

# OUR NDIS JOURNEY

This article was written by Natalie Malcolmson from BPD Awareness ACT on her and her husband Todd's experience with the NDIS: the process he went through for being approved under the NDIS and how they have successfully used his NDIS Package to improve both of their lives. BPD Awareness ACT provides Peer Support and Mentoring for people with BPD and their loved ones. They also provide information, resources and awareness raising seminars on BPD and Dialectical Behaviour Therapy (DBT). Natalie can be contacted via email on [bpdawarenessact@gmail.com](mailto:bpdawarenessact@gmail.com).

## **SUMMARY**

This article details the NDIS Journey of Todd and I. Todd has struggled with mental illness from childhood. He has a diagnosis of Borderline Personality Disorder, Anxiety, Depression, Bi Polar2 and PTSD. He has tried for many years to get well but has never been able to access the right services to meet his needs. Too often services would put him in the "too hard basket" and withdraw services.

In January this year he was granted an NDIS Package. Being able to be in control of the services you use has empowered Todd and he has been able to put the supports in place that he needs to get well, and life for both of us is improving. It has saved his life having the best supports tailored for his needs. Things are still up and down, but the breaks in between episodes are getting longer and are less intense, he is engaging in the community and is developing a sense of accomplishment and his self-confidence is slowly improving. We decided to write our story together as we felt it was important to help others in their journey. Applying for the NDIS is not easy when you have a psychosocial disability and face a rather invalidating, frustrating and traumatic experience. It can be hard, but get the support you can, let any counsellors know you are going through this process and ask them to support you.

The process wasn't easy and was back and forth at first, which was frustrating. We contacted the NDIA and had the first lot of forms sent out. We considered the questions and answered them ourselves before we made an appointment with our Doctor (GP) who Todd had seen a long time and who has been a constant in the management of Todd's psychosocial disability, he understands the impact on both Todd's and mine lives. We did the same process again when the NDIA sent us another form for further evidence, thankfully our GP has always given Todd and I valuable support, he understands and is non-judgemental and very compassionate. He has always done the best he could for Todd despite his complex needs. Finally, Todd was accepted on the NDIS and the Case Manager made an appointment to meet with both Todd and I. She was compassionate and empathetic at the assessment meeting. She asked questions on what Todd's life was like day to day and also mine as his wife and carer. She asked him to tell her what the last 30 days had been like. It had been a tough time for Todd with hospital admissions after suicide attempts and also self harm incidents. He had withdrawn from the wider world and struggled to stay alive each day. She asked him what supports would assist both of us and make life living with his psychosocial disability better. She asked him to determine what his goals would be under the NDIS Plan and what services would he need to achieve these goals. The assessment finished and she went back to the office to complete her final assessment of what Todd's needs were under his NDIS Plan. A few weeks later she rang and asked us to come to a meeting at her office to explain Todd's NDIS Plan to both of us. Supports were primarily included for Todd however counselling sessions were also included for me. Once his Plan was approved we sought the services of a Plan Manager and a Support Coordinator. We sought the services Todd needed a DBT Group, weekly therapy with a psychologist/mental health social worker, weekly art therapy, a drop-in art group for people with mental illness and support workers to mentor him and help him engage in the community. This is the first year of his plan and we are still working out what can and can't be included. But for the first time ever, Todd is accessing appropriate services to meet his support needs and its only early but things are improving and we are not living in constant crisis. There is hope of recovery 😊

The NDIS is in a constant state of flux, with everyone feeling frustrated. Lots of scare campaigns are run, the NDIS will run out of money etc. I am not going to cover that in our story, that is for another audience and purpose. What I will share is how my husband and I worked with our Doctor and support agencies to present to the NDIS, what his and our life looked like in terms of his mental illness effecting our lives to the level that showed he had a psychosocial disability.

### **THE LESSONS WE LEARNT THAT MAY HELP OTHERS**

- Get support for yourself during the NDIS process. For people with a mental illness, with or without a psychosocial disability, the application process can be traumatic and upsetting. It is hard having to prove you have a psychosocial disability, especially as I believe, we don't all have a shared understanding of what that means yet.
- You need to be patience and also learn to cope with continual change, otherwise the NDIS will do your head in. You also need to accept that the process takes time and there can be lots of back and forth with the NDIA, its definitely not a quick process. So stay patient and hang in there, don't give up.
- Specific mental health diagnosis' are NOT guaranteed to be considered to cause a psychosocial disability. Make sure you have documented in reports, supporting evidence and NDIS Access Forms contain information on the behaviours that cause difficulty in your or your loved ones lives.
- Focus on the impacts of the mental illness on daily life, rather than focussing on the illness itself.
- Think about what help is really useful for YOU, and also what isn't helpful to YOU.
- Talk to others if you can find them that have been through the process. Ask them what they found important to focus on
- Make sure counselling is included for Carers.
- Find a good Support Coordinator. Ask them what level of experience they have with psychosocial disability, how many clients they have, do they understand the complexities of mental illness and comorbidities. Do they understand the diagnosis you or your loved one has? Do they have experience in supporting people with this illness.
- And finally, GOOD LUCK on your journey!

### **OUR NDIS JOURNEY IN DETAIL.**

In January 2017, my husband Todd was accepted onto the NDIS and was given a significant package to help manage his psychosocial disability. We have decided to tell our story to help others navigate the mind field that is the NDIS. Along the way we heard lots of competing, opposite anecdotes about what works and what doesn't. I worked for a long time as a public servant, so I understood how Australian Government programs and policy worked. But it just didn't seem to have any concrete and clear pathways, no easy guidelines that said what was and wasn't covered, what you could do etc. What we realised was, we had to accept the reality, that this was the biggest change in health care since Medicare. The new NDIS was a total shift in disability funding, of which psychosocial disability has been included. This has also become a topic of great discussion and conflict. Do we all share a common understanding of "psychosocial disability"? I don't think we do, at this stage. As Consumers and Carers, Advocates, Politicians, Health Professionals, Policy Makers we are all still struggling to come to a common view of what a psychosocial disability "looks like" as unlike many physical disabilities, diagnosis and needs can be much more subjective. We have very different perspectives, and it is vital that we listen to each other so we can find a middle path that ensures psychosocial disability is recognised and those with psychosocial disability and their carers, are provided with the support they need to live a life worth living and participate to their fullest in their community and Australian society. The NDIS is here so we must help mould it so it can do what it was envisaged it would do. It's a steep learning curve, things are constantly changing and evolving.

## **HOW TO YOU GAIN ACCESS TO THE NDIS?**

To become an NDIS participant you will need to meet the availability, age, residency and disability or early intervention access requirements

A fact sheet on access information can be found on the NDIS website:

<https://www.ndis.gov.au/medias/documents/hac/hef/8797799546910/Factsheet-Accessing-The-NDIS-PDF-85KB-.pdf>

You can also look at the NDIS Operational Guidelines for Access. This is also available in their website at:

<https://www.ndis.gov.au/operational-guideline/access/disability-requirements.html#8.1>

The availability, age and residency requirements are easy to determine. The hard part for psychosocial disability is to prove that your mental illness creates a level of disability in your everyday life. Having a particular mental illness/es diagnosis does not equate to having a psychosocial disability. It is HOW that mental illness affects your functioning on a daily basis and if the impact causes you to experience severe effects and social disadvantage.

## **WHAT IS A PSYCHOSOCIAL DISABILITY**

The NDIA in the fact sheet [Factsheet: Psychosocial disability, recovery and the NDIS \(PDF 774KB\)](#)<sup>1</sup> States that:

*Psychosocial disability is the term used to describe disabilities that may arise from mental health issues. Whilst not everyone who has a mental health issue will experience psychosocial disability, those that do can experience severe effects and social disadvantage. People with a significant disability that is likely to be permanent may qualify for NDIS support.*

It then goes on to state Recovery from Mental Illness as:

### **WHAT IS RECOVERY?**

*When people talk about mental health recovery, they are actively seeking to create a contributing life, despite their mental health issues. This does not mean living without the symptoms of mental illness or the impairments and disabilities that it can bring. Even for people whose mental health issues are responsive to interventions, further episodes can occur. This can result in functional impairments and psychosocial disabilities that may be episodic or persistent, debilitating and long lasting. Recovery is about achieving an optimal state of personal, social and emotional wellbeing, as defined by each individual, whilst living with or recovering from mental health issues. We are committed to ensuring that recovery and hope restoring recovery practice are supported for participants with psychosocial disability through the design and implementation of the NDIS. Importantly, we understand that hope and optimism are elements in recovery. The NDIS provides: Choice and control for participants: The road to recovery is best judged by the participant. Support includes capacity building for self-management, including choosing supports and who provides supports. A lifetime commitment to supports and funding as required: Recovery is possible. The journey is personal and support when you need it is a key component of recovery. Increased independence and social and economic participation: Engaging with the community through social participation, education and employment helps build resilience and purpose. The NDIS is committed to funding supports that help participants increase their independence and social and economic participation. Support for a partnership approach: Support provided under the NDIS is disability focused but recovery oriented. It is connected to diverse supports as required.*

## **WHAT THIS MEANT FOR TODD PROVING THAT HE HAD A PSYCHOSOCIAL DISABILITY FROM HIS MENTAL ILLNESSES**

Rather than looking at Todd's diagnosis and what they were we had to look at the IMPACT that his diagnosis had on his behaviour and on his every day life. We had to prove that his mental illnesses caused him to have a psychosocial disability that resulted in him experiencing severe effects and

social disadvantage. We had to look at the questions on the access form and ensure that evidence was provided to show this. As such the diagnosis becomes kind of irrelevant (although can be used as proof of disadvantage) as it was the EFFECT of this on his daily life. As we know mental illnesses whilst they have common traits, can vary from individual to individual. Not everyone with a particular diagnosis will have a psychosocial disability. So it is imperative to provide evidence of the negative impacts that make daily life extremely difficult.

### **BACKGROUND INFORMATION AND DIAGNOSIS**

Todd is 50 years old and we have been married for 17 years. All during our relationship Todd's mental health has impacted on it. He has had difficulty managing relationships all his life. The strength of our relationship reflects the hard work we have done to maintain our relationship despite the odds.

Todd has always had erratic behaviour, he is afraid of being alone and does not cope on his own without company, his mind takes over and thoughts come from dark, destructive places. He has never had a good understanding of who he is or what he wants, he could never answer the question So who are you? What do you want in life? These unstable and extreme emotions have led him to being impulsive and having self destructive and maladaptive behaviours. When upset and overwhelmed he has engaged in sensation seeking behaviours (binge eating, overdoing it with alcohol) that feel good in the moment, but are short lived, and in the long term hurt him and those around him. He constantly experiences lots of thoughts about suicide, and has made suicidal gestures and threats and has carried out suicide attempts. He has also used self harm as a coping skill for many, many years and his arms tell stories of his pain through the scars they have left, both physically and mentally. One moment he can be happy and feel joy, and the next that feeling is gone and he feels despair and hopelessness. Intense mood swings are triggered by the smallest things, that others would just simple brush off. He has constant feelings of emptiness, feeling like nothing or nobody. He is often suspicious of others motives, as he thinks why would he deserve their help? At times he experiences explosive anger, where he is consumed by rage, and a lot of the time this is directed inwards, he gets angry with himself, feels hopeless and is extremely judgemental of himself. Living like this is very debilitating. Can you imagine how hard it would be to survive this chronic behaviour persistently, day after day, fighting against your own thoughts, trying to stay alive? He has been hospitalised multiple times, and has sought help to make change and get well. For him recovery means being able to function without being controlled by extreme emotions that may or may not be valid. To be the person he wants to be and admires, to be out of hell and have a life worth living.

Todd remembers feelings of being anxious and "different" since early childhood. He was a sensitive child and remembers suffering anxiety from five years old, when he would get the terrors if left alone at home while his parents went out. He was scared and frightened. Sometime in early adolescents he suffered what he called a "nervous breakdown" with his Dad carrying him to hospital.

He was diagnosed over ten years ago with Generalised Anxiety Disorder and Depression. He was first put on anti depressants by a former Doctor (GP). The meds however were not quite working, they helped a bit but not of great benefit. We seemed to be living in a constant emotional rollercoaster, never quite sure what would happen next or when things would erupt.

Three years later we took him to The Black Dog Institute, a mood disorder clinic, in Sydney. There he was diagnosed with Bipolar2, along with anxiety and non-melancholic depression. He followed the plan, but again something was missing.

After 18 months with a wonderful psychologist, who was using CBT with him, but it wasn't quite working, he was diagnosed with Borderline Personality Disorder.

His long term psychiatrist also diagnosed PTSD and substance abuse disorder (alcohol).

He worked for himself, as working for others was never successful as his irrational behaviour and anger at times became prominent. Being self employed he could work when he wanted and on his own. It was also hard as it was very stressful trying to maintain an income in a slow economy and also some clients would walk away shocked after seeing him at his workshop after he had self harmed and was covered in blood. He constantly saw himself as a failure and was his own worst critique.

### **SO WHAT WAS THE PROCESS TO APPLY FOR ACCESS TO THE NDIS?**

Initially we rang the NDIA and requested ACCES forms to be sent out. Once we received them Todd and I sat down and we discussed the impacts on his daily life that were included in the access form. This required evidence that the disability impacts his mobility/motor skills; communication; social interaction; learning; self-care; and self-management.

We filled in the Sections of the Access Form that he needed to do. For the form at the time (September 2016) that was to Part F. In Part F he had to list his Primary Disability which was Borderline Personality Disorder, along with his other disabilities Anxiety, Depression, Bi Polar 2, PTSD and Diabetes Type 2. He also had to list his current treatment which was a Psychologist for therapy and behavioural support and a Psychiatrist to manage medications.

Todd was using the option for a Professional to answer the questions below as evidence of his mental illnesses and that these resulted in him having a psychosocial disability. We asked our Doctor (GP) to fill out this part of the form as Todd had been seeing him for seven years and he was the constant health professional that understood Todd's illness and the impact on his daily life. Before the Doctor filled in this form Todd and I went through each questions. We had to ensure that Todd did fit the criteria and that his evidence was presented in a way to provide evidence of his disability.

We ourselves decided to think about the questions asked in the Section to be answered by a professional. This would help us review our lives and the impact that Todd's psychosocial disability has had on our lives.

### **ACCESS REQUEST FORM QUESTIONS TO BE ANSWERED BY PROFESSIONALS**

#### **QUESTION 1: MOBILITY/MOTOR SKILLS**

The first question was on mobility/motor skills. This first report we answered that he did not need assistance. This answer was to change once we thought about it more and what it meant for Todd. We will discuss his mobility issues updated answer later, under the *Access Request Supporting Evidence Form*.

#### **QUESTION 2 COMMUNICATION**

What we considered and the questions we asked ourselves for this answer was:

- How did Todd have difficulties in communicating with other people? Was he often misunderstood? Could he accurately express himself?
- Did Todd have difficulties forming and maintaining professional and personal relationships?
- Did services often not offer the help he needed as he fell in the "too hard" basket?

- Did Todd understand information clearly from others? Did he need someone else to explain things to him and interpret information to and from others?
- Can he make his own decisions and could he problem solve from himself?
- With his illnesses did his communication difficulties fluctuate? Were they episodic? Did the level of difficulty increase when he was unwell and decrease when he was managing well?
- Were there any other factors that impacted on his ability to communicate effectively with others to maintain his independence?
- How often did he need assistance from others to communicate? And what sort of assistance?

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

Todd needs assistance to interpret information in a way he can understand. He requires therapy to increase his interpersonal effectiveness and skills. He is often emotionally dysregulated and dissociated due to his illness and he needs assistance with problem solving and decision making?

### **QUESTION 3 SOCIAL INTERACTION**

What we considered and the questions we asked ourselves for this answer was:

- Was Todd able to develop AND maintain friendships?
- How does he interact in the community? Does he find this interaction easy or difficult?
- Does his mental illnesses keep him isolated and unable to fully participate in the local community and environment?
- Has he had negative experiences in interacting in the community?
- Are there times when interacting in the community is difficult or impossible due to his mental illnesses?
- Does he experience severe effects and social disadvantage from not being able to interact in the community or not coping with his feelings and emotions?
- Does he have the skills and capabilities necessary for managing his illness? With the appropriate assistance and support would this improve his ability to do this?
- Can he regulate his emotions? If not how does this impact on his ability to interact in his community?
- What sort of experiences does he have when interacting in the community?

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

Todd requires therapy to learn to manage his illnesses and engage in positive relationships with others. He has great difficulty in coping with his feelings and emotions and is often emotionally dysregulated. He needs support to interact within the community. He experiences high levels of anxiety engaging in his environment.

### **4. LEARNING**

**Understanding and remembering information, learning new things, practising and using new skills.**

What we considered and the questions we asked ourselves for this answer was:

- Is he able to understand and remember information? Do the medications he has to take for his mental illnesses affect his ability to understand and remember things?

- Does his mental illnesses affect his ability to comprehend instructions? Are there certain kind of instructions that are more difficult than others to understand eg. written, oral or visual instructions?
- As he suffers from emotional dysregulation and disassociation, how does this impact on his ability to learn new things and practising and using new skills?
- Is he able to self learn? or does he need assistance?
- What kinds of things would it be helpful to learn in order to manage his disability?
- Does he experience social disadvantage due to his difficulty to learn new skills? If so how is he disadvantaged by this in comparison to others who are able to learn effectively?
- In order to change negative behaviours, you need to be able to learn new coping skills, is he able to do this on his own? With assistance would this be possible? What sort of assistance would he need?

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

Todd has difficulty with comprehending written instructions and needs guidance and prompting to understand information. He also has difficulties remembering information. He requires assistance to practise and use new skills.

## **5. SELF CARE**

### **Showering/bathing, dressing, eating, toileting, caring for his own health.**

The fifth question was on self care. This first access report we answered that he did not need assistance. This answer was to change once we thought about it more and what it meant for Todd. We will discuss his mobility issues updated answer later, under the *Access Request Supporting Evidence Form*.

## **QUESTION 6 SELF-MANAGEMENT**

### **Doing daily jobs, making decisions and handling problems.**

What we considered and the questions we asked ourselves for this answer was:

- Could Todd undertake daily jobs? And make decisions and handle problems?
- Did the episodic nature of his mental illnesses affect his ability to do these things 100% of the time?
- Is he able to make decisions? When he is emotionally overwhelmed how does that affect his decision making and problem solving?
- He may be able to make decisions, but are they good and helpful decisions or does it involve risky behaviour and impulsive decisions that have negative consequences for him and his family?
- Does his ability to do daily jobs get impacted on when he is unwell? Is his inability to do this episodic, and how often does it happen?
- Does his decision making and problem solving result in severe consequences and social disadvantage for himself? And/or his family?
- Does his inability to undertake daily jobs at all times have a negative impact on his carer and put at risk the carers capacity to care for him?

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

Todd requires assistance with undertaking daily chores. When he is unwell, he requires help with decision making and problem solving. He is often unable to emotionally manage problems and finances.

### **SUBMITTING THE ACCESS FORM AND NEST STEPS**

Once we had done the exercise above of providing evidence of psychosocial disability we made an appointment with Todd's Doctor (GP) that he had been with for the past six years. We went through our answers to the questions with him and had a discussion. From that he was then able to complete the section on the Access Form that was for his treating health professional to fill in.

We submitted Todd's Access Form for the NDIS to the NDIA in September 2016. A week later we were sent a letter from the NDIA requesting further information to support Todd's access to the NDIS. At this time his mental health had deteriorated and he was finding it difficult to manage daily life. His self harm and suicidality had increased. He was almost constantly emotionally dysregulated and disassociating and using maladaptive coping techniques that included high risk and harmful behaviours. We were living in constant crisis and did not have the capacity to submit the further evidence. A few weeks after we received the letter requesting further information we were sent another letter from the NDIA stating that he had not submitted the requested additional information and so therefore they were unable to make a decision and were going to close his Request to Access Application. I rang the NDIA and spoke to them about the situation and he was given a three month extension to return the Access Request – Supporting Evidence Form.

### **ACCESS REQUEST – SUPPORTING EVIDENCE FORM**

When we could gather the information for the Supporting Evidence Form we again sat down and reviewed the form questions together again, as we had done with the previous form. During the period in between the two forms Todd's mental health had deteriorated further and he was extremely unwell and struggling through each day. His self harm and suicidality had escalated, his anxiety had led to him closing down from the world, he was not able to leave the house without me being with him. The Supporting Evidence Form required Todd to fill in Section 1 and his treating health professional to fill in Section 2 and 3, most of the questions were the same as the initial form so it gave us the opportunity to add further information and re-evaluate the previous answers. Todd and I decided to go through this form and answer the questions on the effects of his psychosocial disability, just as we had done with the first form, as we had both found this was an informative process for us to go through. We could also re-evaluate the previous answers and provide additional information that had not been included in the first form, as we had gained a better understanding of the impact of his psychosocial disability on his and our daily lives.

### **ACCESS REQUEST – SUPPORTING EVIDENCE FORM QUESTIONS TO BE ANSWERED BY PROFESSIONALS**

Todd's Doctor gave his primary diagnosis of Borderline Personality Disorder, Anxiety and Depression, with secondary diagnosis of PTSD. He stated that the impairment was likely to be life long and that his functional capacity fluctuates and varies in intensity. He listed his past and present treatment as being CBT, DBT, Physical Exercise and Personal Training, Medication, Alcohol Use Counselling and mental health support worker programs. He noted that Todd had been living with impairment for 40 years and that it was likely to be lifelong. He also stated that the provision of early supports would improve Todd's functional capacity and that early intervention supports that would assist were Comprehensive DBT, Group Program and Psychological supports and mental health support workers to assist with social integration. He also gave details of the assessments undertaken and that Todd had met nine of the nine assessment criteria in the DSM-5 for Borderline Personality Disorder in 2004 when diagnosed by his then Psychologist.

The discussions that Todd and I had on each criteria in this form is as follows:

## **MOBILITY**

### **Moving around the home, getting in and out of bed or a chair, mobilising in the community including using public transport or a motor vehicle.**

In the initial form we had marked this Criteria as not needing assistance, however on reflection we realised that Todd is unable to be mobile within the community on his own without support.

What we considered and the questions we asked ourselves for this answer was:

- We realised that this question was not just about physical mobility, Todd had a psychosocial disability that impacted on his ability to engage in the community and access community services. Think of “mobility” in terms of psychosocial disability rather than physical disability.
- Were there times when he could not get out of bed due to his disability? And if so how often?
- Was Todd able to get himself, on his own to the local shops to buy necessities?
- Was Todd able to go to support groups, shopping malls, appointments without support? As this was in fact a mobility issue.
- Was Todd capable to use public transport?
- Did he need to be accompanied anywhere he went?
- Could he get himself to health appointments?
- Did his disability impact on his ability to interact in his local environment and community?

We updated the answer to this question as Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd’s answer was:

Needs support and assistance to catch public transport due to social anxiety.

## **QUESTION 2 COMMUNICATION**

We added further information to this answer as we realised that self harm, suicidal thoughts and actions had an impact on his communication with others. There was stigma associated with these behaviours within the health sector.

What we considered and the questions we asked ourselves for this answer was:

- What impact does self harm, suicidal thoughts and actions and disassociation have on his ability to communication with others?
- What impact does self harm, suicidal thoughts and actions and disassociation have on his ability to make decisions and problem solve? Is he able to use these skills when experiencing these behaviours? How of do these behaviours happen on a daily basis? And what is the impact of the frequency?
- Was there negative experiences and any social disadvantage within the health sector caused by others attitudes and stigma associated with self harm and suicidal thoughts? How did this impact on Todd and his life?
- How did Todd have difficulties in communicating with other people? Was he often misunderstood? Could he accurately express himself?
- Did Todd have difficulties forming and maintaining professional and personal relationships?
- Did services often not offer the help he needed as he fell in the “too hard” basket?
- Did Todd understand information clearly from others? Did he need someone else to explain things to him and interpret information to and from other?
- Can he make his own decisions and could he problem solve from himself?

- With his illnesses did his communication difficulties fluctuate? Were they episodic? Did the level of difficulty increase when he was unwell and decrease when he was managing well?
- Were there any other factors that impacted on his ability to communicate effectively with others to maintain his independence?
- How often did he need assistance from others to communicate? And what sort of assistance.

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

Todd needs assistance to interpret information in a way that he can understand. He requires therapy to increase his interpersonal skills and to learn to control his emotions. He often self harms and has suicidal thoughts and attempts. He also experiences disassociation and needs help with problem solving and decision making.

### **QUESTION 3 SOCIAL INTERACTION**

What we considered and the questions we asked ourselves for this answer was:

- We added further information to this answer as we realised the impacts of his disability on his maladaptive behaviour and how the communities attitudes to this behaviour impacted his ability to socialise in his community.
- Did Todd form positive relationships? Is this difficult for him? Can he maintain them?
- When he is unwell how does the community see and understand his behaviour?
- Was it easy for people to see his disability and accept his behaviour as a symptom of an illness? What was the impact of this on Todd? Did he face social disadvantage due to socialising in the community when he is unwell?
- Was Todd able to develop and maintain friendships?
- How does he interact in the community? Does he find this interaction easy or difficulty.
- Does his mental illnesses keep him isolated and unable to fully participate in the local community and environment?
- Has he had negative experiences in interacting in the community?
- Are there times when interacting in the community is difficult or impossible due to his mental illnesses?
- Does he experience severe effects and social disadvantage from not being able to interact in the community or not coping with his feelings and emotions?
- Does he have the skills and capabilities necessary for managing his illness? With the appropriate assistance and support would this improve his ability to do this?
- Can he regulate his emotions? If not how does this impact on his ability to interact in his community?
- What sort of experiences does he have when interacting in the community?

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

To manage his illness and engage in positive relationships with others he needs assistance. He has great difficulty in coping with his feelings and emotions. He needs support to interact with others in the community. He experiences severe anxiety when engaging in his environment and needs a support person to assist him engaging in the community. .

## **4. LEARNING**

**Understanding and remembering information, learning new things, practising and using new skills.**

This was pretty much the same response as the initial answer.

What we considered and the questions we asked ourselves for this answer was:

- Is he able to understand and remember information? Do the medications he has to take for his mental illnesses affect his ability to understand and remember things?
- Does his mental illnesses affect his ability to comprehend instructions? Are there certain kind of instructions that are more difficult than others to understand eg. written, oral or visual instructions?
- As he suffers from emotional dysregulation and disassociation, how does this impact on his ability to learn new things and practising and using new skills?
- Is he able to self learn? or does he need assistance?
- What kinds of things would it be helpful to learn in order to manage his disability?
- Does he experience social disadvantage due to his difficulty to learn new skills? If so how is he disadvantaged by this in comparison to others who are able to learn effectively?
- In order to change negative behaviours you need to be able to learn new coping skills, is he able to do this on his own? With assistance would this be possible? What sort of assistance would he need?
- Todd requires to learn new coping skills in order to change his self harm and life threatening behaviours. What would he need for this to be possible? Is he able to do this on his own? Does he have high needs in this area?

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

Todd has difficulty with comprehending written instructions and needs guidance and prompting to understand information. He requires assistance to learn new skills to limit his maladaptive skills, in order to cope with life on a daily basis.

## **5. SELF CARE**

### **Showering/bathing, dressing, eating, toileting, caring for his own health.**

In the initial form we had marked this Criteria as not needing assistance, however on reflection we realised that Todd does require assistance in this area.

What we considered and the questions we asked ourselves for this answer was:

- Todd's illness can be episodic and unpredictable. When he is well he does not need assistance in this area. However, when he is unwell he does require assistance.
- When he is unwell does he shower, eat, and care for his own health and personal hygiene?
- What restricts him from doing these things when he is unwell?
- Are the things a symptom of his illness that contributes to his disability? Does he need to be prompted?
- How do these things manifest when he is unwell? What does it look like? What are the impacts on his quality of life?
- How often is he unwell and it impacts on this area?
- What assistance does he require to ensure that he is able to undertake these daily tasks

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

When unwell he needs prompting to undertake eating and drinking as well as maintaining his personal hygiene.

#### **QUESTION 6 SELF-MANAGEMENT**

##### **Doing daily jobs, making decisions and handling problems and money.**

We added further information to this answer as we realised that his self harm and suicidality had a big impact on his self-management ability.

What we considered and the questions we asked ourselves for this answer was:

- Was Todd able to manage his emotions? If not what was the resulting behaviours?
- When unwell was Todd able to keep himself safe?
- Could Todd undertake daily jobs? And make decisions and handle problems?
- Did the episodic nature of his mental illnesses affect his ability to do these things 100% of the time?
- Is he able to make decisions? When he is emotionally overwhelmed how does that affect his decision making and problem solving?
- He may be able to make decisions, but are they good and helpful decisions or does it involve risky behaviour and impulsive decisions that have negative consequences for him and his family?
- Does his ability to do daily jobs get impacted on when he is unwell? Is his inability to do this episodic, and how often does it happen?
- Does his decision making and problem solving result in severe consequences and social disadvantage for himself? And/or his family?
- Does his inability to undertake daily jobs always have a negative impact on his carer and put at risk the carers capacity to care for him?
- Is he able to maintain his finances when unwell? What is the financial impact of his illness?

He answered Yes, needs assistance from other persons (physical assistance, guidance, supervision or prompting).

Todd's answer was:

Todd requires assistance with undertaking daily chores. When he is unwell, he requires help with decision making and problem solving. He is often unable to manage problems and finances. When he is unwell he needs support to stay safe as he has a history of self harm and suicide attempts.

#### **SUBMITTING THE ACCESS FORM AND NEST STEPS**

Once we had done the exercise above of providing evidence of psychosocial disability we made another appointment with Todd's GP. We went through our answers to the questions with him and had a discussion on the level of psychosocial disability, the impact it had on his life and how this could be improved with supports. After this the Doctor complete the section on the Access Request – Supporting Evidence Form. The form was submitted in early December and within a few weeks they rang to make an appointment to interview Todd as we had provided enough evidence for the NDIA to consider that he had a psychosocial disability and had moved to the next stage of the NDIS journey, which was to meet with an NDIA Planner. The appointment was made for a home visit in early January 2017.

Before we met with the Planner we had a meeting with a NDIS Support Worker with a local mental health service. With him we talked about the application and how Todd's life was impacted by his psychosocial disability. He also gave us information on the NDIS and the kinds of supports they would and wouldn't fund. They gave us an idea of what questions they may ask at the interview.

They helped us prepare a list of supports that would be beneficial and helped us prioritise these supports in term of urgency.

We also looked at a copy of the NDIS Planning Work Book that we had received in a NDIS Information Pack. Going through the questions with that helped us with the planning and to set goals. It gave us discussion questions that helped to determine what goals Todd had and what areas he needed support in to manage his psychosocial disability.

There is also a *Guide for **Mental Health Carers on the NDIS*** that is helpful. This guide is for people who provide unpaid care and support to a family member or friend with a psychosocial disability associated with a mental illness or mental health condition. This guide is available from the Mental Health Australia and Carers Australia websites: [www.mhaustralia.org](http://www.mhaustralia.org) available here: <https://mhaustralia.org/fact-sheets/mental-health-carers-ndis-guide-and-checklist> And [www.carersaustralia.com.au](http://www.carersaustralia.com.au) available here: <http://carersaustralia.com.au/storage/guide-for-mental-health-carers-on-the-ndis.pdf>

### **THE NDIA PLANNING MEETING**

The Case Manager from the NDIS had agreed to do a home visit to undertake the NDIS Planning Interview as Todd was extremely unwell at that time. The NDIA conducted a quick risk assessment about coming to our house for the interview prior to approval. The home visit was approved after the risk assessment.

At the NDIS Planning Meeting were Todd and myself, the NDIS Support Planning Worker from an NGO Mental Health Service(mentioned above), the Case Manager from the NDIS and their co-worker.

At the interview the Case Manager explained what the purpose of the NDIS was and how it supported people with psychosocial disability. She asked for background information on Todd such as his living arrangements and who he lived with, who the important people in his life were, did he have family and friends that supported him. What his daily life was like and what support he felt that he needed. Todd and I had discussed this prior to the interview as we were aware that goals would be set in the plan. In order to determine his goals we looked at what was THE most urgent thing for him to learn to deal with, what supports would provide him with what he needed to help improve his daily life, what he wanted to achieve out of this support. After some discussion he realised that the most important goal he needed to set for the next twelve months to work on was to stay alive and to reconnect and engage with the local community.

In determining your goal I think it is important to set yourself two priorities to work on in the year. You want to have goals that are both attainable and allow you the greatest flexibility to build the supports around you that you need for that period. Goals must allow for the episodic nature of mental illness so that you can access the greatest amount of support when needed when you are unwell and that you can also reduce the support as required when you have periods of time when you are doing well. Services and supports will be funded in your NDIS to assist you to achieve your goals, so you need to remember that. Think of what you, as an individual wants to achieve, what would enable you to have a life worth living and what goals help you achieve this? Then what kind of supports to you need to meet your goals. The goals you set are important as they underpin the NDIS Plan and Todd would receive the funding he required to achieve these goals within the boundaries of the NDIS Operational Guidelines. The NDIS Operational Guidelines are available on the website at: [www.ndis.gov.au/operational-guideline/overview-sitemap.html](http://www.ndis.gov.au/operational-guideline/overview-sitemap.html) . It is helpful to have an idea how the NDIS will operate.

This was the first goal he decided on:

***My Frist Goal is:***

*During this plan I want to be supported to improve my physical and mental well being so that I can reduce my self harm and stay alive.*

He then also decided that as well as staying alive he also wanted to be supported so that he could successfully engage in the community.

***My Second Goal is:***

*During this plan I want to be supported to be able to build my skills to be able to increase my level of independence and my social participation.*

She then asked us to explain what daily life was like for Todd. She said to think about the last 30 days and describe those. This was good timing for Todd's interview as for the prior seven months he had been extremely unwell and had struggled with daily living and had withdrawn from the wider community. He had been unable to experience any joy and his behaviours were extremely risky and life threatening. He had spent 2 ½ weeks in an Adult Mental Health Unit at the hospital over Christmas and New Year due to constant self harm and suicidality. He had been dysregulated almost constantly over that time and he was frequently disassociated and for long periods of time. In the prior six months he had around 10 trips to the hospital via ambulance as a result of self harm and life threatening behaviours. In the previous six weeks he had on two occasions been in the ICU on life support after attempting twice to take his own life. Whenever he was left on his own his sense of abandonment and hopelessness would spiral out of control, this of course increased my own level of stress and anxiety his only carer and also his wife. He was not accessing many supports at that time. He had been recommended to do a comprehensive DBT program, as this was evidence based treatment for his diagnosis of Borderline Personality Disorder, and also anxiety and depression, however we were not in a financial position to afford this. Living in constant crisis was having bad side effects on both our lives and was having a negative impact on both our health. Todd did not have the supports he needed to get well and to function in the community. For others who are having their interviews, make sure that you describe your life in terms of how things are for you at your worst, when you are the most unwell and not functioning. It can be hard with psychosocial disability as your ability to function can fluctuate, due to the sometimes episodic nature of some mental illnesses.

We discussed what supports Todd would like in his plan. What he thought would be helpful to improve his life. He spoke about the need for a comprehensive DBT Program, this was available where we lived, but unfortunately we did not have the finances to be able to afford it. Todd also required weekly therapy visits with a psychologist/mental health social worker, the 10 visits per annum subsidised by Medicare were not meeting his need. Art therapy had also been recommended for him and he was wanting to try this. Due to his social isolation he needed support workers that could help him reintegrate within his local community. He also was keen to find a mental health based social group in order to build his confidence and skills in attending groups within the community.

The interview went for approximately an hour and 15 minutes. The NIDS staff were respectful and aware of how unwell Todd was feeling at that time. They were non-judgemental and showed compassion, for which I am grateful. It was not a horrific experience as we expected. However it was still all just as clear as mud. She said she would return to the office and complete the final assessment which would generate Todd's NDIS Plan.

A week after the interview Todd received a letter from the NDIS saying that his NDIS Plan had been approved. The Case Manager contacted us to arrange a meeting so she could go through the Plan

and explain it to him. It was important that Todd understood what was available under his Plan and how he could use it, as the Plan is customised to his needs. The Plan is in place from January 2017 until January 2018. The Plan will be reviewed and updated before his current Plan expires.

### **THE APPROVED NDIS PLAN**

Getting Todd's NDIS Plan was very overwhelming. Even with all the knowledge we had accumulated it still made no sense and we couldn't work out what each category met, so it was good to have a meeting with the NDIA Case Manager as she was able to interpret it for us and let us know what could be funded under each category.

His NDIS Plan has provided funding under the following Support Areas:

### **SUPPORT AREA – IMPROVED LIFE CHOICES**

**Details:** This Category is funded for assistance with financial and service intermediary supports to assist with Plan management

What this means: Under the NDIS there are three options to administer your Plan.

- Option 1 is that your Plan is managed by the NDIA, they co-ordinate services for you and pay supplies directly. With this option, it is the most restrictive. Any Service Providers you use MUST be NDIS Registered Providers and are paid exactly to the payment scale set by the NDIA.
- Option 2 is that you self manage the NDIS Plan. The NDIS deposits funding directly into your bank account. You are responsible for paying all Service Providers invoices. You must also do a financial acquittal each year and provide a report to the NDIA that shows what funds have been spent and provide all invoices paid as evidence. This offers total flexibility as you are not restricted
- Option 3 is a hybrid model of the two above. The NDIA in your Plan funds a Plan Manager. They are responsible for managing the finances. NDIA deposits your funding with them and they pay the invoices to all your Service Providers. They will answer questions on what can and can't be funded and if in doubt you can check with them. If you chose this option then the NDIS will also fund a Supports Coordinator for you which is discussed in a further section. It is also fully flexible and allows for you to engage with Suppliers who are NOT NDIS Registered Service Providers.

### **SUPPORT AREA – IMPROVED RELATIONSHIPS**

**Details:** This category is funded for assistance to engage support from allied health professional/s for skills development, training, assessment and therapy. Support will work closely with the participant to increase independence and progress towards the goals outlined in the NDIS Plan. These supports will also include progress reports on outcomes of current goals/objectives and the participant's ongoing functional needs at the scheduled review. Includes 10 hours for Counselling for the Carer.

**What that means and the Services Providers we engage:** I can receive 10 funded Psychologists visits in this years Plan's as Todd's carer. This is to help enable me to continue to provide the care I currently give Todd. We also access these funds for Todd to be able to have weekly sessions with an Art Therapist. This has proved to be very therapeutic for him as he is an Artist and therefore a very visual person.

### **SUPPORT AREA - IMPROVED HEALTH AND WELL BEING**

**Details:** This category is funded for assistance from appropriately qualified professionals to improve a Participant's health and wellbeing as outlined in the goals within this NDIS Plan.

**What that means and the Services Providers we engage:** This section can be used for sessions with a Physiologist for Individual advice to a participant regarding exercise required due to the impact of

their disability or for a Personal Trainer for personal training provided to a participant required due to the impact of their disability.

#### **SUPPORT AREA – IMPROVED RELATIONSHIPS**

**Details:** Specialist behavioural intervention support. Behavioural Management Plan, training in behavioural management strategies. This category is funded for assistance with the development of positive behaviour management plan to progress towards the goals outlined within this NDIS plan. Support may be used at the standard or high intensity levels.

**What that means and the Services Providers we engage:** This funding is used for Todd to attend weekly therapy with a Mental Health Social Worker who is trained in Dialectic Behaviour Therapy (DBT). It also funds Todd to attend DBT Skills Group offered through a comprehensive DBT Program. We will also see if this section will fund Todd's and mine attendance and the annual BPD Conference as this would provide training in behavioural management for his primary diagnosis.

#### **SUPPORT AREA – INCREASED SOCIAL AND COMMUNITY PARTICIPATION**

**Details:** This category is funded for assistance in skills based learning to develop independence in accessing and participating in community, social and recreational activities. Individual skills development and training.

**What that means and the Services Providers we engage:** This funding can be used to engage in activities within the community, so Todd uses this funding to attend a Mental Health Consumers Art drop in for 3 hours once per week. It is also being used for a Support Worker who will take out Todd on outings in the community.

#### **SUPPORT AREA - SUPPORT CO-ORDINATION**

**Details:** Assistance to strengthen Todd's ability to coordinate and implement supports, strengthen his informal network and coordinate a range of both mainstream and funded supports.

**What that means and the Services Providers we engage:** This is the Support Coordination that I mentioned under Option 3 in the Support Area – Improved Life Choices, that is funded as well as the Plan Manager so that you can have flexibility in your plan and chose Option 3 for administering your plan. The Support Coordinator sources the service providers for you to use and they prepare and monitor the Service Agreements you have with your Service Providers. Todd was assessed as having high level needs in this area due to the funding in his plan and his need for multiple services to be provided given his complex mental health needs and level of psychosocial disability.

#### **SUPPORT AREA – TRANSPORT**

**Details:** A contribution for transport to access community recreational, social, employment or leisure activities.

**What that means and the Services Providers we engage:** This is a small amount of money that NDIS pays directly into Todd's bank account fortnightly. It is to cover the additional transport costs of going to all these new appointments. It is a standard payment based on the level of transport assistance you require.

#### **SUPPORT AREA – CORE SUPPORTS**

**Details:** Core Supports to assist with daily activities and community participation. Support MAY include transport, group activities, community access, community activity costs and assistance with self-care. Participant budgets are flexible across the four sub-categories: Assistance with daily living, Transport, Consumables, and Assistance with Social and Community Participation. A participant may choose how to spend their core support funding, but cannot reallocate core support funding to other support purposes (i.e. capital or capacity building supports).

**What that means and the Services Providers we engage:** This is the most flexible part of the funding, the funds can be used for any activities that will support him to achieve his Plan goals. Under this section we use the funding for:

- Assistance with household tasks. This includes the provision of supports to enable the participant to maintain their home environment. This may involve undertaking essential household tasks that the participant is not able to undertake. In this category Todd has funded a House Cleaner for two hours per fortnight and a gardener to maintain the yards
- Health and Well Being Mentor and Peer Support for minimum of 4.5 hours per week. They share an interest in exercise so they exercise together in sessions, practice mindfulness, breathing techniques and relaxation
- Mental Health Support Worker for a minimum 5 hours per week. The support worker attends a mental health consumer art drop in sessions at the local community services centre for 3 hours once per week. They also spend approximate 2 hours per week with Todd in the home teaching him how to cook. They are also available to take him to any appointments as required.

### **THE RESULTS OF THE NDIS PLAN SUPPORTS**

Todd's NDIS Plan has been in place for four months now. In that time it has made an incredible difference to his and our lives. He is now accessing the supports he needs to be able to get well and build a life worth living. It is baby steps at a time, and recovery will be a marathon not a sprint. Having a NDIS Plan has however given him the opportunity, through his supports, to now work towards recovery instead of living in a constant state of crisis. His self harm and suicidal actions has dramatically decreased. He still is plagued by the thoughts, however he is slowly decreasing his vulnerabilities and increasing his resilience through learning new skills. In the past month he has not had any incidents of self harm or life threatening behaviours. He is much more positive about the future and himself. He is slowly building his confidence and independence. Things are still difficult for him in managing his psychosocial disability, however they are improving as we are able to access the supports he needs now that he has an NDIS Plan in place. It has also had an impact in improving my life and my ability to continue to provide him with the help he needs whilst maintaining a life of my own. The support with household tasks has taken a load off my shoulders. I have also been able to get back to doing things for me and that I enjoy.

### **WHERE TO FROM HERE**

Todd will continue to access supports through the NDIS to meet his goals. He will continue to work with his Support Coordinator and build on the current services he has in place. He is planning to seek funding to attend the annual BPD Conference. His NDIS Plan will be reviewed at the end of this year so that a new plan can be drawn up for 2018.

### **FRUSTRATIONS WITH THE PROCESS**

As this is a complete change in how disability services are funded in Australia and the fact that there is still not a common shared understanding on what a psychosocial disability is, it can get frustrating with a lack of clear and concise information and finding out exact examples of what can be funded. Also the goal posts continually move and sway as things progress. But I think it is important that we keep giving the NDIA, politicians, advocates and policy makers feedback on what the needs of consumers and carers are so that we can shape the NDIS into a successful and positive funding program that gives people flexibility to manage their disabilities.

Sadly for those with mental illness the NDIS process can be extremely invalidating, triggering and traumatic. We recommend that you have the support of a good counsellor or support worker to help you through this process to support you on a personal level, as its not an easy process when you are struggling with mental illness.

It can be a challenge finding appropriate Service Providers that have the right experience, especially for psychosocial disabilities. The sector has had to grow fast and at times demand out ways supply. Ensure you check the expertise of any service providers that you engage with.

Some of the Operation Guidelines put barriers in place for people to access some services. For example Todd wanted to learn guitar. The problem was that the NDIS will not pay for his individual lessons, as they expect consumers to make contributions as well. They will however fund him to purchase a guitar and they would fund a support worker to go with him to lessons, but as we can not afford the lessons in the first place he is not able to learn guitar, which is a shame as learning to play guitar is a good distraction and it also allows him to practice mindfulness, both these skills are imperative for him to manage his disability. It's the same if you want to do a sport or something say like Martial Arts once per week. They will pay for a support worker to go with you, but you have to find one that is prepared to pay the tuition fees for themselves and you have to be able to pay the fees for yourself.

There are lots of inconsistencies across the NDIS. If you are approved or not can depend on what worker you get, again as this is so new and such a drastic change, unfortunately they can still be playing catch ups in the consistency area. I believe if people are not approved for access on the NDIS and they feel they have the evidence to prove they meet the requirements, then you should appeal and have the application looked at again by senior staff. We still have a long way to go to ensure that all those with mental illness, whether they have a psychosocial disability or not, should receive supports. The problem is that state and territory governments are not continuing to provide funding for services for those who do not qualify for the NDIS, but need some level of support. We need to hold them accountable to provide the services that they should be providing in their jurisdictions.