "a burden" in the absence of a sense of hope ... that the future is one of increasing bleakness. The NDIS has given me more hope than I have ever had in terms of Elise's future. |
| 35 | Penelope McNally | I am a widow with secondary progressive MS. I have no children, and what remains of my family live in another state. The NDIS has taken a huge weight of my shoulders about my future care. |
| 36 | Robert Altamore | The NDIS has changed my life because it has given me the ability to set my own goals, exercise my choices and given me control of my money to spend on the adaptive technology and the training I need to change my life and participate in the general community. I can now get my adaptive equipment repaired and maintained. access braille with my own braille embosser and access digital information because I am being trained to use a mobile phone. This makes me independent and able to access information which sighted people access and has enhanced my life. |
| 37 | Del Childs | The NDIS has not yet rolled out in my area but from what I am hearing there are many positive stories of people who are getting funding approved for a range of needs that they haven't been able to access previously. Having said that, I am sorry to say that for me personally the NDIS will mean nothing. Why? Because I am over 65 and at best only the Continuity of Support program will apply to me. It seems such a discriminatory decision to make an age related cut off line. At this point in time neither the CoS nor the Aged Care system will provide anywhere near the same amount of support that the NDIS offers. Just because we are over 65 doesn't mean that our disability disappears and our needs become age related. I sincerely hope that Every Australian Counts will do what it can to change this situation, so that in fact every Australian DOES really count!! |
| 38 | Peter Day | NDIS is unaffordable for our daughter, Janine, who is 41 years old but functions as a 10 week old baby at which age she suffered her first catastrophic seizure. From 2006 Janine attended day care at Kankama in Mornington. For 8 years her annual fee including transport in facility buses never exceeded $800.Kankama merged with Connecting Skills Australia in 2014 Taxi replaced buses. Fees immediately were monthly $ 270.In 2016 CSA introduced fees for the individual activities offered at day care These initially were $30 per week but protest bought them down to $20 per week. When further challenged CSA claimed justification because of a $10000 loss on activities ,concern that NDIS was slow to pay providers for services therefore there was a need to build up considerable cash reserves to stave off cash flow problems and bankruptcy as had occurred in similar circumstances in the U.K.. I refuted these claims: $20 per week for 50 clients was a lot more than $10000, Every Australian Counts refuted the slow payment claims and the UK failures were due to austerity measures arising from the GFC CSA are unmoved an recently announced transport fee increase due to $170,000 loss providing client transport. The claim is that the NDIS does not provide transport assistance and therefore user pays. Consequently Janine's monthly transport fee has jumped from $170 to $359.33 and this represents only 50 per cent of the increase which will be charged from July. Presumably her transport fee will then be approximately $540 per month plus $6 per day attendance fee plus daily activity fees. In total about $8500 per annum. Unaffordable. |
| 39 | Susanna Goodrich | My son Toby is sixteen. He has Down Syndrome. He's had a rough few years with an autoimmune condition. Until the NDIS funding, Toby was isolated, withdrawn and I wondered if he was depressed. He was a young man needing lots of contact with his peers and the wider world, yet he was confined to activities and socialising that his mum and dad could fit into their busy lives of full-time work and caring for 4 children. Toby’s social behaviours were becoming more unpredictable and his self-esteem and mood seemed to be plummeting. He had few experiences of his independence as a 16 year old young man and he was not learning essential living skills like travel on public transport, how to socialise with peers with and without intellectual disabilities and how to be an employee, like many of his peers.The NDIS has provided funding that has changed Toby’s life. His week has opened up from a routine of school, family life and the occasional social event, to a week that looks much like his other teenage brothers: he plays sport, goes out with peers, works in a part time job and will soon be learning how to catch the bus to the local shopping and entertainment hub. He walks taller, smiles more and behaves more like a young man ought to behave. He just needed the opportunities and support that the NDIS has provided him with. His life has become more healthy, independent, and enriched. It reflects back the amazing success and productivity of this ground breaking social policy. Thank you so much. |
| 40 | Erin O'Donnell | To the Productivity Commission, I remember when the NDIS was announced as government policy, and I felt an overwhelming sense of relief. People with disabilities (and those who care for them) already face massive hurdles in living productive, happy lives, and the NDIS is a much-needed funding and support program that makes it just that little bit easier. I am living with a chronic health condition that makes it impossible for me to work full-time, and I am extremely aware of how dependent I am on the support of my family and my husband. We should guarantee all Australians the ability to live safely, with the capacity to access the funds and therapies they need to be productive members of society. The NDIS makes this dream a reality. I am also watching my best friend navigate the difficult process of finding support for her baby daughter, who has just received a diagnosis of cerebral palsy. She will be dependent in some way on the NDIS for the rest of her life, and it is heartbreaking to discover that the process of making the NDIS available to everyone has created a real gap in funding support. For children, this means that they cannot yet access the funds they need when they need it the most (which is as early as possible, to make sure they build strong and healthy bodies, and limit their need for future treatment). The slow and geographically limited roll out, and the problems it creates, also shows how crucial the NDIS will be when fully operational.The NDIS, when fully available to everyone, will be a huge success story for people living with disabilities, and caring for people with disabilities, throughout Australia. For the first time, we have made it clear that these people are not alone with the hand they have been dealt by fate. The NDIS is our collective commitment to support people like me, and my best friend and her daughter. Thank you for considering my submission. |
| 41 | Janis Clague | (My name is Janis Clague, Taylor's grandmother. I'm writing this on his behalf.) Taylor is blind, autistic & epileptic.With the funding Taylor received last year, 2016, he spent two days a week at Breakthrough learning independent living skills, people interaction, physical development, social skills......He has progressed very well & is continuing this training this year. He studies music at Sound Sculptors Studio twice a week, learning to play the drums, piano, & use his voice. He has been learning drums for several years & is very adept. Piano he started last year to settle his brain activity, develop his fine motor skills, & help his focus. This has been a struggle but he has learnt how to use the keyboard, where all the notes are, & can play several songs. He's learning how to develop his voice - enunciate, articulate..........He is part of the Sound Circle Can Do Programme through Disability Matters one day a week..........It's important that Taylor stays busy & is learning & testing his ability, & this last year has helped him develop enormously, whereas school was a bit of a waste - although he was in the Special Education section, there was no special curriculum for someone with his disabilities. |
| 42 | Jessica Millen | I'm not sure if I'm even allowed to write this because as it stands we are about to submit our third round of forms to try get some funding for my son. He has severe verbal despraxia, fine motor skill issues aswell as some behaviour issues and severe learning difficulties. He really needs needs the extra help which this funding would do if he did get it but they keep telling me he doesn't have a disability and this won't be an ongoing issue, like they can tell! Of course it's going to be on going because he needs extra support which he isn't getting yet I'm reading stories from people who have said their kid is getting social funding so they can attend concerts and go out for tea etc? How is this using funds wisely? What about the people like my son who really need it? I'm so disappointed with this whole situation and set up more needs to be done to screen the people who are already getting funds  |
| 43 | Karen Wakely | We began implementing our plan in Jan 2016. In a little over 12 months, the change it has facilitated has been extraordinary. For the first time we have been able to access meaningful therapeutic supports. Previously therapy was only once a month, and was inadequate for gaining any momentum. Now we access either psyc or occ therapy every week, and it has been far more effective in developing the social and practical skills needed for independent living. For the first time, my child is beginning to successfully participate in mainstream community activities. Watching the way in which the psyc works with and responds to my child has also been of immense value to me as a parent. He has modelled strategies that have helped me to adopt more effective responses to difficult situations. We have been somewhat isolated as a family, with all other family living overseas or interstate. Outside of school, there were few other adults in my child's life, but I can now hold over difficult issues to discuss with my child at therapy in a supported environment, and we are actually making headway on issues that we have been struggling with for years. Therapists help me to reinforce expectations of respectful behaviour, and this provides support to me as a mother that I have not had before.There is room for improvement in the way plans are structured. We have 3 goals, which tend to duplicate each other. Only 2 of them identify strategies to achieve them, and there are no KPI's. We have had our difficulties with the planning process, and it is still not all that clear to me what the objectives of the NDIS are, and what it will/won't fund, but overall our experience has been very positive. I am beginning to see a more positive future that includes a greater prospect for independent living, and may also include employment. |
| 44 | Yuri Gregorian | I don't got too much to say you. It’s just the NDIS is a little hard to get my head around. I have no idea if I’m eligible or not and have no idea how to get through all the paper work and other stuff to join it. It would be much better if it worked just like the disabled job finding people where I have a disability pension so I can just show up, sign a few papers and get on with it............I think it might save money that way, it’s not like Centrelink don't put you through the ringer is it so I don't see the need to do it twice. Sure, people that don’t got pensions need to get checked out I guess. The least you could do is have people whose job it is to help people do all the paper work and stuff?? |
| 45 | S Lawson | The NDIS means nothing to our family yet - it is yet to commence in our region. It does however promise three things:1. The NDIS promises to be an umbrella, a gateway, for the multitude of services, equipment, and personal support hours we currently access through countless other mechanisms and providers. 2. The NDIS promises to place that umbrella in our own hands. 3. The NDIS promises to recognise our changing needs over time, whether that be due to the degenerative nature of disability, or the changes in our family as we grow/age. We look forward to its arrival in our region, so we may continue to participate in the community, in the workplace (as taxpayers), and as parents, in an equitable manner. |
| 46 | Brian Stanton | Hello,My son is a 27 year old with multiple, complex disabilities that leave him with a range of behavioural disorders resulting in confusion, anger, aggression, violence, property damage, self-harm and injury to other persons.As such he is "deemed" not suitable for group homes, where the potential dangers to other "customers" would be too great.My son absolutely has to have "one-on-one" supervision and management at all times simply to control his rages and meltdowns that occur on a regular basis.My son is still at home with his family. This has proved very debilitating to all concerned, as we are often faced with a "war zone."I am my son's Primary Carer - I am 68 years old this year, with heart/health problems.We have been "trying" to have my son placed into permanent care with providers in Brisbane for over 12 months.Attempts have failed thus far.THE PROBLEM is, for my son to have adequate, safe and effective care in his "own home" he has to be the single occupant with a Carer to look after him, and this will cost in excess of $320,000 PER YEAR.Disability Services Qld are not prepared to provide this funding. So I am forced to keep my son at home until funding for 1-on-1 is available, as a group home would certainly result in injuries, if not fatalities.Caring for my son in the home environment is extremely taxing , dangerous and simply not acceptable.Will the NDIS be able to fully fund the requirements for my son and those like him?My son requires in excess of $320,000 p/a just for support workers.He also requires adequate funding for therapies and a host of other needs simply to keep him going.How will the NDIS cope with this huge, critically needed, funding demand - especially when it is spread out over all of the needs base?Life can be "hell" at times and full of terror caring for my son at home - but how can I subject other "clients" to this "clear and present danger." |
| 47 | Bruce Wilson | hello,just briefly.i have been a high level quadriplegic for the last 34 years and i currently receive only a fraction of what i need in terms of care, in order for me to have some quality in my life.i currently rely on people giving up a lot of their time so i can just manage. i have a lot of pain which dictates to me what i can and can't do most of the time. pain doesn't seem to get mentioned very often.i believe the NDIS can change my life considerably so that i am not dependent on 'charity' and i can rule my life again. i want my life back as much as possible doing what i want, when i want. it's all about funding. give me enough and i'll be happy. simple as that.over to you NDIS.Bruce. |
| 48 | John Neve | An ndis is a barometer of a truly compassionate western society that cares for all the members of its community without regard for their circumstance |
| 49 | Carly Foat | The NDIS has not yet been rolled out in our area of Gippsland and isn't due to be until 2019. I am feeling very anxious about this. My son is 3 and he Angelmans Syndrome- he requires full time care and around the clock. He doesn't walk or talk and sonhis needs and wants rest heavily on our shoulders. Feeding, toileting, sleeping and getting around as well as suffering Epilepsy are all difficulties of each day!! I want the NDIS to help take the financially AP burden off these things because it is sometimes stressful enough just caring and worrying about him day to day. |
| 50 | Narelle Polley | We have 26 year old Down Syndrome sons that live at home with parents on our dairy farm. They have been on NDIS since last September and we are definately not better off. We live 30km away from services and their Maccas work which they love just as they do the farm. Their social outing had to be cut back due to transport costs and I have had to do more transporting. They both need social times with being isolated on farm. My health has not been the best and have two operations coming up, their father works seven days a week running two dairy farms so he is tied up and has not the time to help with transport & support. We are also having trouble with service providers to have the time and staff to do the extra workload involved in admin with NDIS. NDIS support in our area are very un informed with everything and very little support when you go to them. Good staff though they are not getting correct and precise details. I have not came across any carer that says their child is better off. |
| 51 | Angie Mclaren | My son has severe dyslexia and can't receive any help for assessment or treatment due to being a single mother of 3 we often don't pay for food just to pay for 1 30 min session per fortnight with a therapist. Every day the 3 year educational gap between my son and his peers gets wider. |
| 52 | Lauren McGowan-Slee | My experience of the NDIS hasn't all been smooth sailing. There's been problems with plans and providers that are part of the teething problems, but it has still been worth it. My condition got worse about 7 years ago and at my worst I couldn't get out of the house and sometimes even bed. Last week I started full time work, a feat that was once seen as impossible. It's not easy, I get fatigued and crash out most evenings and end up in bed quite early but I don't mind because I am living a meaningful life! Because of the NDIS I have supports that mean I can do a job that works with my disability and have the physical home tasks I can't do taken care of. I can sit and use my brain with no worries, so that is what I do for work, but I struggle to do physical tasks so I get help for that. I am excited to be a taxpayer again, it fills me with so much pride to be giving back again. With the NDIS I can afford to get to work, the transport contributions mean I don't have to reduce my work days to afford taxis. I have adaptive technology which means I can do things by myself and be safe. I am also blind and I can finally read again and I used funding to get me to a functional level so I could work. I can go places I have never been able to go, finally I am not only alive, I am living. I am paying taxes, I am giving people work when I purchase supports, I am happier and healthier. I can afford to buy healthier food and get help preparing it instead of having to buy pre prepared meals so I have had less digestive problems, and I don't see the doctor as often. I have a person who can be with me when I do exercise so I can exercise effectively without being afraid of falling over or getting injured when I lose muscle control. The NDIS for me makes sense. I have supports that contribute to the economy, so I can contribute to the economy. |
| 53 | Paula Greenough | I write for my 19yr old daughter who has Down syndrome. The education of my daughter at a "special needs" school left my daughter disengaged and withdrawn for a multitude of reasonsWith our early departure from her special school, my daughter was only wanting to sit in dark rooms doing only those things that did not require leaving the house, interacting with the greater community or any of her peers Anxiety and stress whenever she did need to leave the house left us in a circle of struggle and frustration.The ongoing funding at the time (Pre NDIS) known as "Futures funding", grossly under estimated her needs; her assessment done by an independent body advised by a school she was no longer engaging in, left us falling through the cracks.The funding was to help her transition into the greater community but its use was constrained to sheltered workshops or daycare centres. Both inappropriate for her health and emotional needs.The timing of our NDIS care plan and improved funding overtaking our futures funding has literally given my daughter a chance to springboard into the community and a hopeful life. One that would otherwise have been a corner in a dysfunctional group scenario that invariably would leave her withdrawn It has given us the ability to choose a one on one for skills building and a buddy for community engagement at a pace, and with people she can connect to encouraging even further participation.It has allowed us to design a programme that improves her functionality, her health; both mentally and physically but even more a life she can enjoy.Additionally I am a widow and my daughter is left with only one parent who cannot sustain full-time employment due to her care needs.So she has further been marginalised by the inability to access private services due to financial constraints ;services that can transform her life. Services that we can now access thanks to the NDIS and how it is delivered in a flexible and relevant way.We need the NDIS. |
| 54 | Sue Ferris | I have 2 daughters on the autism spectrum. Both are very high needs but at different ends of the spectrum. The oldest (26), who is non verbal and 24/7 care, had her first planning meeting on 1 July 2013. The younger one (24) has huge social issues, and has left home, and sees no need to communicate with any family, leaving her isolated and extremely vulnerable. Main problem is scheme far too bureaucratic. We have spent a huge number of hours working on many plans which do not work, and despite plenty of evidence of need, many expensive reports are demanded and ignored. The time and energy spent in dealing with plans which don't work has just about brought us to our knees with exhaustion, all the while having to care for our older daughter.Lack of accommodation has been huge, and we are now having to transition our oldest daughter to living away from home sooner than anticipated due to no hope of obtaining short term accommodation and assistance. This has placed an enormous additional financial burden on us and family.The NDIA say they assist with goals for participants to engage with society, help them to become ready for employment, but it seems too hard to follow through in the case of my youngest daughter.It concerns us greatly that while we are able to advocate for our daughters, not everyone can, and so we also fear that a large number of families will not receive the help they urgently need. For many of us, there is still no emergency care even.I receive approximately $360 per fortnight in carer allowance and payment combined, but when our oldest daughter transitions to living away from home, her NDIA plan allows for $9,614 for carers per fortnight. Had accommodation been available this sum would be much less. It also shows how much carers are taken for granted by governments.If in paid employment, carers would not be allowed to put in the hours that they do.The scheme is too complicated, red tape too costly and the portal is a disaster. |
| 55 | Katherine Thomas | I have a son who is 9 and severely dyslexic. I have paid for ALL his assessments and intervention/assistive technology myself. This has financially crippled us at times. Currently evidence based MSL therapy costs us approx $ 600 per term (60 per session) at a private centre with qualified tutors. I also know of families paying more. Some of the children we have met are unable to attend mainstream school due to the impact on their self-esteem. At times I question whether my son will make it through the education system with his mental health intact. Fortunately our local school does care, but their budget at this time does not include any evidence based literacy program such as multilit . Dyslexia is a real diagnoses which effects my son significantly and currently we get no financial help at all. My daughter will possibly also be diagnosed this year and our costs will double. I would love some funding to be available for us for therapy, assistive technology etc. At this time there are many children with learning disabilities like my son, who are not getting any intervention at all because their families can’t afford it. Children should not be slipping through the cracks and finishing school completely illiterate, when we know there are ways to help them. |
| 56 | Robert Maley | I have a 46 year old son who is autistic (among other things). I live in WA in the city of Swan as well as my son who is currently in Supported accommodation with the State Disability Commission (DSC). The supported accommodation management for Timothy and his house friends will imminently be managed by Identity a not for profit provider.Timothy lives in the city off swan NDIS trial site however I have been frustrated by the procrastination of the WA state government and the DSC in deciding over the previous 2 years on how the NDIS in WA will be managed. The process has been complicated by the outsourcing of DSC accommodation service. I am aware of the current agreement between the WA government and the Federal Government on the administration of the NDIS in WA.After much negotiation I was able to obtain an NDIS plan that meets some of Timothy's needs. This plan is up for review on 23 June and I am optimistic that Identity will be managing Timothy's Accommodation and together we can negotiate a more comprehensive plan. |
| 57 | Frank Shapcott | My early impression is good of the NDIS.1. Our son's hydrotherapy sessions twice a week, are happening more regularly than before.He is in supported accommodation, which we rate as good, but the system cannot achieve the routine he enjoyed at home.His bathroom, very poorly designed, is being renovated to suit his disability, an occupational therapist has contributed to this.A lady with cooking and domestic skill is going to visit his unit once or twice a week, to work with our son to encouragehim to be involved in these skills. This one on one, maybe 6 hours a week, will improve the quality of his life definitely. |
| 58 | Nereda Pinker | Being a parent of 2 children who have ADHD & Dyslexia it is a terrible decision where there is only so much money and you have to choose which service tou can afford. After private paediatrician fees as public wait list is too long, psych consults, OT visits, clinical psychological consults for testing. Add medication for ADHD, but Dyslexia there is no medication - just hard work. Tutoring costing in excess of $55 per week per child, which we are paying on top of catholic school fees - yet my child is still behind and all the school could tell me is it's not a diagnosis that attracts any funding so there isn't much we can do to help. It's a deplorable situation and one that needs to be addressed . |
| 59 | Audrey Yim | My son is 10 years old, he has an intellectual disability and is non-verbal, We transitioned to the NDIS end of last year. In the lead up I had read a lot about the NDIS, largely horror stories. So I was pleasantly surprised when we got our plan and were able to access services and equipment with little intervention. What a difference from the previous model, where I largely waited for people to contact me when funds and services were available. The flexibility and power to chose your service provider and drive/lead my son's needs has been greatly empowering. Like any new scheme, it has its problems:- the inability to review the plan prior to finalisation leading to multiple request for reviews.- lack of personalised follow up once a plan has been finalised to ensure individuals understand how the plan works. I have attended implementation workshops and read through guidance but we are talking about people with a disability who struggle with access or comprehension.- policy on the run and inconsistent advice. Universally I have heard this from service providers, and agencies acting on behalf of the NDIA. However despite all of this, I strongly believe this is the step in the right direction. I know there are concerns about budgeting and sustainability of the scheme. From my own experience I am not asking for more funds that what is fair and reasonable to allow my son to live a life with meaning and I hope the Government will understand that for the majority of us this is the case. |
| 60 | Lisa Teager | I have a 7 year old son who has been diagnosed with a learning disability in writing and spelling. This disability makes it extremely hard for him at school where he finds it difficult to write, get his thoughts down onto paper and also focus. We are currently taking him to a specialist tutor twice per week which is definitely helping.However we pay the tutor $1600 per term with this going up every year. This is a huge cost to our family as it has effectively eroded our buffer of savings and pushed us into some very uncomfortable months where we have literally run out of money after paying this, the mortgage and other bills. This is despite both parents working full time.We are committed to helping our son learn strategies to overcome his disability and meet his potential and will continue to try and find the very best assistance. We would like the NDIS to included learning disabilities in their remit and provide funding for tutoring and other learning specialists. |
| 61 | Linda Henton | I am yet to join NDIS, 2 years away. But I worry that funding will be reduced for my son therefore his quality of life will suffer. I am hoping that he can incorporate more into his plan to cover weekend activities and costs of carers so that he can have a life that he apires too and like other young men.I was told hat his Post School option $$ was for life and can be used to fund social workers etc to train him for transistion into his own place and then fund carers to drop in to help with cooking etc, now I worry that there won't be enough funding for that. |
| 62 | Helen Harrop | My son has been a NDIS participant since August 2016.He is 26 years old and while it should be acknowledged that while the NDIS is not without its problems, the benefits to my son within this short time span have been terrific.For the first time in his life he has control, within his plan he has more opportunity to get out and experience many different options so he can enjoy life.He is receiving increased assistance to develop the skills to be able to not only to look after himself by learning to cook, clean and shower himself but to participate in society which is the right of every individual.As a parent, the NDIS gives me certainly in the knowledge that once I am no longer around, their will be a variety of options for my son so he will be supported to have a greater quality of life. |
| 63 | Graeme Rouillon | We have a daughter aged 33. She was born with developmental dyspraxia which took nearly 5 years to diagnosed. At 12.5 years she developed Rheumatoid Arthritis. It is a very aggressive and rare form of RA. At 19 she had one shoulder replaced. She has had both elbows replaced.She fell through the cracks when she left school. We were advised that she qualified for post school options funding through Disability Services Queensland but was not eligible for funding. We have had to fund her care ever since and cover her medical costs. Her disability Support Pension does not cover all her costs especially medical matters. My wife and I have retired and we built a house with a friend's assistance for her future needs and our own.Her needs have always been significant. We would like NDIS to assist her future needs especially medical needs as this is the matter that will affect her future. The RA has affected her whole body even her jaw has no Cartilage. She is on a soft food diet. As her parents we have made the commitment to care for her as long as we are able and built our house with that in mind.Our greatest fear as parents is who will care for her in the future like we have for these past 33 years.The area we are in in Queensland will not access NDIS funding until 2019. I also have concerns about future funding and sustainability as it is Government money and would be monitored by Government officials.Now we deal with a real person and have always given her the best care available even though it has cost us financially, physically and emotionally. |
| 64 | Iris Ives | My 13 year old Grandson has Autisum and is none verbal. My daughter has recentley moved from the country to acsess more assistance. It is vital he has ongoing support so he can reach his full potential and does not end up institutionalised wich will cost far more in the long run and be very distressing for him and all the family. |
| 65 | Agnes Vukovic | My son Adam has Down Syndrome. He is now 35 and my husband and I have been caring for him at home. However we are ow in our 70s and worry about getting assistance for when we have limited capability to continue. The initial NIDIS plan did not maintain Adam's current services and we had to request a review. This took about 4 months during which time we found difficulty in contacting the 'planners'. The revised plan still does not cater for emergency respite for which we had provision in the past. Also the the funding we received was not clearly explained and needed considerable research to identify exactly what it covers.In particular we are still not clear on how to use the transport component. It is not clear when it is appropriate and how much to allocate to each to activity. Because of this confusion we have not yet tapped into this funding.Despite being IT professionals, we are finding the website extremely onerous and difficult to navigate. It seems as if very little user needs analysis was carried out. |
| 66 | Gavin Greaves | The NDIS means nothing to me as it isn’t rolled out in my area and appears to be a self-serving job for union members by providing for a whole range of increased services that are really just Bureaucratic positions not service provision. |
| 67 | Estelle Shields | Our son was born with a severe intellectual disability forty years ago. We felt driven to give him every intervention possible and for his first two decades, it was our privilege to do this for him. For the next two decades, as we cared for him, we felt exploited and abandoned by our country. Our son needed to gain his independence and to move out of home and I needed to return to work. This was out of the question because there was no way for us to achieve this. I had returned to university and gained a Masters degree so I could be more employable but the state disability agency had no funding for non-urgent cases like ours. The years went by and we all lobbied, held meetings, wrote submissions and letters and then finally - there was the NDIS. It has had a difficult birth but it is up and kicking. Our son's funding has enabled him to move out of home and he is so happy in his new setting. He has committed carers and a better quality of life than we could give him, because it is not cool to hang out with one's ageing parents. He has a new lease of life and has taken on new roles. These days, we sleep in and have weekends away and do things spontaneously - without applying five months in advance for respite. For me, the NDIS came too late to go back to work but there is comfort in knowing this will not be the case for future carers. For all our family, there is the most profound relief in knowing that our son and brother is settled and content and that there will not be trauma and upheaval when we depart this world.I cannot express adequately the transformation that the NDIS has made for me. I was ashamed to be an Australian. I felt that disability comes randomly and that those whom it visits are left to cope unsupported and alone. Now I feel that my country has taken responsibility for its disabled citizens and that we as a nation are sharing the caring, looking after each other and acting as a civil and humane society should. Advance Australia Fair! |
| 68 | Sean Cousins | Please keep the NDIS going. My 70 year old Mum needs it as much as I do. I need to get out working for the three days per week but with help. I need to get out meeting with a mate or two. I need Living Skills & also do a few things I love to do eg 10 Pin bowl & travel half an hour two ways to my hourly radio show, my first passion. I cannot drive so need help. If I don't get out & even on days I'm normally home with my Mum I drive her crazy with incessant talking & headbanging & touching her head a lot through the day. She needs to carry on with the things she loves to do too, but I claim an awful lot of her attention as I still live at home. So I really need this NDIS thing to succeed & to continue. My Mum & I are very grateful for this funding. It might cost more than the old system for disabled people but it seems more people are covered. I am intellectually disabled so have always had funded help but there are many, many more who need help. Please help them too. God bless this NDIS & Australia for attempting it & carrying it through. My Mum helped me write this. Thank you. |
| 69 | Peter Macpherson | I have been disabled for 7 years, l have a progressive Neurological disability, l am 61 years old. I am totally reliant on the disability pension and will be for the rest of my life. I worked for more than 30 years, educated and raised 2 children. What money l managed to squirrel away for a rainy day l have been forced to use because of my disability. As this disability is progressive, l would not be able to provide financially into the future.Apart from the much needed physical assistance that the NDIS will bring into mine and my family’s life, it will also help me to retain some of my dignity. |
| 70 | Pat van der Beek | Our intellectually disabled son is 41 years old this year and my husband and I are 73 and 72 respectively. When the NDIS rolls out in our area in July, we are hopeful that we will have additional resources to enhance his life. His siblings are busy with their own families, careers and lives in general and there is no certainty that they will be able (or willing) to provide the necessary support for their brother when we no longer can. We have spent the last four decades working hard to ensure that he has a rounded life with dignified employment, a sound education to his ability level, safe accommodation (at home), good health care and opportunities for extending his social networks. Despite our efforts with the last point, he has virtually no friends of his own age, Most of the people he regards as 'friends' are actually our friends, people in their 60s and 70s. We are very hopeful that NDIS funding will allow us to employ workers who will find ways to assist our son to make genuine friends of his own age which would enhance his life immeasurably. We also naturally have all the concerns that people in our age group have for an adult child with a disability in a future which will not include us. While we are currently both is reasonable health, there is obviously no guarantee this will continue; inevitably, our son will be without our support in the later years of his life. We are determined to ensure his future welfare and trust that the NDIS will make our endeavours in this regard less complicated. We have genuinely done our utmost to give him the best possible life to this point and welcome the introduction of the NDIS which we hope will enhance his future while also lifting some of the responsibility from our shoulders. Thanks for the opportunity to share our story. |
| 71 | Lynne Foreman | What the NDIS meant to me, I can now choose who cares for me, as I now have a choice.I have the hours I need to live my life and also because of flexibility in my plan, I am now an employee, so in a way the funding I have left over because of my life now, it will go back into the Scheme to help others, these day we are saving on the funding as most can get out and enjoy life to the full, yes some with support. But I know if something happen, say I fall out of my wheelchair and break something the NDIS would but more hours in until I was back on track. so its also there for a lifeline if you need it.Most of us now feel we can take part in the community, and I know some because of the NDIS have part-time jobs. We are healthy in our mind and that's a good thing in its self. |
| 72 | Tania Hornberg | Hi, I have C4-C5 spinal cord injury and use a Powerchair. I require a lot of daily assistance not just with my personal care needs but with my social life and #2 jobs (part time Administration Assistant & casual Workshop Presenter). I love my jobs but I need assistance with some tasks. I have a very active social life and need aassistance with getting in and out of bed/dressed, etc. My transition to the NDIS has improved my position compared to the state funding. But, I am still underfunded and it's extremely important that the NDIS is improved so that people like me don't have to continually worry about not having the funding to employ support workers when you need them. If you don't have adequate funding then you end up in bad health and cannot work. I want to be able to work for as long as I can. So it's important that the NDIS functions well and is in a position to funding people well and in a flexible timely manner. The NDIS also needs to allow more flexibility for adults with disabilities to employ their relatives especially in situations where the relative knows how to provide support better than anyone else and can be utilized as trainers for new support workers who don't have a clue what they are doing. With spinal cord injury you need well trained workers and there aren't many available and it's worse in regional areas. The NDIS needs to be kept in good working order, otherwise it has dire consequences for people with disabilities. It's extremely important for people with disabilities to have timely support when it's required otherwise there are serious health issues that develop. Disability issues don't wait for bureaucracy, so the NDIS needs to be timely and flexible. The board needs to have people with disabilities on for personal insight and input into flexible policies and procedures. The NDIS needs to gather ongoing feedback from people with disabilities and their families to make improvements and make it the best it can be for everyone. |
| 73 | Andrew Brak | Our son had his NDIS plan approved at the end of September 2016.Since then the activities he's doing and ongoing support have been fundamental in developing a better future for him.Without the NDIS his possibilities in developing a better life would have been very limited.It's extremely important for the NDIS to continue for many years to come helping people with disabilities with their already challenging and difficult lives. |
| 74 | Hadley Manuel | I am a 40yr old high needs Non-Vocal Intellectually Disable Person. I believe the NDIS will benefit the new generation of disable persons with opportunities I missed out on.Everybody is focus on independent living and moving into their own accommodation etc.I am concerned that I am being left behind, the way the NDIS is being implemented and how Service Providers are ignoring those still on block funding without a plan for those with a NDIS Plan.My other concern is the cost to my core supports have gone up since the NDIS.My major concern is accommodation. I have been on a SDA List of some sort since the age of 5yrs. I am confused what the NDIS SDA Policy is about and its refusal to assist persons like myself to live permanently in my present accommodation where I have oversight by my formal supports over my core supports and will be close to my community network of supports built up over the years. I was offer to purchase a life time interest in my accommodation which would give me more certainty than another twenty years on a waiting list or incompatible situations. It would also put me on a even footing to those in group homes and other assisted living arrangements. I also believe it would save the NDIS long term as I would grow old with the people that make my life worth living.Regards,Hadley |
| 75 | Jane Bringolf | As a campaigner for universal design across all design disciplines so that everyone can be included in the designs of our world, I find the talk only of costs of the NDIS very discourteous. You are saying that some people cost too much - some people are not "worth" as much as others. And then you forget the other side of the ledger - the benefits both social and economic. It has started a wave of new jobs and employment for carers and supporters who will pay tax. And it opens doors for people to work now where they couldn't before. It has also released family carers from 24/7 care so that they can now get jobs, pay tax and get superannuation benefits. If our policies as well as environments and products were designed more universally, we wouldn't even be talking about people with disability (and older people) as a separate group needing separate treatment. We would be an inclusive society. We would be enacting fully the National Disability Strategy and complying with our obligations under the UN Convention. |
| 76 | Christopher Klepacz | My name is Christopher and I have cerebral palsy. Once the ndis comes out in my area next year it will have lots of benefits for me. I currently have a carer currently funded by the state's dhhs individual support plan but it's not even enough to have a carers regularly due to the budget with isp. Even though I still living with my dad who is a full time carer every single day it is very necessary for him to have a break from caring me while I enjoy going out in my community like any other people. I am saddened when I hear people with a disability who can't enjoy life because of many factors like no equipment like a wheelchair to transport them or even can't afford a carer to come and take them out due to a lack of funding, which this is in my case. I must keep budget with my funding so I can plan what I need equipment and carers.I'm going to finish high school at the end of next year which is perfect timing as the ndis will roll out by then. I'm also under psd funding from the education department which it funds me an education support officer assistant and a physiotherapist it will end when I leave school at the end of 2018. I'm planning to go to tafe in 2019 and the ndis will hopefully fund me a carer to assist me at tafe and the ndis will pay for my physiotherapy. The government needs to know the ndis will be a good investment as it will change people with a disability and a give us a better quality of life. |
| 77 | Amerson Stephenson | Why isn't Dyslexia included in disabilities covered by the NDIS? It affects between 10 - 15% of our population and we are about 25 years behind the rest of the developed world in providing programs and support for the thousands of Australian children struggling with Dyslexia. I have 2 dyslexic sons, my middle son was finally diagnosed at the age of 11 (yr 6) with the reading age of a 6 year old. He had received no specialised help for his condition at our local state school in Brisbane, despite showing up in every reading indicator test from Yr 2. Luckily my husband and I were able to extend our mortage and pay the thousands of dollars it cost for private tuition for him and his brother with reading expert Dr. Jason McGowan. I also had to give up my part time job to help them with their program at home, so not only did we get no financial help from the government, we also had to give up my income to help them. Successive Federal Governments since Kevin Rudd held his Dyslexia talk fest in 2009 have shirked responsibility to address this disability which effects so many thousands of Australians. Why can't Dyslexia be included with the other disabilities in the NDIS? It is said that up to 60% of our prision population is Dyslexic and that is where many children who can't read end up - they can't read, they drop out of school, they can't get a job because they can't read, this also leads to low self esteem and high suicide rates. Please don't let this disability be forgotten any longer! |
| 78 | Graham Lawrence | Our daughter Michelle was born with severe brain impairment, reduced mobility and Epilepsy. She is now 42 and we, her parents are 68. Her NDIS story is covered in the attachment.Michelle Lawrence NDIS Story to Productivity Commission 17/3/2017(Written by Michelle’s father, Graham Lawrence)Michelle was born with severe brain impairment, epilepsy and restricted mobility. (She displays characteristics similar to cerebral palsy but is not diagnosed into that category.) Michelle is now 42 but still suffer seizures daily although not as severe or frequent as when she was a lot younger. Her speech is about equivalent to that of a 2 year old and her comprehension is similar. As a result, Michelle is incapable of performing the majority of daily living tasks without one on one assistance and support.Michelle is totally incapable of completing any of the most fundamental daily living activities and has no concept of safety or self-preservation in the home or in the community. She requires 24/7 supervision and support to survive.It has been possible for Michelle to have access to the community and some independence from her parents due to the existence of a range of government supported programs, including centre based community access programs and short stay accommodation in group homes. Michelle loves and is stimulated by these programs and her interaction with her friends/peers and the independence they provide her from spending 24/7 with her parents. The introduction of NDIS has now enabled Michelle to transfer her arrangements to her recently approved NDIS Plan Support Budget. It has improved her arrangements by enabling greater freedom of choice of Service Providers and choice of support programs.Without the new NDIS, Michelle’s life would become very different, as would be the life of her parent carers. This is because Michelle would not have access to a life outside of home and would almost certainly be placed in a facility remote from her parents and other family members. Given her inability to create her own circle of friends, her life would be cruelly cold and isolated, with her resultant confinement. Under her NDIS approved plan, Michelle has the ability to purchase a 5 day/week community access program with a group of her peers, with arranged leisure, craft and life education activities. Michelle also has the ability to access short term accommodation support independent of her parent carers. The importance of these programs is that they are an essential part of Michelle preparing for the day when her parents are no longer capable or available to provide a home and love and support for her. |
|  |  | By continuing to access her community based support programs from her family home, under her approved NDIS Plan, Michelle makes it possible for the Government to save an estimated $300,000 -$400,000 p/a. This is the typical net cost of providing care (equivalent to their own home), for people with the severe levels of disability which Michelle has.The NDIS Support Plan now allocated to Michelle makes it possible for Michelle’s parents to cope with the pressures of being constant carers. It also gives Michelle the best of two worlds, in that she can have a very full home life with routines and comforts she needs, while also accessing the outdoors and community and other people she enjoys in her life.An added benefit of Michelle’s NDIS Plan is the ability it gives to self-manage the support budget. This creates an opportunity to save costs and increase access to services and service providers. |
| 79 | Anita Howard | At 61 I'm still struggling with the damage to my self esteem that resulted from the lack of understanding and support, from teachers and society as a whole. I found reading, comprehension, spelling and writing my thoughts down on paper in a logical fashion near to impossible, however, I was an able debater. In my finial year of school when asked by an English teacher what I planned on doing next year (this was the bottom English class and others had responded, to be a hair dresser, work in the bank or shop) . I responded that I intended to go to university and study clinical Psychology. The teacher laughed and said ' Anita you are dumb, you won't even matriculate.' I did and went to university to study Clinical Psychology, though I changed to teaching.I have always felt trapped in a mind that for some reason will not function as it should, as other people's do and for this I have been penalised. Today we have a clearer understanding of the reasons behind problems like mine and therefore there is NO EXCUSE for not providing students with Dyslexia or any difficulties that can be assisted, with assistance.The Present government or any ruling party has the responsibility of providing education for ALL its citizens, this includes the assistance that is needed to access the education. I understand that there are many demands on the government purse. But, to me making sure EVERYONE is ABLE TO ACCESS THE INFORMATION provided by teachers through text and or verbal is of primary importance. And funding should NEVER BE WITHDRAWN instead it should be INCREASED. Education for ALL is a societies greatest investment, when our future potential scientific, medical, engineering, creative, political, educators, agricultural, computer scientists, carpenters, plumbers... all mentally healthy people are ignited into existence or destroyed; their abilities channeled into negative and undesirable areas. |
| 80 | Paul, Jenny & AaronThompson | To The CommissionDear PeopleI don't want you to cry with me or wallow in my mud. Because this isn't about me its about our son. Aaron Who is 45 yrs of age and needs to be counted as an individual just like every other human. The NDIS is the most important support Aaron will receive in his life time and in the future for human kind. All of Aarons support at the moment is from Regional care provider, Gladstone Community Linking Agency, and family who are either aged or are very involved in there immediate family. Our son needs the support of ever one but mostly the NDIS.RegardsJenny & PaulPs; Aarons Mum has been in a comer for 5 yrs & no one is sure how solid my perch is, thank GOD for the NDIS |
| 81 | Guy Gustard | Our plan was $1,000 less than the old system: Provides for even less services: There are less professionals in our area, (due to partial retirement,) to provide basic services like speech therapy: Couldn't contact NDIS through 1800 number for more than three-months, nearly missed-out lodging review in time: Review lost in office, informed three-weeks after date, emailed a new copy, another two-weeks more before review date is awarded... maybe: Incorrectly placed on self-management against strict instructions desiring plan-management, told I would just have to learn the system despite the mistake being made by Planner/LAC/NDIS: Threatened with cessation of respite if back-payment of respite not paid immediately, email to local NDIS told me to ring 1800 number as they couldn't help me... by God's Grace finally contacted NDIS 1800 number – who told me to email local NDIS as they couldn't help me: Contacted PM's Office to get action, suggested crucifixion of Christian Porter, will supply nails and hammer them in myself: Still no action....Wish to be placed BACK on to old ADHC scheme; NDIS is a scam!If you want to know WHY NDIS is a total joke, this is why.... The old ADHC scheme was 'broken and needed replacement', so politicians with no personal experience said "We know how to fix this!" They then threw together a lot of good intentions, THEN they employed exactly the SAME worthless bunch of buffoons who stuffed-up the old system and 'retrained' them to deliver this mess.... How the hell can you expect a different result when you hire the same old useless bastards who couldn't run the old system? Obviously, you can't!Finally told review granted… no date. To be contacted by ‘appointments team’, someday….This is no-way to treat distressed clients by offering no security; just open-ended promises.Here is the nub of your failure; you pretend to give control to clients THEN decide what is best for them, this is just as patronistic as before. The best example is what caused the need for the review of our plan in the first case…. I sat at the meeting with the LAC and my planner, the LAC taking wads of notes – by hand – despite technology superseding a clumsy, distracting, pitfall of bias opinion… then, when things couldn’t be more error prone, I asked when I could see the plan before it was submitted for approval, “No, you can’t possibly see the plan before it’s submitted, that is against protocol, it may even be illegal!”I thought this was ridiculous at the time and questioned the right to review and edit, but was fobbed-off with this is procedure!Perhaps my recollection will be challenged, but the FACT is, if I had reviewed this plan BEFORE it was ratified, the plan wouldn’t have needed a review… any idiot can see the sense in that: So, as my vision is clearer and better informed than the fool who has engineered this disgrace of a system, can he please be sacked and so I can take his job! |
| 82 | Brad Rossiter | My name is Brad Rossiter. I was not born with a disability but at age 6 I was diagnosed with Type 1 Diabetes. I didn’t let my condition stop me from living life to the full. I played cricket at A grade level, A Grade Soccer and Baseball plus plenty of other sports and activities. I am married with one son. I was a butcher by trade but in 2000 at age 36, I was declared legally blind and commenced dialysis. Over subsequent years, my left leg was amputated in 2002, I received a pancreas and kidney transplant in 2007 and in 2008 my right leg was amputated due to diabetes.My disability has meant my life changed. No longer able to work I have nevertheless worked hard to raise organ donor awareness as well as being a community representative on a number of committees. Wherever possible I have contributed in the community as and where I can.Since being forced to give up work I have covered the cost of replacement prostheses, home modifications to enable me to get around my home as independently as possible and purchased computers and mobile phones with the accessibility features I need, as a vision impaired person, to effectively use them. Not everyone understands that prosthetic limbs require regular repair, maintenance and replacement, all of which cannot be done locally and requires a trip to Canberra.For anyone who does not hold a drivers licence and lives in country Australia, transport will always be a massive issue. Until recently I have negotiated with the local Council’s community transport to access appointment. I will now need to use my NDIS component to fund transport. It remains to be seen whether this will cover all my transport needs. I am pleased that my NDIS plan can be reviewed annually to ensure all reasonable and necessary supports are met and I am able to live an ordinary life. The NDIS has the potential to make a huge difference to the lives of people with disability.I trust this review of NDIS pricing ensures a fair outcome. |
| 83 | Jodie Martin | The Ndis is helping make the life of our youngest child, a much better life and easier for her to live her life to the fullest. Before the Ndis, we found it hard to be able to get her in to programs, activities, therapy and the equipment she needs to live life easier. Although it's hard to set it up and it takes a lot of time, I know that the Ndis is going to change her life drastically and make it easier for her to live, the ndis gives her the same chance as an able person gets and makes it easier for us as her family, to provide her with the what she needs. It also gives us the power and gives us a choice of what we want for her. It ain't about the money for our family, the Ndis, helps us met her needs and helps her met her goals and live life to the best. The Ndis actually is something that will change many disabled Australians and their families, as it allows each and everyone of them who receive the Ndis, to be able to make the choices on their own, with the help of a family/carer and gives them the rights all Australians get. |
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| 84 | Paul Weichman | I became legally blind last year and the last time I checked, the NDIS is not in my area, therefore I am unable to access any of it services. To be honest, I still am really unsure how the NDIS will help me once I can use it services.I am now unemployed, as I could not continue in the job I was doing, but I would love to have a role in the NDIS. This would help me to learn more, but also give me the opportunity to help others who are struggling. |
| 85 | Samantha Baker | Well I live in the Northern Territory and still do NOT have access to the NDIS and I have a severely disabled son! I think the wait on the roll out has taken far too long and it has fallen down in helping those who need it most with the roll out being done by areas rather than need. My fear is that by the time we are meant to have it roll out in Darwin the whole scheme will be bankrupt. |
| 86 | Dianne Cook | I am very pleased (on behalf of my daughter who has Down Syndrome) for her to have some of the opportunities offered by the NDIS. Admittedly it is early days and there will be streamlining of procedures etc but I am pleased that now persons with a disability will be able to get help and even know how much service providers are being paid on their behalf as well.I believe this is a very positive step and thank the Government for making this help available. |
| 87 | Kath Williams | Sadly, we do not have NDIS, and we will not have it until 2019, as we live on the Sunshine Coast QLD, and have been told we are the last region in the whole country to receive it...that is, if it still even exists by then ?I wonder how it was decided that the need in our community was less than any other ?My 28 year old son with ASD lives at home with us, we are not rich, and does not have "a package" but has a small post secondary funding amount which we utilise as YLYC... so we are very limited in respite options, and residential care is out of the question unless I "have a breakdown and relinquish" my son into an unsuitable crisis care situation many miles from our home and his social and community contacts, with residents not of our own choice.Is the NDIS a mythical holy grail that will be snatched from us before it even gets here ?What, as a now emotionally exhausted parent who works very hard at maintaining compassion, motivation, kindness and functional family and exemplary care after 28 years as a carer, do I believe ?I am also working hard to pay off a property so that my son has a home to live in in the future. We have geared our whole lives around my son's care, needs, comfort and lifestyle.What do you suggest ?I await your reply.Kath Williams. |
| 88 | Rosie Read | We as a family are struggling to manage giving our son (35yrs) a good life in the community and ensuring he is not in a 'Day Placement' forever!! For us to have organised for him to be living in his 'own place' four nights a week.......(and wanting it to be 7 nights); has been and still is A HUGE EFFORT; but as the support dollars are not here now to do this..............it makes it so much more difficult!! We have come this far on our own........NOW...........we really NEED the 'NDIS' funds to get our son that bit further into the community; to 'live like others live' and to try 'to work like others work'. PLEASE SEE OUR PLEA and HOW IMPORTANT THE NDIS funds will be......... to be able to go the whole way, after all the effort we have already put in to get our son this far!! THANK YOU |
| 89 | Jackie Noyes | My middle aged son requires direct support all day and night and has behaviours of concern. Even though ISP funding has helped him to live in his own home, he has still required an average of 60 hours a week support from both of his parents working with support workers, managing supports and filling in gaps in the roster.The NDIS means he can look forward true independence and family members can look forward to a normal life too.It is not just about to dollars spent. It is about the dollars saved when we get it right: fewer visits to the hospital; no need to call on police assistance; no injured workers. It is about opportunities to learn and enjoy life. It is about the benefits to those who gain employment, and their families. It is the opportunity to support local businesses by taking part in more programs and attending community events.The money spent will not just improve one life: the effect will ripple out through the whole community. |
| 90 | Sara Sutherland | I am now in my 70's, and my intellectually disabled daughter, Anita is 40. Anita is living in a house managed by Multicap and I am forever grateful for the care she receives as, although I remain as involved as I can, I could no longer care for her by myself. I see the NDIS as an essential improvement in funding for people with disabilities - a step towards providing them with the lifestyles available to others, placing them, in fact on the same level as the rest of the population, where they deserve to be. In this part of Queensland, we have not yet completed a planning process - although we are aware of it and have been working towards it. Multicap is making every effort to assist parents and carers to be aware of the choices and the need to ask for what will be required now and into the future. I realise that it is important to get it right - or as right as possible! I feel confident that I will be assisted in this regard. I am also part of a small group working on the future needs and desires for people with disabilities in my area (Redlands), when completing their planning for NDIS funding, and we will shortly be holding a "conversation" which will be professionally facilitated to seek responses from people in the area as to what they want and need - so that local businesses/community services are able to provide it. We see this event, which is being funded by the Redland City Council, as a win/win situation for the area and its population, both disabled and non- disabled. A lot of work has gone into planning this event and a report will be available summing up the findings, in due course. |
| 91 | Janet Barkell | I am the mother of a 36 year old woman who has aspergers syndrome, tourettes syndrome, menieres disease ( a balance disorder) and Fibromyalgia. She also suffers fom Anxiety and Depression due to her Autism and many years of stress caused by the lack of a coordinated response to her disabilities, resulting in a great deal of emotional abuse by services whovwere charged with assisting her and 4 years of recurring homelessness which occurred before she was finally diagnosed at age 24. My daughter has self harmed and although to her credit, she has managed to address this herself with the help of an online community, she still struggles to have a happy, healthy life as she continues to live with an uncertain future. The stability that NDIS may offer her, that is ongoning assured funding for house cleaning and specialised counselling by autism traned psychologist may finally take fear away from my daughters life. She has failed to complete attempted tertiary study, has never worked and until receing a scooter from the SWEP program, was a virtual prisoner in her flat. My daughter has an IQ of 130 and should have been able to be a productive member of our society instead she had lived in fear and poverty. I too have suffered as I have paid to support her and now live in a home which parts of are in danger of collapse due to lack of maintenance. I am now only a few years from retirement and both myself and my daughter will struggle to live financially. If we had been given support our lives and outcomes would have been far more positive for us both and neither of us would have been the drag on the public purse that we will both now be for mnay years to come. Please consider not penny pinching so that others do not suffer as we have. Everyone deserves support and the ability to work and have an income which gives them stability and dignity. I look forward to some dignity and stability for my daughter as NDIS rolls out in Bendigo this year. |
| 92 | Stephen Grealy | I am very happy that the NDIS is here. It is a true blessing for a family like ours. It is very helpful because it will assist my daughter in making friends and learning new life skills and assist her in being able to give back to society. We are just as the beginning phase of the process but are very excited about the prospects. The sign of a truly evolved society is how well it takes care of its most vulnerable and this program shows the caring heart of Australians. Thank you. |
| 93 | Chris Baggarley | My adult daughter and I await NDIS starting in Redlands where we live. To counter low utilisation rates seen in other jurisdictions I work with other volunteers to implement a local community based response to the NDIS which will enable all to thrive. Our aim is people with disability (PWD), their families, NGO's, local business and developers work together to build capacity in our local community to offer meaningful activities for PWD which will eliminate low utilisation rates and keep NDIS investment in the local economy. PWD, NGO's, business owners and local entities will have a community conversation in April to map common goals and how to form a partnership to leverage growth and development so all members including PWD, families, seniors business owners with and without disability can thrive. I welcome your interest to find out more about My Community Our Way. regards Chris B |
| 94 | Evelyn Scott | The pressures of having a child with a disability - in my case my daughter with Down syndrome, an intellectual disability - never go away. At 37 my daughter has been through under-supported inclusive schooling, little supported TAFE learning, part-time meaningless jobs, and part-time employment in the APS which finally resulted in medical retirement due to a total lack of understanding of the support needed or any willingness to make it work for her. So there's been depression, the search for meaningful activities, health issues, little support for me, a move to Sydney from Canberra to be nearer family, the search all over again for constructive employment (and the DES she tried was not it), eventually leading the 2 of us to register a public speaking and art business for her. But the workload and frustrations never lessen. ADHC's ILSI program helped considerably to develop her independent living skills - but where to find her a home? No social or community housing near her family. After several knockbacks an expensive new apartment was found to rent and my daughter moved in - needing lots of support, confidence building, me joining all the dots with lots of phone calls and visits to keep the process rolling. Will the NDIS now help us to keep the momentum rolling along - especially now she's a student at Sydney Uni as part of the uni2beyond program - or will we find she'll again have the rug pulled out from under her through a lack of real understanding and recognition of the support she needs to achieve her goals and realise her (and my!) dreams? The NDIS goals are admirable, and the achievements and opportunities across many fields for people with disability can be boundless, but the perception is all around (and it's frightening!) that governments will be tempted to trim, to tinker at the edges, and undermine not just the 20 per cent of people with disability but exhaust and depress the huge numbers of carers around them who are hanging out for help! |
| 95 | Stephanie Dower | I view the NDIS as when my independent adult life can fully be realised. I like to think of myself as a pretty independent person but when you're physically dependent on others, there are most certainly going to be some limitations. Having a carer to help deal with the day to day monotony of life will, crazy as it sounds, be liberating for both me and my family. That is what the NDIS will mean to us, long overdue liberation. |
| 96 | Karene Gravener | The NDIS has changed my life. If this stopped, it would devastate me, and my family. I have improved physically, emotionally and mentally because of the support of the NDIS. We, as a family, have been able to live life, and pursue our dreams. My husband has been able to be in full-time employment without the stress of being a carer, and we are building our own home.If my level of support was to change, or if any of the assistance through the NDIS was to be stopped, I would suffer in so many ways. I am improving dramatically with support in personal care, physiotherapy and occupational therapy. Before the NDIS, I was a different person; life was always stressful and I was always wondering where the next amount of funding was going to come from. I was on edge; upset because I could only ever have MY VERY BASIC LEVEL OF CARE NEEDS MET, so I didn't go outside of my funding allowance. I could never plan ahead in the hope of being more independent and being a part of my community. Now, I've been able to dream and set goals; some of which have already been achieved, and some are well on their way. I have been able to be the mother that I want to be and live my life. Everyone deserves that. The NDIS is in its beginning stages, and I appreciate that some mistakes have been made, and people have not got the plans that they wanted, but I believe that through a thorough review process, and clear communication with families and individuals, we can only get better from here. We need more professionals supporting families and individuals to piece together appropriate and strong evidence based plans. This CAN be done!The NDIS needs to stay. Lives will potentially be shattered if it doesn't. Furthermore if it's financial scope is altered; lives will be limited, and we will be back to a "deserving v's undeserving" model of service, as opposed to the power of choice and control that we have now. PLEASE don't take our human right of choice away! |
| 97 | Phillip Sanchez | The NDIS has made a great change to me and my mother. Previously, she was doing a lot of work to take care of me now at least the burden has been spread between my carers and her. I am now able to do things independent of my mother.Given she is in her mid seventies this pleases me greatly. I no longer feel like such a burden on her. I really hope this lasts as being without severely cause great difficulty in our lives. I am eternally grateful for the assistance that we have received through the NDIS. |
| 98 | Amy Calcott | I have friends who suffer from disabilities, and I believe people with disabilities should have the same opportunities in life as people who do not suffer. |
| 99 | Seema Gandhi | I have yet to enjoy the benefits of NDIS. I am hoping it will provide me with an opportunity to live a meaningful, enjoyable and independent life. |
| 100 | Judy O'Connor | What the NDIS means to my son and our family is choice making, services applicable to his individual needs, support. Peace of mind that my son will be as independent as possible as we all grow older. |
| 101 | Diane Steffensen | The NDIS will make such a big difference to my 25 year old daughter. She would be able to choose her carers to help her live as independently as possible. Also we are hoping it will eventually help her to live away from home with the supports that suit her. My husband is retired. We would like to enjoy some traveling knowing our daughter is living a life of her choice. Independence with dignity. |
| 102 | Susan Mason | Hi,I have a family member and a few close friends who are finding life a little bit easier thanks to the NDIS. My sister has a beautiful daughter with Autism, and thanks to the funding she now gets from the NDIS her daughter's life (as well as the family life), are a little bit less stressed. Her daughter now has more opportunity to experience classes and activities that other children take for granted, and I'm sure my sister feels just a little bit more comforted knowing that she can now help her daughter to reach her full potential.Although I've had very little to do with the NDIS, I am a big fan of it. Keep it going :)Susan |
| 103 | Ken Bull | Dear Sir/Madam ... I had to retire invalidity with Primary Progressive Multiple Sclerosis at age 53 and have had to live on a pension from a modest superannuation policy. I walk (very badly) with two walking sticks or a rollater. There are no drugs for this type of MS, and I do all in my power (with diet, exercise and meditation) to slow the downward progress. I spend a lot of my pension monies on a personal trainer/ gym/ swimming/ physiotherapy/ and walking on an underwater treadmill. I can only do this while my wife is still working. Once she stops I will not be able to afford the "luxury" of these very effective physical actions to stop the downward progression of MS. I am hoping and relying on the incoming NDIS to help me in that regard. I believe in general that money wisely spent by the NDIS will be offset by gains keeping people like me out of hospital and government-funded rehabilitation facilities. Thank you, KB. |
| 104 | Karen Kerslake | I was looking forward to transitioning from ADHOC to NDIS. I didn't receive a letter so I rang to see why. I was told I could submit my application myself which I did. I don't have anyone to help me and I found it extremely difficult.I heard nothing for ages so I went into the NDIS office to ask, Only to be told I'd been knocked back. I got a phone call saying I didn't meet their requirements and a vague letter, but no specific explanation. An internal appeal was automatically raised, but no one asked for more information. They didn't even know I was registered with ADHOC! I was again knocked back. I supplied more information and was knocked back for a different reason.My experience with NDIS has been awful and extremely stressful. I depend on my subsidized assistance that I'm already getting. I've no guarantee that I will get to keep it. All assistance programs that I find (by myself as I have no help) are all transitioning to NDIS and don't know what to do with me. I am only as good as I am at present because of my support. If I lose that I won't cope. I am not alone. There are any of us that are falling through the system. We're not classed as bad enough to meet your intake requirements, but are unable to work more than a few hours a week and need help to manage at home. What happens to us NDIS? |
| 105 | Steve Bullock | I am quite unimpressed with the 'bully boy tactics' so far used on people with a disability, the deliberate lack of information provided by NDIS and apparent efforts to dupe vulnerable people out of supports. I am aware of numerous instances of NDIS representatives calling people and coercing them into assessments that they are not prepared for, these people are unable to self advocate and are being exploited, I wonder if they would have some recourse through disability rights?Disability Standard 1 - RightsStandard 2 - Individual OutcomesStandard 3 - Individual outcomesStandard 4 - Feedback and complaintsStandard 5 - Service AccessAre NDIS actually observing any of these standards?It is quite concerning that NDIS appears to be more of a gatekeeping exercise for the most vulnerable people in our community. |
| 106 | Terence Hunter | As pensioners and caring for our retts syndrome girl which we have custody of for the last 20 years.Our concern is that there is no financial support for us as parental carers to have a break. The cost of external carers on the penalty rates and 24/7 care is to expensive and uses up the normal day care.There should be some built package for genuine pensioners who have a life time care for disabled who can't care for themselves especially the defenseless. |
| 107 | David Ingerson |  Our 13 year old Daughter has a serious medical conditions that means that she has a current mental age of 2-3 years old. She suffers about 2-300 seizures a day, is unable to walk, talk or look after herself in any manner. Based in Logan in Brisbane we may see the NDIS in 2018.Currently we see that service providers are reducing available therapies in preparation for NDIS, with much more disruption and lack of services than seen previously.WE are hopeful that NDIS will delver what promised (although we expect that will not happen due to government watering down and repeated alterations of what will be delivered) My wife is a full time carer for our daughter, with her attending hospital at least twice a week as well as therapies that we fund as we have found that promised therapies are rarely delivered frequently enough to make a difference. Due to financial constraints the house is unsuitable with us having to resort to carrying Tara through the house (at 45 Kg) as hallways will not allow the use of a lift. Due to this home help is also refused as the house is deemed to be unsafe for a helper. Holidays are something you dream of , as financially we have been unable to afford one since Caroline had to give up work when Tara was born. when a special wheelchair was needed for Tara we were able to purchase that privately, with it costing $6,500 , instead of the government approved supplier at $27.000 this was funded by money saved up towards a wheelchair accessible car. Flexible use of funding and the ability for funding to not be cartmentalized is critical as in cases its just a matter of what is the most important at the time, you just go from one critical event to the next. DSS advised that the lack of services was so great that there was nothing that could be done and therefore we should surrender her to government services- a far more expensive situation and with the commission into child abuse- would you trust the government to care for your child. |
| 108 | Susan Merciadri | I am not good English well done that try writing this best for me. I must always issue interpreter for Doctor, Hospital, Phyiso excrise pool , counsellor and etc since I was 30 years old in 1989. It felt lot of better for making me more confident and self esteem. I went to a vet with a vet nurse who can Auslan because of her deaf brother. I had patient with my mum or youngest sister who used finger spelling since I was 15 years old to feel low self esteem sometimes. My mum had her middle daughter was deaf. I am disappointment unable chatting my cousins, aunties, families but they can't use Auslan. It made me very frustration with them who didn't tell me any things and health. I really wish chatting my family tree with interpreter. I love to interest about making up or tafe, pottery, artist, Now I feel improvement for catch up lot of new words better with interpreter and Lecture than before . If I don't understand a word to ask person by interpreter ask by my responsible. Interpreter is very good professional service and policy. I am very sad to watch a movie name was shatter. A daughter of deaf parents who need her to interpreter a funeral service for her little brother died on 1934. They needed know the price to cost for his body. She was a little girl. It sounds awful. I want them stop asking their kids do for them anymore...... I need interpreter very much.Kind regards Susan Merciadri |
| 109 | Elizabeth Dumont | I'm carer for a relative living with Autism. They're not with NDIS yet, transitioning from July 2018.However they have been in receipt of support funding under QLD's Your Life Your Choice since April 1 2014. In that time, thanks to the level of support received they've been able to successfully lose about 45 kgs, have learnt to keep house and are currently engaged in attaining their school leaving certificate.Long term they're looking to run their own small business. All of this has been made possible through access to funding to pay for the supports required that have helped them make the changes in their life.Please ensure that NDIS is properly funded to enable people with disabilities to become fully participating members of civil society - because without suppprts - they can't participate. This is important - people with disabilities have been offered hope for a better future. Please don't take that hope away because the initial cost is too high. |
| 110 | Jane Scott | All the talk about finances and the NDIS seems to be about cost. I haven't seen anything about potential economic benefits. Reducing the load on carers frees some of them to work in paid or better paid jobs as well as potentially improving their mental health. Assisting people to address what they see as their greatest needs more quickly is likely to waste less time and resources. Personally, I plan to use the NDIS to engage people with appropriate knowledge and experience to help me find employment. Four years with government service providers has been useless because they don't have disability experience or recruitment experience. If I am successful as expected, I will pay more tax and contribute more to the economy, as will others with a similar experience. Providing individually targeted services is likely to increase the participation of people with disabilities in the community, which in turn will raise our profile as customers and motivate more businesses beyond NDIS providers to meet our needs. This could lead to a higher level of inclusion which could lead to improved mental health for people with disabilities and those whose lives they share as well as growing the economy. |
| 111 | Richelle Carta | I am a woman with quadriplegia-spinal cord injury since I was 13 yrs old. I am now 40. I am married and a mother of 2 daughters. I work fulltime. I require personal care support every day to help me maintain my busy lifestyle. I was struggling to sustain my lifestyle with very minimal funding but due to the NDIS I can continue to be a wife, mum, work full time and have a life with my family by having ongoing funding to provide me with morning and night personal care support seven days a week. |
| 112 | Julie Vesovic | The NDIS has transformed my life so much as now i will be able to get out a lot more as i have personal care now on a regular basis. NDIS has opened so many different windows for me as in being able to have a input of were my carers come from. I have choices now as before i didnt. It makes a huge difference in my life. Before the NDIS a lot of what i needed to get out and about wasn't funded or not enough funds to cover itI am a person with feelings and want the opportunities that everyone else have to get out and about and just try to normalise my everyday life as I can. NDIS has done this and covered may other areas needed in my life.Thank you NDIS and everyone involvedJulie Vesovic |
| 113 | Karen Angus | Being a Personal Care Worker I have seen clients struggle for years to get only the very basic help. Being in situations where they have no assistance and finding hard to get through each day sometimes with no help or assistance for their basic human needs. I have known of clients who have sat around in wet clothes as they had no funding to allow someone to assist them to go to the toilet. Clients who have dropped plates and broken them while trying to get a basic meal for themselves. Only to find they were stuck because they could not get around the broken plates in their wheelchair. These are basic human rights that these people who struggle with and not allowing assistance is taking away their human rights. The Nids has brought help into the 21st century and needs to be continued. These people with disabilities have a lot to offer the community and with the proper assistance NIDS can get these people back into the community and give their lives the power to do amazing things. |
| 114 | Allison Schultz | After becoming diagnosed with a chronic and auto immune disease my whole life changed at the age of 40! The once fiercely Independent woman who had worked in the health care industry for over 20 years had suddenly became the cared for! As a single mum with 2 Independent children I was doing it tough. I had to give up work and finacially it was tough. Not only did I have that to contend with I was suddenly left with a disease I knew nothing about and no help! I struggled to find any medical specialists within my area and had to travel backwards and forwards to Brisbane. My two daughters had become my carers. Doing the housework, day to day chores, attending to me as I had falls, struggled on days even to get out of bed! I finally got some assistance with home help once a fortnight to clean the house but only in the areas I frequent! I need help some days to dress myself and as of late walking any distance is also limited! I also need to self-catheterise. The amount of catheters supplied through mass and hacc are insufficient for my needs. I am limited to what I can do and exercise is just out of the question. As my illness progresses more ailments and auto immune diseases are added to the list. My brain when not in a fog is very active but the body just cannot do what it wants me to do. I see myself in the future having to be looked after by somebody if and when the girls move on to start their own lives. I will need daily help, walking, bathing and movement assistance and aides. I will need physio and massage. Unfortunately I will progressively worsen and there is no cure beside pain relief. Please we need all the help we can get! |
| 115 | Martin Grillo | I had polio since I was born, and each year it gets hard for my body to cope, due to the polio my body is weak and so I had 2 accidents which has not made my life any easier, where I was able to cope with minor issue now it is not possible without any assistance. The NDIS is going to give me the assistance. ie: careers for the everyday living, modifications so I will be able to live in my own home and a electric wheel chair so I can go down the street and buy some basic items. I need the NDIS funding ASAP and I am waiting for the day that I am granted the funding as at the moment I am stuck at home 80 % of the time which is causing me distress and my anxiety levals are very high. So I am asking the commission if they could speed things up, as apparently I still have to wait as NDIS will not be in my zone for another year and I do not know what to do if it is true that I have to keep waiting So please grant me the NDIS for all of the above reasons Thank you Martin Grillo |
| 116 | Alison Weavers | Our daughter has a very rare genetic condition with no known "syndrome label". As a result she has a permanent intellectual disability and will require support for the rest of her life. We have always paid privately for her therapy and now the NDIS has provided a significant financial contribution to her ongoing support costs. In particular she is able to participate in community and civic organisations such as dance classes and swimming lessons, which we would not have previously considered. There are many children who fall between the gaps of known diagnoses and miss out on so much due to costly speech, physio and occupational therapy sessions. We are grateful for NDIS and hope it continues to receive government and public support. |
| 117 | Ken Bryant | The NDIS, if put in place correctly and in full and whatever the initial cost, will be a saving for future generations.As the initial footprint will make it easier to add or modify at any time in the future.Cheers Ken |
| 118 | Joyce Schroeter | I would like to inform the Commission on how important the NDIS has been to me.I also wish to advise I see what a significant change it is giving people with a disability. They are being given more opportunities than ever before to reach their potential, this has not been obtainable prior to the NDIS.I am an ageing parent with health issue and advocate for my 44 year old daughter and her 20 year old son, both were born with acrodysostosis and intellectual disabilities. Prior to the NDIS they were on waiting lists for supports and it was becoming more stressful for me every day wondering how they would ever manage.They both now have NDIS Plans with goals and aspirations. This is giving them the best opportunity to help with capacity building, build independence and have support to access the community and respite. The support from the NDIS is vital to our family, without this help we would not be able to manage. |
| 119 | Angela Borbelj | NDIS means we can choose private allied health practitioners who have significant experience and provide much more useful and extensive therapy than traditional public system. Support aids the whole family - critical in a single parent family. Supports for extent of socialisation aids at this level didn't exist previously. Innovative aid can be chosen instead of outdated supports. If NDIS were not to continue into the future in the way it currently is, I believe many more people will fall through cracks and end up not socialising and not joining the workforce. Wish: that NDIS could extend to school. Schools do not have the funding needed and students who attract funding don't always receive sufficient supports as they are shared with non-funded students. While schools are expected to provide for learning disorders, autism, ADHD etc, in reality, most teachers don't know what these really involve, let alone understand what individual children need (even at the basic level). We need NDIS for schools to allow parents power to enable innovative practice and support. |
| 120 | Angela Duffy | Hi, I'm Ange, Jessi's mum :) Jessi has severe cerebral palsy and is totally dependant on a wheelchair to move and me (or someone) to do EVERYthing for her.We started on Jessi's NDIS plan in November 2016, timing wasn't great, we are in The Whitsundays so there are not a lot of services available to us and for all of Jessi's life we haven't had much access to any assistance from any government funded schemes.The introduction of the NDIS into Jessi's and our lives has been life changing. Jessi now has access to funding for a support care worker, enriching her life, helping out mine and giving myself and Jessi's Dad much needed time together that has been so scarce ever since she was born.Jessi outgrew her wheelchair early 2016 and we have been waiting and waiting for the NDIS roll out to get a replacement, no-one was willing to assist under the old schemes available, they all told me to wait for the NDIS :( easy for them to say when they are not dealing with an ever growing pre-pubescent child - I am happy to say that within the next few months (fingers crossed) Jessi will have new wheels which will improve her life even more, as she will be comfortable - very important when you spend at least 10 hours a day locked in a chair that you can't just get out of.At first the whole NDIS thing was confusing but I have now taken over the managing of the funds for Jessi's plan and that has made the whole process much easier - especially in this area when Allied Health folk are few and far between, it gives me more control over who I can access if they are not a registered provider with the NDIS.Jessi and myself and of course her Dad are over the moon with the NDIS, yes it had/has teething problems but for us it has been life changing and I'd be devastated for Jessi and other extremely high needs kids/adults to no longer have it and have to go back to the old system of MASS and waiting a year or more for much needed and in face, essential, equipment.Thanks |
| 121 | Sharon James  | Money being wasted I have had 4 months of stress and trying to get home modifications done $6668.15 in OT, Builder $937.50 Plans that are no good No work started. NDIS have approved plans that they had drawn up with scope. I had no input to this. You mention to NDIS the amount of money being wasted and I was told don't worry about the money we can top your portal back up. I think this is wrong when I have a book that I write every entry in so I can see where my money is going and not being wasted. I now have to appeal the plans that are no good through the appeal board for something that should have not been approved. Therefore why should the government give more money stop the NDIS from wasting it. |
| 122 | Nepean Food Services | Through providing meal services at Nepean Food Services, we have seen the improvements that the NDIS has had on individual lives. The ability to provide a support that enable's participants not only with significant health benefits at their convenience, but also the freedom to explore other opportunities as a result, is great to be a part of. To communicate with individuals that finally feel a sense of equality in the world of every day opportunistic possibilities, is how it should be. Freedom to follow one's talent/ interests/ passion & goals, as well as ensuring they receive reasonable care through a scheme that supports their disability to enable them to do so, is right. |
| 123 | Nita Harvey | My nephew has a child with Angleman Syndrome and they need all the support they can get. Particularly as he grows and constantly needs his wheelchairs and other assistanceneeds renewing. They are so strong and supportive of their boy ,things will only get harder as he gets older. The Disability Trust has been very supportive and I would like to see my nephew and his wife have confidence that support will be there in the future |
| 124 | Jill Aitken | My son, Tom, is 34 yrs old and has Down Syndrome. He lives with his ageing parents and like most young people, he dearly wants to live independently of his Mum and Dad. Tom works in open employment 4 mornings per week from 7am - 9.30am. He would like to have more hours but is pleased to have something rather than no work and he loves his job. Tom is lonely and needs the opportunity to develop a fulfilling life with friends his own age.Tom has no personal funding so his wish to live independently is just a dream. The NDIS will provide Tom with the opportunity to achieve some level of independence as well as the chance to develop friendships and a good life that should be available to everyone. |
| 125 | John Coyle | My name is John Coyle and I am a 63 yo widower and the father of three young adults, the two eldest of whom have intellectual disabilities. We had navigated the state based block funding model for disability support for the best part of 20 years and not until the introduction of the NDIS for my children's age bracket in Tasmania has that type of support held any true security into the long term future. The types of supports that have now evolved are far more practical and appropriate going forward dealing with the relative developmental abilities of my children. The funding is targeted and less 'diluted' as it works it's way through a far less bureaucratic system. My eldest daughter has found a placement in fully supported accommodation not far from our home giving her an opportunity for a degree of independence that I couldn't have provided on my own. All this is thanks to the NDIS funding. The support agencies are rationalising their services to better reflect the needs of the individual, giving them a legitimate role in our community, building acceptance not just tolerance. The NDIS represents a consistent, secure standard of living for my children and the estimated 460,000 participants when rolled out nationally. It is indicative of a mature, egalitarian, compassionate first world country that the protection of the most vulnerable members of our society are catered for. I am incredibly grateful and humbled by the creation of the NDIS which affords me peace of mind in knowing that when I can no longer advocate for my children a strong support network is in place to perform that very important, life long commitment. |
| 126 | Sue O'Neill | I live in the City of Moonee Valley in Melbourne.Unfortunately, the NDIS won't roll out in my area till 2019, by which time I'll be 57.I have Spina Bifida & I feel strongly that if someone has had their disability since birth, they should be able to access the NDIS for the rest of their life.I live in my own unit & love going out to sporting events, concerts, theatre etc. At the moment I feel restricted as to how late I can go out, because I have to be assisted into bed.I am hoping the NDIS will allow me freedom to choose carers at times that suit me better.I also sing in choir & we perform at different events throughout Melbourne. I travel in maxi taxis for all of my transport needs & I am hoping the NDIS will relieve the financial difficulties I have while travelling to do the things I love.I hope you will take into consideration the points I have made above |
| 127 | Lynne Bullen | It is discouraging to see initial NDIS plans being provided for children with the same sorts or priorities and wording that is meant for adults. There is great variability in how the plan is written up, depending on which area the family lives, and there is typically little reference to the goals and costings the families discussed with the planner. They think they have been heard and then when they receive the plan, all their preparation and thought feels useless. Families have been told that NDIS will respond to their indivualised needs, but that isn't proving to be the experience for families with young children, leading to many requests for review.The funding is often also unnecessarily inflexible due to the categories the funding has been bundled into. While adults with signficant intellectual or mental disabilities may not be able to manage their own plans, it is disheartening and wasteful that families who are capable of self managing their funding are not being offered this option. If they mention it, they are typically told it is too hard and there seems to be little information and start up support for families who insist on self managing. Often, even when they have asked to self manage, the plan that is provided has neglected to take notice of that, and families have had to chase that up.Just in case, even some families who self manage their funding, have been allocated $4,290.49 for financial intermediary set up costs and fees for a plan manager to manage their plan and a further $2,214,48 for Support coordination by a plan management agency. These costs are creating a heavy middle management layer and lots of waste that could be used to directly support the participant when they have capable families who can self manage their funds. The payment structure for providers is not suited to my mobile service. It doesn't allow travel time under 10 kms. All home visits take extra time. I don't want to charge families different fees. |
| 128 | Kyliedownsbarriers | I am speaking up on behalf of people who have a disability who can't speak for themselves. I'm doing my Business with Pubic Speaking and Art Work, to break down barriers and to achieve what their striving to do. They don't even know how to find families who have their children with any kind of disabilities. And some of them are afraid to speak up for themselves.I have a dream that people with Down Syndrome and Disabilitywill get the help we need to live good lives.Look at our abilities as humans. We want to be treated with respect, I have a dream so we help our communities too. |
| 129 | Karen Bloomberg | I think the NDIS will be useful if I can work out how to activate my plan. There is an assumption that people accessing the scheme will understand the terminology and know the steps involved in making something (anything!!!!) happen. I do not know the difference between a support coordinator, support provider and my plan management agency. So far, I have been waiting over 6 weeks since I received my plan. In the meantime, one of my mobility scooters has broken down and I would like to get it fixed. I went back to the service provider and they said my plan would be escalated - whatever that means, so I am waiting. Being made to wait is not unusual when you have a disability but I had hoped for a little more direction. |
| 130 | Caty Baker | I have 3 children, the youngest two with Autism, ADHD, and General Anxiety Disorder. I found all the preparation useful to get me thinking about what a "good" life could mean for them. I researched what I could, listened to other's stories, and planned what was necessary for that to happen. I found the Planning Meeting to be a little of an anti-climax, not really understanding whether what we put on paper would culminate in the achievement of our goals. I'm still a little unsure, not knowing whether the dollars that were approved will be enough to see us through a year, but I guess that time will tell. Certainly I am very grateful for the NDIS, as this gives us, as a low income family, the means to provide them exactly the therapies that will help them to develop the skills they lack, and the means to expand on the things they love most. Without the NDIS, my children would be getting only the crucial therapies, with nothing left over. Like I said... I am grateful! |
| 131 | Eunjee Kim | NDIS enables (and will enable) my son to have the Positive life experiences that only "normal" children has the previledge to experience. His carer has taken him ice skating, his speech therapist is teaching him how to follow instructions to make a simple meal, his psychologist gives him the trust to talk about how he doesn't like it when his mum and dad gets angry and keeps talking about his "seizures". My son is 13 now - and with the supports he can get through NDIS I know he has a high chance of being more accepted by the society and become a more healthier, contributing and well rounded human being who won't hate the world and the disabilities he lives with. Beyond that - NDIS is improving our family unit as we finally get the breathing space to get our heads out of the world of our disabled son and actually be there for our 2 normal children and even consider the possibility of myself (an IT/business executive) to go back and pick up my career which I had to give up to take up the full time Carer role.NDIS is an enabler of change - a positive social economics and society change which impacts far greater circle of people than the disabled individual alone. |
| 132 | Sonya & StephanieNicolaides | My Daughter Stephi has been on the NDIS for three months now and it has made a dramatic change to her life. She now has the same life opportunities other Australians take for granted. She is able to have regular physio and hydro therapy now, which helps with all her tight muscles. Stephi seems to be a lot happier within herself and able to move a lot easier without much pain. We were able to get ramps to the front and rear of the house, making it very easy to get Stephi in and out of the house in her wheelchair now :)We all have choices now, which makes life so much more easier and bearable. We have the NDIS now please DO NOT let them take it away.Thanks Sonya Nicolaides |
| 133 | Kim Allen  | My son has severe cerebral palsy and is 18, I am about to be introduced to ndis funding in the next year or so and look forward to having more control of how Patrick can benefit from having NDIS. I am hoping that he will be able to have accommodation in the future that would suit him like a shared house and wheelchair friendly modified. I know how much equipment is needed for him to have good quality life, from bath chair to ceiling hoist, to bed sides and wheelchair ramps and vehicle modifications. Its a full time job looking after him and my life needs to be supported too. Accommodation could make the difference we need to balance family life and support Patrick with his life too. |
| 134 | Rosa Miot | The NDIS is crucial to my future.I have a 40 year old daughter with an intellectual disability. I have been her full time carer all of her life.40 years ago I gave up a professional career to devote myself totally to my daughter and enhance her opportunities to live happily in the community and participate in as many social activities as were/are available and access services that would/ will benefit her throughout her life. I still continue to support her to this day.However, I am now 70 years old and I will need the NDIS to provide her with the ongoing supports she will need to be able to remain living in the community as she has done all her life. I would like to be able to concentrate on my own life and health needs and not be overburdened with the caring role. Please ensure the NDIS is fully funded and not leave ageing parents like myself and my husband with the continued daily responsibility we have had to carry for 40 years. She has a right to and deserves the support.My husband and I are worried that the Budgetary uncertainties, that are aired daily through the media, will leave our daughter unfunded. We need to be reassured she will be supported through the NDIS. This is critical.ThankyouRM |
| 135 | Ann Simic | My family has been blessed physically and mentally. I realise how fragile these abilities are. I want all people to have the help they need to achieve their potential. |
| 136 | Grace Chiew | I have a 24 year old daughter with Down Syndrome. We are waiting for the NDIS to roll out in our area. We have put in place the building blocks for her independence and have raised her to be as independent as possible, participating in the social community and contributung back to society via voluntary work. However, we cannot do this alone. We need support to achieve our goals for her to be a full member, contributing to the community she lives in and I see NDIS as a vehicle to help her and us achieve this independence and become an fully integrated member of her community. NDIS gives us hope that she will be able to lead as normal a life as others especially when we, the parents are not around to support her anymore in the future. |
| 137 | Evelyn Ware | My husband and I are 89 and 82 years old respectively and have a daughter aged 55 with autism and intellectual disability. Although living in the community she requires a considerable amount of support with budgeting, health matters, cooking and general management of her life. She receives minimal assistance at present via her ISP but once we are unable to provide the assistance we are now providing she will need to have more support from NDIS, or go into supported accommodation as her disability prevents her from living independently in the community. Her lifestyle is very good now but we are very concerned for the future. |
| 138 | Scott Reid | I am the sole carer of my disabled son who is 26 years old and has a mild to moderate intellectual disability.NDIS will not only focus funding but community awareness for this sector of the Australian community (Sufferers and carers alike) both of which are important elements.As yet we are not directly impacted however my Son's service provider has been proactive in preparation for the full impact of the NDIS.I would like to see standard templates developed for those carers whose responsibility it is to develop plans for the person suffering the disability.In addition I think it is important that as community service providers are engaged via the NDIS that appropriate and stringent accreditation process are developed and implemented.Fundamental aspects including impacts of GST on services being provided should be clarified as some agencies or service providers previously GST exempt under NFP status may be subject to differing tax obligations if their service delivery model changes.I would like to see the NDIS become a catalyst for intelligent accommodation for the disabled community whereby clients of aligned abilities are accommodated within communities that nurture and develop their abilities and provide opportunity for contribution to that community through work opportunities and social contributions -Yarra View nurseries is an excellent example of an employment hub that has become something more than employment alone to a significant community of disabled clients.Establishing models based on those with existing success is an area that should be leveraged by NDIS. |
| 139  | Natalie D'Antonio | As a Developmental Educator supporting young people in Australia meet their life goals, I have concerns about the pressures the NDIS places on service providers. Being a recent graduate, I still require time to develop my professional skills allowing me to provide quality service to my clients. Working within the NDIS framework, I feel pressured to meet goals instantly while sometimes managing unrealistic funding within plans. Where is the support and allowance for new professionals to continue developing and receive the support to do so, when we are also expected to achieve billable hours as evidence of our productivity? I have concerns that working under such restrictions can only be a detriment to the critical work that we are attempting to provide to our clients. |
| 140 | Liza Maloney | Almost 14 years ago our family lost the little girl we thought we had. The beautiful, independent woman that she would grow to be. We hoped that she would be university educated, maybe one day marry and have her own children. Then the devastating diagnoses came 'severe autism'.Today our focus and priorities have changed significantly. We still have our little girl and she is more beautiful than ever, but in many respects she will always be a 'little girl'. She will never live independently, she will never have her own voice. We hope that the NDIS will give her a voice, give us choices, give us a family a life and make our future a brighter one.For a small insight into our lives and the impact our daughter's disability has had on us read the attached story I wrote in 2009. |
| 141 | Michael Mormina | The NDIS has completely forgotten about me. I have registered and attended most gatherings with little to no answers as to how I can be assisted with my everyday living. I have however heard plenty about how the government plan to cut my current services. I am aware of hundreds of other people in the same position. Please do not pat yourselves on the back as there are so many more lost disabled people without any support. NDIS is a pipedream imo... A big nothing... NDIS has never even offered me a drink or food at events.... I had to send my carer out to buy a meal so I could eat. I was not made to feel welcome nor was I encouraged for contributing. They were not interested is the opinions of those who had it together. |
| 142 | Gretchen Young | Just a few points...I don't have a disability, but friends of mine, and children of friends of mine do.If achieving sustainability of the NDIS, in the form originally intended, means that I must sacrifice something of my own very high quality of life, I'm 100% happy to do this - I'm happy to pay higher taxes to achieve this end.To date, not enough is communicated about the financial return to the community arising from the NDIS - rather than the absolute dollar cost of funding services. The current story that is told is not communicating both sides of the ledger.I worry that some individuals/categories of individuals are currently being included in the NDIS who do not necessarily have significant disabilities. However, this population does still need to have access to services appropriat to their needs, rather than becoming the next group of people with significant (but quite different) unmet needs.I worry that support for the NDIS will reduce if implementation problems compromise its reputation. Difficult as it is for people to wait for the services they so desperately need - establishing a high quality service should be prioritised over political expediency in meeting originally agreed deadlines. A well designed and implemented system will also contribute to a more sustainable and economically efficient system. |
| 143 | Tony Wilson | Dear sir /madamOur son Jack has just registered with the NDIS as it rolls out in our suburb of Northcote, and in these early days, we can see how life transformative it will be. Jack has cerebral palsy that affects all four limbs, he cannot walk, he cannot see as a result of cortical vision impairment, he needs regular physio, OT, and speech therapy. The NDIS promises therapy support where Jack was previously missing out, and even a few respite hours for us as his carers. We could cry tears of happiness that there has been bipartisan and community support for the NDIS. Jack has now started mainstream school in prep, and we are hopeful that the NDIS will help him maximise his potential, and become a productive member of this compassionate society that is Australia. Thank you, australian government. Thank you, Australian people. tony and tamsin |
| 144 | Naomi O'Byrne | My daughter, who is 18, and has an intellectual disability, has just been accepted onto the NDIS. She has never had funding before. The NDIS sounds very exciting but we are in the early stages and there have been a few teething problems. My hopes for the NDIS are that my daughter can become independent and participate in activities that others may take for granted. I want her to be able to access the community without me tagging along and for her to be able to enjoy expanding her horizons. She has already begun accessing services that were not available to her before she had the funding. |
| 145 | Lyn McHugh | My daughter is 19 years old and has Down Syndrome. Her first NDIS Plan commenced on 26 Oct last year. Much of it covers the key programs she accessed under the Victorian FFYA funding - her day program. However the NDIS enables us to procure services we would not have considered without it. The key long term goal for my daughter is for her to happily move to supported shared accommodation. In order to achieve this, she has many skills to acquire. My daughter has not proven to be of an independent nature, therefore, she is happy to be waited on, hand and foot, by me. The NDIS has enabled me to procure the services of a personal care worker who is initially accompanying her to her evening activities so my daughter can gain skills and confidence to travel via the taxi system independently. Soon, when a relationship of trust has developed between the PCW & my daughter, we will initiate showering and hair washing. My daughter will be far more likely to seize the initiative and gain determination to do this independently when I am out of the equation. When my daughter gains new skills, she experiences such pride in herself, and learns the benefits of the struggle to achieve more accomplishments.We have a long way to go, but I feel so grateful to Julia Gillard and her government for enabling he NDIS, and subsequent governments for not dismantling it. |
| 146 | Lynette Sie | I think if the NDIS was executed properly, it'd be such an assistance to individuals and families with disability. However, I do have some concerns about it. I met up with a Planner to discuss a plan and goals for my son who has autism. I had put a lot of thought and many hours into this Plan and specified in details what goals we had and outlined the support and funding we would like to support my son to achieve his goals. I submitted this Plan, together with medical and reports from OT & Speech pathologist to our Planner. Despite the effort that was put into the planning meeting and also reports to demonstrate why we requested the funding we did, the Plan that was approved fell short of what we requested and did not seem to take into consideration the goals and support we requested. As a result, I've had to spend time again submitting a Request for Review form which is additional time wasted by both myself and another person who needs to review my appeal. Had my original request for funding been considered thoroughly, this would have been unnecessary. I have also requested Self-Managed for the funds. Whilst the NDIS site has more information and guide targeted towards NDIS funded, I feel there is insufficient information and guidelines on how to approach self-managed funding and I've had to work through things via trial and error. For example, it was explained that for Capital Funding, one needed to upload a request for approval via the My Documents Upload page and obtain approval before being able to proceed with purchasing the resources or equipment for my son. I did this when I wanted to purchase books to teach my son about emotions. I waited about 6 weeks after uploading the document from my OT for someone in NDIS to approve this request, only to get a call from my Planner (after emailing him to understand if it was normal to wait that long) that for self-managed, approval wasn't necessary. So it would be good if more guidelines for self-managed.. |
| 147 | Shaun Rowlands | Hopefully become more independent. Learn to tidy my own room. Catch public transport to the cinemas and shopping centres. Find an apartment for myself to live in. Find a girlfriend and fall in love and maybe live with her further down the track. I would love to live in a suburb and start my own family. Learn to do my own dishes and ironing and make my own bed. Housework and budgeting. Paying the bills. |
| 148 | Carla Ryan | My son is a 12 year old that has Autism . He was given one on one time on the weekend with a career. You would think wow great but not really. Because his outing are costing between $25 to $40 a week depending on the activitys they do. As I have to pay the entire to pool or other entertainment for my son and the career.I now find myself say that if movie comes to the cinema or I would like to get him a treat that its being held off until he goes with his career. Due to this add cost . I'm a single mum and I don't work full time .im paying off our home . So when it's $80.00 a month that can be hard to find as there is no support payment for this . Also now that my son has been getting the one on one support he doesn't want to go to group care as the younger child often bite and scratch him. So if I don't pay this money💰. there will be a end to rest for me except his school hours . |
| 149 | Bryan West | I have three disabled children I care for accessing the NDIS.Positives have been life changing. My 10yo with CP and ASD has overcome a lot of severe anxiety, mobility issues and Encopresis. Without NDIS support we would not have achieved these results.Our 12yo is intellectually impaired and has ASD and epilepsy. She is hard work and has to be watched 24/7 leading to sleep deprivation and stress health issues in my wife and I. The NDIS has meant we can have access to respite. This has been a blessing. Once a month, my wife and I have been able to be a couple again and be 'normal'.Our 20yo has been able to access desperately need support from professionals outside of our meagre budget as carers. It is too early to see much progress yet, but we now have supports to help him have a far better quality of life.Sadly there have been some negatives. We chose to go with financial intermediary to reduce the stress burden, as we have both suffered health problems from the stresses of long term caring. The agency stopped doing financial case management six months in to the process, which caused a setback. We signed up for another agency only for them to stop doing it as well. Now we have had to find a third. In the meantime all support work has ceased as we sort it out. In my city, we went from a dozen options to one. Instead of a decrease of stress and work load, the process has added more stress and difficulties, like running out of incontinence aids.Some of the decisions made by the NDIA are frustrating. An example, therapists recommended my 10yo use communication software and ipad, cost of about $1000. We were told no, as she could play games on an ipad. We then suggested to just help with the software, no. NDIA recommended a wheelchair fixed communication device costing $7000. Our 10yo uses a walker for short excursions, this expensive option meant she would be wheel chair bound instead of encouraging her mobility. NDIA can be very slow and confusing |
| 150 | Mary Viney | NDIS may be a means of assisting me to take much of the burden off my family. Three years ago if fell, fractured my tibia, splintered the lower tibia into my ankle and foot. Instead of an 8 week healing time and regular physio I am at a standstill. In fact I suffer (like today) ongoing problems with walking and chronic pain. Pain Medication causes other problems like bowel & bladder control. My life is not the same and I cannot walk anywhere. I can only drive short distances and thanks to ACROD can park near and use a walker or walking stick with a trolley to get into shops. |
| 151 | Leila Barreto | I am concerned that those with a psycho-social disability will miss out. I am also concerned that services will compete with each other so secure funds at the expense of clients in need. I am also concerned that mental health services will loose funding because of the new funding structure which will lead to worse outcomes for those struggling to recover from their illness for example will there still be Day to Day living programs? Some people on DSP have been knocked back for a package. Some need home support immediately and cant get it because they had no existing supports and there are waiting lists because of the transition.The Federal Government says its committed to continuing to provide support for people not eligible for the NDIS, but what does this actually mean in service terms for mental health consumers? |
| 152 | Jenelle Wells | I am fortunate enough to see the benefits of NDIS as I have my son as a participant and I also work within the Disability Sector. My greatest concern is the ongoing viability of the scheme for taxpayers into the future. I have seen cases where participants were funded by State Government for a fraction of the cost they are now funded under NDIS. I'm aware of a case where a participant who was previously funded for $500,000 is now funded at greater than $1 million. This is not a one off case and concerns me as a tax payer greatly. If this continues the scheme will become a significant burden on tax payers and Government into the future. |
| 153 | Ana Guterres | On behalf of my 15 old son Tony with high level of needs and severe disability physical and intellectual, I would like to express my view about NDIS transition and NDIS operational system which impact on the participant and family members well-being. In my son's case, it has negative impact in terms of his safety, life risks and psychologically on other family members. I am thankful on my son's package that he is already using but follow up work and submissions that we need feedback from NDIA team are not resolved. I am struggling to find out right support to achieve the best outcome for Tony. My son's support coordinator is not getting respond from line NDIA support planner. My urgent priority is major home modification as part of Tony's NDIS goals which includes conversion of the garage and laundry into accessible bedroom and bathroom is not resolved yet and I am still waiting on NDIS funding approval. I submitted two major mods plans and quotes requested by NDIA support planner longer than month ago so I need your help if you can make a difference to my son's case. I am stressed, I can not manage my household duties and my son is suffering due to unresolved major home modification on daily basis which puts his life under risk. In my opinion, NDIS do not care about risks or crisis of the individual and made their internal procedures to lengthy and difficult on participants because the outcome of the requested assistance can impact further on the participant's health and safety. I do understand that NDIS is not funding peg feeding formulas and it needs to come from the parent's packet but you have to be aware that formulas price has increased since you introduced the NDIS in SW Sydney from private provides which it should be discussed with appropriate bodies. I believe, peg food needs to be funded in some level as this is special nutrition and it is not classified as normal food. I am happy to talk more in details about my NDIS unpleasant experiences. |
| 154 | Kerrie Newton | Since starting my NDIS plan 6 months ago my life has changed considerably.I have a chronic degenerative illness- Primary Progressive Multiple Sclerosis, which prevents me from doing most normal activities. I am in a wheelchair permanently and my hands, along with other things are also affected. I have always relied on my husband & two boys to do all washing, chores, cooking, gardening, helping me dress & shower. My NDIS plan has given me funding for someone to come into the home to help. This has taken an enormous amount of pressure off my family so they can live a more normal life. I also received some transport funding and for the first time in four years I have been able to leave the house independently.I am feeling more positive about my future. |
| 155 | Mereana Gordon | Hi, My son Flynn is a happy, boisterous and loving 9 year old boy who goes to school, loves watching footy and has family and friends who adore him. He also doesn't talk, doesn't walk, and requires assistance with every facet of everyday life. He has CP, microcephaly and suffers from seizures. Our lives are filled with appointments with doctors and specialists and together we come up with plans to look after him and equipment to support that. We also haven't had any funding since he turned seven. Today my family and I want to remind the decision makers of Australia that we matter. We voted our government in and entrusted to you the care and wellbeing of all Australians including our loved ones with a disability. Please don't just look at numbers when taking on this job. Look at the people of our great country who are doing it tough. Help us to look after our most vulnerable. The NDIS will do that for us. It will mean not having to go without speech pathology sessions because they cost too much, it means he might be able to join a team sport with someone to assist him in participating and make friends, it means hydrotherapy sessions to keep his joints in good working order. These are just some of the things that the NDIS will provide. It will also relieve families of incredible stress and financial hardship. When doing your job please spare a thought for my son because he's only advocate is us and he deserves more. Thank you |
| 156 | Robert Jacobson | My daughter is aged 29. She has autism and intellectual disability.She has been on the Disability Support Register (Victorian Department of Health and Human Services) for 5 years, waiting for shared, supported accommodation.At home she needs 24/7 supervision, is incontinent, has behavioural problems, and can be very demanding.My wife and I are in our mid-sixties, and have had one holiday without her since her birth. We both have deteriorating physical health issues, and shared, supported accommodation is urgently needed.We hope that the NDIS can enable both ourselves and my daughter a reasonable quality of life in the near future, by providing safe accommodation in a caring environment. |
| 157 | Kim Coleman | I am about to start using NDIS funding for my daughter but I am extremely disappointed with our outcome. My daughter currently attends a school that have a therapy team on site that are employed through NSW Health. With the introduction of the NDIS I have been told my daughter is no longer allowed to access their services as they are not a NDIS provider. Besides being extremely convenient this therapy team is the best and most experienced team I have come across. They have worked closely with my daughter over the last 4 years and provided such invaluable support. Without them my daughter would not be where she is today. Each and every day they go above and beyond for my daughter as well as other students at the school. NDIS is supposed to be about choice but it has taken my choice away. The only therapy team I want to use for my daughter and it's been taken away. Now I must source alternate therapy which means extra travel time, more time off school, extra work coordinating appointments and building trust with new therapists. And on top of that every year I have to go through the whole process of applying for funding again and trying to work out a year in advance of what my daughter needs. And yes apparently we can amend our plans if something changes but the wait time is 3 months at the moment. Too bad if we needed something urgently. |
| 158 | Cobie Smith | I feel that the NDIS will be important for our family as it will allow us to make individualised decisions based on Jakob's needs.I'm hopeful that we will be able to make informed decisions about the type of care/assistance Jakob will require and be able to allocate the appropriate funds to allow him to access that assistance. |
| 159 | Elizabeth Coe | Whilst I am delighted with the fundamental premises of NDIS, the information has been short on detail, and long on lofty aspirations.My son works in a ADE; the cut-off when someone is moved on to NDIS is immediate (that day). But he is [due to his postcode] not scheduled for moving to NDIS for nearly 2 years. How is the ADE to manage when the money comes through at a different rate than the shutoff. it is not seamless, and is causing considerable angst. This action alone risks putting people out of employment and at greater harm.A letter to each individual with step by step instructions is vital, rather than having to trawl through the endless web pages. I work full time, and despite being used to ICT, I find the website complex. How would my son with his intellectual disability manage! ? Also, feedback we are getting is DO NOT DO A TELEPHONE INTERVIEW as it will disadvantage the person on the NDIS, due to it being cursory and "box-ticky." Why would any intelligent person think that a telephone interview would form a sound basis for a first and final appraisal. I have 8 (eight) lever arch folders for my son - school reports, medical reports, Centrelink information, and his disability only has 3 comorbidities! A telephone call should only be used to set up a person to person interview.Is there any way the process can be sped up? the long gestation period is unsettling for many, especially for elderly parents, and a further review will only lengthen that gestation period and muddy the waters. |
| 160 | Catherine McDonald | The NDIS will mean choice for my son. Josh is now 25, he wants to live out of home. Current services are not able to help him learn the skills he needs to do this, as this is not available to him through the funding he currently has access to.The NDIS will allow Josh to experience a greater level of independence while still having access to the support he will require to live the life he wants to live. |
| 161 | Scott Peeler | After 32 years I Moved into shared supported accomodation..I do not have enough money in my package to cover the accommodation therefore have to pay a carer each week out of my pension which leaves me short of money. My mum comes over and I rely on a friend to come over occasionly NDIS I hope will fix this and I can get outta the house more often |
| 162 | Frank Filardo | An individuals story.The individual totally believes the NDIS is the best program ever; viewed from his previous inability to access block funded services to any acceptable level.The individual's current supports were withdrawn from the 30/06/16The participant is provided with a standard NDIS phone interview "Question and answer" in July. This is followed with a standard Plan. (04/Sep/16 $48000)The Planner doesn't take into account the Participant's multiple and complex needs.A plan review is submitted within two days. No Plan Review was provided until Feb/17 (Six (6) months). Also no services were provided during this time even though the Participant had $48000 allocated in his plan. (6 months at $4000/month = $24000. Not one single cent was used)A revised Plan was issued on the 27/02/17 (27/02/17 $65000)The story is that the Participant was Not provided with any services from the 30/06/16 even though a Support Coordinator service agreement was signed within three weeks of Plan acceptance.A Support Coordinator's Service Agreement was signed on the 14/03/17.Now, it took fourteen (14) days to set up an appointment and sign an agreement (without which one can Not access support services).It has taken another fourteen(14) days to arrange a time with the support coordinator,that takes us to the 27/03/17. Still no support services arranged or accessed.That is, one month at $5400/month + $24000 = Totalling $29400 of NDIS unspent support services funding due to the NDIA created Barriers and the Participant inability to access his funds. The unanswered question is:- "What happens to this Participant's unspent funding?" The NDIS Participant's creed of "Independent, Choice and Control".Where is it? |
| 163 | Jared Warden | I'm an individual born with moderate deafness which became profound at the age of 3 with a fever.I also was diagnosed with Asperger syndrome.I've had many issues in life but mostly got into trouble because I was struggling with a wold I didn't understand.Now I've made some headway and now 36 years old, I'll list my issues and where the NDIS would have helped me.My deafness and the devices supposed to assist hearing are limited. Especially words on audio. Having funding for designing and providing an app and working with the Siemens hearing provider to make Bluetooth connection for iPhone ( and others) to play directly rather than a middle device with extra business of charging and cables and all.With my disability( knock out the dis) many others like Albert Einstein , Marie curie, bill gates e.t.c i long for personal one on one support to fast track my ideas for concepts that would benefit the community , government and the disabled. Cut the delays as I've been waiting forever and its almost to the point of torture. What might have been had i have the support i have longed for and now I am doing everything myself which is lagging and almost painful. Someone has to answer for this because while I was on my adult lifestyle package it was still limited on what it could do.What might have been had I had the NDIS support back then?? I would have had my dreams realized and others with a disability working with me and enjoying a safe workplace job sharing their talent improving things for the community.I hope this statement will open doors and fast track the urgency and flexibility for assistance.Many thanksJared. |
| 164 | Nillumbik/Banyule Dyslexia Support Group | Dyslexia is recognized under the Disability Act, however, dyslexic children don’t receive funding for specialized literacy teachers to help them. Why is that? So many dyslexic children are struggling at school which is impacting on their mental health with self-esteem issues, depression and anxiety. If these children receive early evidenced based literacy intervention they will have a greater chance of becoming tax paying employable adults instead of being dependent on welfare, mental health services, or spending time in jail. Having access to one on one support by a specialist teacher who is trained in dyslexia (evidence based literacy program) is critical for the learning needs of dyslexic children. All classroom teachers need extra training in how to recognise, support and accommodate dyslexic students. However even with the extra training, classroom teachers can’t provide the intensive one on one support dyslexic children require. No matter how experienced the classroom teacher is or which literacy program is implemented in the classroom, students with dyslexia require one on one or small group evidence based literacy intervention.Individual funding for dyslexic children is urgently needed so they can have access to the above specialist teachers. The majority of schools in our local area do not have specialized literacy intervention teachers. The schools do not receive enough funding to employ these teachers. Many parents are paying thousands of dollars to have their children privately assessed and tutored. The majority of parents, however, cannot afford private assessments or tuition therefore their children have no access to intervention. All students have the basic human right to learn how to read and write and they are being discriminated against if they don’t have access to intervention. |
| 165 | Keith Nutton | So far very little being the dept of child safety are extremely secretive about what is going to happen. in our area. |
| 166 | Elizabeth Zemanek | The NDIS does not work for families outside main towns. The travel time that clients are charge for specialists to travel to town like Gloucester uses most of the funding. We don;t have any NDIS therapists in Gloucester that families can use. Most of the families are low socio-economic and do not under stand how the system works and how they can get help. Our closest NDIS provider is in Taree. 1 hour drive away. When I have sent a referral form to Early Connections- Manning & Great Lakes their reply is “At this point we have only been planning for existing clients (those previously deemed eligible through their enrolment with an ADHC funded service). We are only able to plan for children who come through on an "access approved" list from NDIA and are waiting for further lists to come.”I have a family who has come to Gloucester from Sydney with NDIS approval already and they can't get any support. They can't use free Hunter New England Health service and their therapist as they have NDIS approval and the private speech therapist in town has not applied for NDIS approval. This family has had not support for the 3 months since they moved to Gloucester.We have a second child that has NDIS funding. She has an OT and Speech therapist that travel up from Mailtand. It takes them 1hr 40 to travel one way. They stay for ½ at the service together. Some of this time is spent talking to the child’s teacher. So she is getting about 15 to minutes for support. It is been charges out for 3 ½ hours of time. Plus anytime they take to write a report. The system was not working before NDIS and it is even harder now. |
| 167 | Tim Prowse | At SACARE we support the intent and goals of the NDIS fully. We are committed to client choice, independence and control. We operate in South Australia and provide in-home care and supported accommodation to people with a disability and in our accommodation we focus on providing support for those with high and complex needs.All our homes are of the highest quality with many family and friends, support workers and other stakeholders commenting how the homes are better than their own. Our philosophy is that if wouldn't live in it why would we expect our client to.Our concern with the NDIS is around the perceived productivity saving that can be made when moving from living arrangements for 2 persons shared to 3 persons shared and so on. For standard needs clients the price drops by 17% from 2 to 3 and then 22.5% from 3 to 4 persons. In our experience productivity gains of 39.5% are not achieved when moving from 2 to 4 people. For Higher Needs clients the drop in price to move from 2 to 4 persons is 31%. Once again this is not reflective of our experience. We believe that what this pricing arrangement will do is remove existing stock from the market and make those who live in these facilities face unnecessary worry about where they will live and move to. We understand the intent of the pricing guidelines is to remove large facilities and promote the integration of individuals into the community but we don't believe that the way existing high quality housing for those with complex and high support needs is being recognised for what it is.As an extra point we have just opened two new housing opportunities for those with a disability. One has 9 individual bedroom suites in the one house and the other consists of 5 time 2 bedroom townhouses. We have shown all prospective clients through both opportunities and 75% have chosen the 9 bedroom facility as their preferred option. This is not in line with the philosophies of the NDIS. |
| 168 | Angela Blakston | My son, Gabriel Blakston, is a part of the Barwon test site for the NDIS. We are thankful for the services and other support Gabe has received. What the NDIS means for disability and quality of life is incredible! I would LOVE to see the NDIS in a situation where it is sustainable. I don't believe the system is sustainable or efficient in its current form. I believe the NDIA Barwon site initially covered too large a test group and the scheme is now being rolled out too quickly, before the system has been properly bedded down. As a result, the NDIS has quickly become unwieldy and inefficient. It also appears there are now not enough NDIS staff to properly service the scheme and, as a result, there are myriad systemic inefficiencies. As a client, the NDIS seems to have quickly become complicated and onerous. SUGGESTION: I would like the NDIS to improve in its transparency and the way it communicates the scheme and its procedures to clients. The NDIS seems to change its funding guidelines and definitions every month. It's like shifting sand for clients so that they never feel they get a firm grip on how the scheme works. Unless you seek out the information yourself, clients are given no real indication of how to prepare for a plan meeting or what to expect in a meeting. Importantly, they are not given a clear and realistic expectation of what they might be entitled to under the scheme. It's made even harder for the fact that the client portal has often been down or funding information on it meaningless. And with not enough NDIS staff, it's difficult to get questions answered or issues resolved in efficient time. SUGGESTION: There needs to be much more focus on communicating clearly and simply with clients. For instance, at the moment, plans are vague and written in "government speak". If the government is concerned about clients overspending, the NDIS needs to give clients clear information on what their funding is for and clear conditions under which it can be spent. |
| 169 | Ann Lorenz | HelloI am on a disability pension due to epilepsy, depression and anxiety. At present I have to cope with cost of private health insurance plus ancillary benefits to be able to get some money back from my vitamin compound. My overall Pharmacy, Vitamin Compounds and other vitamins all prescribed are most expensive.I made contact with the government some years ago without any luck or consideration re pharmacy and vitamin expenses. The Safety Net has increased so much that I never reach it to be able to benefit from it plus this excludes my vitamin compound. I was told some years ago that as a single person one has to reach the same amount as a family to reach the Safety Net. I apologise if I am incorrect.Please HELP those who are more needy than myself a voice. I personally would like this paragraph put first as I want those who don't have any-one to complete this submission, parents of intellectually challenged adult children who are probably too tired to be filling in things like this, those who cannot because of their disabity (ies) and people who cannot use computers or don't have access to one. PLEASE LISTEN to these clients and/or families.Kind regardsAnn |
| 170 | Beryl Power | My eldest son had severe cognitive disabilities, was non-verbal and profoundly blind. He passed away at age 54 having lived in supported accommodation from age 6 after he was expelled from the Blind Institute School as 'ineducable', even though he was a day pupil. Neither was there any day support service then for children with intellectual disabilities that had adequate resources for him, simply because he could not independently feed and/or toilet himself. Had such a place been available, it would have been possible for him to remain with his family, as he and his family wanted. Geoffrey had two younger brothers one of whom also had special needs.Individual day support did not become available to him until he was 40. Up to then he and others with very high support needs - especially communication deficits, received significantly less developmental support than other individuals. For the next 8 years, 18 different 'individual support' workers came and went because they did not know how to help him, due to their inadequate training. Then when he was 48, he was finally lucky enough that the right person came along for his individual support, formed a relationship with him and transformed his life for the next 6 years, during which he was the most contented he had ever been.For 42 of his 54 years he was frustrated by being unable to communicate, due to both inappropriate and inadequate levels of developmental activities resulting in sensory deprivation leading to self harm.He shouldn't have had to wait until he was 48 to receive the meaningful support he needed. The NDIS is the most encouraging development I have seen in 50 plus years, which I believe has the potential for children with multiple and severe disabilities to get appropriate and on-going developmental support from the earliest age possible.People like my son have been the hidden consequences of ignorant outmoded beliefs that 'nothing can be done for him' when the reality is the opposite. |
| 171 | Melinda Patten | We have a 17 year old son that has a rare syndrome, life for him and us as a family has been hard but, get through each day as it comes. Our son is in a manual wheelchair he is hearing and vision loss and has a cleft pallet, heart condition, fed by specialised formula, is incontinent, physical and intellectual disabled and requires assistance with everything.The NDIS will hopefully make a huge difference to our family, at present the NSW Government does NOT fund specialised formula therefore, it is up to us to pay for all his formula that he needs to meet his daily nutritional requirements. It is a huge cost on top of his medications, continence products, Dr & Specialist visits, stimulation toys and equipment ,specialised clothing needed and many more things.We hope for our son to have a happy fulfilled life whilst he is with us still, as life expectancy for him is unknown. I would love to be able to have his specialised formula paid for by the NDIS and not have the worry of trying to find the money for it or ask a Charity that I shouldn't have too. Its not right or fair or healthy to be worried about this constantly. Our son will need a wheelchair in the next 6 months, I don't want to have to wait around for funding to become available again. If he has no wheelchair that means NO School or NO Social outings.Our son will need therapist, Peadetricans, Specialist, Drs so on, the list continues and will not stop. Our son will need a specialised bed, he has a hoist, he needs help with all transfers and there will be a day he needs another hoist and other equipment as he grows. My husband and myself have bad injuries due to lifting our Son over the years, we have a 13 year old son also that needs his time with us and to be able to go somewhere with just us and for his Brother to access Respite that is an highly Important part of our life to give to our other Son who has missed out on a lot. We want to be happy and enjoy life and be properly supported. |
| 172 | Mick McIntyre | Hi Productivity Commission,My interest at the moment is how is the NDIS going to work for my clients with a disability / and my secondary interest is as a client of Disability SA.Currently we are having fortnightly updates on how to prepare for the adults in Disability SA, are going to be migrated over to the NDIS.We were informed last week about the Cos Scheme, or Continuity of Support, for clients who are turning 65 years of age or are about to turn 65. My question is the Cos Scheme going to be dated, as in will it start in April 2018 or before, and finish sometime in 2019, when all adults with a disability in South Australia, will have been m9grated to the NDIS.I also believe that clients who are 65 and over, if they need more than $8,000.00 extra funding for support, equipment and therapy, to continue to live in the community, this will disadvantage clients who have a greater need for support, yet would like to continue to live in the community. That is all at this time, although on a personal note, I am a paraplegic and have been in a wheelchair for all of my personal mobility, and have been for the last 39 years and would like to continue to compete in the Australian Sprint Canoe events in Australia, well into my seventies ; at this moment I am 62. Thankyou. |
| 173 | Charmaine Rendell | On my own for 23 yrs raised 3 children as well pus held my career ups ,but never good enough for the dept of housing on their list 23 yrs.due to a break down at work from bulling etc ive had a break down in the last 3 yrs.body week mind boarded feel worth less do not want to see people plus do not have extra $ to go out i pay 700 f/n.Having know one around me as in family or friends it becomes very hard on your mental health thank goodness for programs like ndis nova especially when there is know family or friends willing to help.Learning how to live with out the kids has been hard but having that person come from ndis who knows you can lift that sadness bring out happy memories and work round how to be busy etc full back into memory sadness looking forward to being part of the program as my needs for the body pain are the hydro pool acupuncture physio more counseling sessions.Obliged |
| 174 | Laurel Lambert | My adult daughter & her friend have benefited greatly from the funding received via the NDIS. It has enabled both women to study for capacity tests linked to contracts connected to home ownership, They are now firmly ensconced in the home of their choosing, paying their mortgage & becoming responsible home owners, This is with great thanks to the continuity of support they receive from a great team of staff. Her friend has also managed to acquire a position in open employment. This means both are economically productive women. These results have seen both ladies relying less on Centrelink benefits & a total absence of reliance on the housing market. Such an outcome can only be described as pretty darned amazing given their intellectual & other disabilities. |
| 175 | Nihal Iscel | I am blind and need some supports to fill the disability gap so that I can live an ordinary life. I believe for the first time in our lives, through the National Disability Insurance Scheme (NDIS) we will get an opportunity to get our specific individual needs met. NDIS is not available in my area yet and I don't receive much supports. I live independently and would love some help with going shopping and getting the things from the shelves that I need. It would be so good to have someone to come once or twice in a year to help me with my gardening. I clean my own unit but I would really like someone to come and do some cleaning for me maybe once a fortnight to see the stains and whatever dirt I might have missed and clean it for me. I don't want to continuously depend on my parents to get supports as they are getting too old and need supports themselves. NDIS is a revolution in our lives to get the appropriate supports so that we can get out there and get a job and work; live independently with the right supports; have an ordinary life rather than to grovel to the service providers to get supports. I would love to have the control of managing my own supports and services and choosing which provider would be most appropriate to meet my support needs. However we need to get the NDIS right from the beginning. NDIS must not become a political football where we are again forced to grovel to prove that my need is much greater than someone else who is also totally blind to get supports. There needs to be a bipartisan support for it. NDIS needs to be based on a human rights model; should not be dependent on the discression of the service provider - on their pity or charity. Unfortunately, living in Western Australia, that choice and control have been taken from us and given to the service providers. We are again forced to continue with the broken old charity based WA disability scheme where we'll be worse off than all of our peers living in the other states. |

### Brief submissions provided to the study directly

| **Brief Submission**  | **Submitter Details** | **Submission** |
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| 176 (numbering continues from above) | Stephen Grey | The issues paper, most notably the section on experience to date, seems to make no mention of the responses to the trials of end users and their carers. No doubt this has been surveyed in some way. It is almost certainly a very complex matter, not merely multifaceted and complicated. Without some sense of target outcomes and the relationship of quality to cost, any areas of uncertainty in the costs that have a bearing on quality are likely to be forecast optimistically in favour of low cost and build in risks for quality and end user satisfaction. A study of costs in isolation is unsatisfactory. |
| 177 | Rebecca Hartley | Livecare Australia is an emerging leader in healthcare innovation. Founder by Doctors. Our mission is to deliver high quality healthcare to patients at home. Our platform allows patients to record their personal health information with essential healthcare devices, such as thermometers, stethoscopes, blood pressure monitors and glucometers, which is shared with clinicians for remote diagnosis. Together with our JV partners CliniCLoud and Jayex, we aim to deliver a self-sustaining telemedicine program which incorporates essential peripherals and medication delivery systems that align with practitioners’ vision in creating a better, sustainable health care system. We will provide a fully integrated PHR and/or EMR, which enables data collection to improve health delivery and provide timely and accurate diagnosis and treatment. We believe this program could deliver significant cost savings to Australia’s healthcare system through optimising healthcare resources and a dramatic impact on the wellbeing of those living with chronic diseases and disabilities.Our proposal is to provide all paticipants of NDIS with relevant devices and a telehealth platform through their chronic and complex conditions can be tracked, measured and remotely managed. Data will be stored with medical grade security to a PHR by the patient and transfered to an EMR by the clinician. Our platform provides participants with a user-friendly turnkey system that is easily integrated to all the protocols. This will improve the ability to answer the demands of the program by its administrators and will save travel stress, time and money to all the participants . According to a 2013 Study\* (IJTAHC), telehealth for chronic disease can lead to large reductions in hospitalisations, hospital stay and emergency room visits, resulting in an overall net gain of 41% relative to traditional home care. |
| 178 | Lorraine Tydeman | I am a widowed mother of a 35 year son with an intellectual disability getting ready for NDIS 1 July 2017. I live in Wauchope and my son attends a day program in Port Macquarie. They have vans that currently that currently pick up clients and they cover a large rural area to pick up clients. We have been informed that due to the funding change this is going to stop unless they can find away to subsidise the vehicles. And we have found reluctance by taxis to travel long distances as their argument is if they hit a kangaroo their vehicle can be damaged and they lose their business...As people living in the cities have a variety of ways to travel but in the rural areas with people living on properties it is different way of life. I have a friend with a disabled child and she is 12 kilometres from a main road. With the pickup she just has to bring the child to main road and then she is picked up by one of the vans of the service provider. My son is incapable of catching public transport, in the past we have tried. The NDIS is great in some areas but has left a big black hole for ageing parents esp those in the over 70's group who still have their children living with them |
| 179 | Quang Nguyen | I am with the N D I S and plan my own supports through e-mail. I am involved in a large variety of activities including being on multiple boards including Diversity and Disability Alliance, Multicultural Disability Advocacy Centre (MDAA), Centre for Intellectual Disability (CID) fundraising, wheelie perfect team, toastmasters, wheelchair sports, presenting in the community about transport, confidence and the N D I S. I have a team of people working with me including a co-ordinator from Plan Management Partners a co presenter from Think Act Achieve and staff from Better Caring and Hire Up, which includes some family and friends. This is because I want to get the right staff members who are helping me with the right things. I am able to communicate what I want and book appointments. I have assistance to coordinate supports I what and I have had training to learn how to self-manage in the future. I tried self-managed and I want to learn more over the next 2 to 3 years, for now I am using plan management to help with payment of staff. In the future I would love to continue speaking up for the presentations and speeches. I would like to give them to share with other people about my experiences. I would like to be speaking up to Sydney, Perth, Brisbane, Hobart, Darwin, Melbourne, Adelaide and Canberra for my presentations and speeches. Please fix: More funding for transport Make the change to NDIA easier Make communication NDIA easier Staff members who are working on the something that could be easy for them e.g. the answer of the questions |
| 180 | Angie Trewhella | All but one of my Service Providers are hiking up their standard prices by $40-$90 per hour in some instances because "the NDIS says we can". This is a real problem that affects clients because: A) they're not getting any more service for the increased price B) it reduces the hours they will get (hours that were decided upon based on invoices for evidence pre-NDIS) C) It reduces the sustainability of the plan as clients ask for more money to have the same amount of hours they used to have. I don't have any solutions, but this does need to be addressed because most SP's are seeing it as free game and there's not enough choice out there to avoid the people who are charging the most! |
| 181 | Duncan Bayly | I've only been accepted into the NDIS for a month and while I deeply appreciate the extra funding, I do miss the flexibility of my old ISP from the Victorian government. By providing cash to me directly, I had plenty of incentive to squeeze as much value from the funds as possible. For instance, I could negotiate better rates with suppliers in exchange for managing my roster, or redirect funds as needed to cover repairs or extra services without seeking permission (of course, as long as they met the goals in my plan and the restrictions of the program). I have found the NDIS's system stifling, with all payments coming via the portal and that disengages me, resulting in less hunt for value in the services I acquire. I would like to see an option for greater control and authority for participants over the money we are allocated. I believe that will result in better outcomes for participants at potentially lower costs for the NDIA. |
| 182 | Gary Blaschke  | The NDIS was originally a great idea which had little chance of not going off the rails. The Productivity Commission said that it would cater for 400,000 Australian's with a profound disability, yet in Australia we have 4.4 million with a disability. Who receives support , who doesn't and what are the hidden impacts, are all issues that are being discovered as the system is rolled out. Genuine respite organisations have been effectively left out of the equation and some organisations are starting to suffer financially, as they now need to deal with individuals instead of organisations as a whole. I feel the whole exercise has become an opportunity for entrepreneurs to infiltrate a system for financial gain to the detriment of long term and existing providers to the disabled. I had reservations when I had a face to face with Jenny Maclin MP in the early stages and nothing has changed. |