

*In regards to the NDIS application of: Beth Darcy  
Name of the Primary Carer: Gillian Darcy  
Relationship to NDIS applicant: Primary carer and mother*

20/06/2017

## **PRIMARY CARER'S STATEMENT**

To the NDIA,

My name is Gillian Darcy, and I have written this Carer's Statement in support of my daughter Beth Darcy's, NDIS application. I have tried to describe Beth's support needs, how much time I spend supporting Beth every week, the impact on me as a carer, as well as show how she would benefit from additional support from the NDIS.

I am 42 and a single mum of 2 kids, Beth and Grace who are in their early 20s. Beth and Grace were happy kids and Beth was happy playing with Grace's friends. My Grace has now moved to Melbourne to attend university, which has left me on my own to look after Beth. I live in a rented flat with Beth in Ballarat. I can't work full time anymore, as I spend most of my time looking after Beth seven days a week. Beth and Grace's Dad left when they were small, so the caring has fallen to me. The only supports I have are my parents, who live a few hours away so they look after Beth some weekends. I get some respite from a disability service who have a great respite worker who Beth gets on really well with. However, this program is being transitioned into the NDIS.

Beth is a lovely, kind hearted person, but has some complex mental health needs that have made things very difficult for the family for the last few years. She had an accident when she was a baby, which affects the mobility in her leg, and she has always needed a little bit of help to get around due to this.

Beth used to get herself around, cook meals and work part time at Bunnings. Then she became very unwell about five years ago - she was put in hospital for months due to an episode of psychosis, and she has been hospitalised a few times again since then. She lost a lot of her living skills during this time. I don't know if it was being in hospital and not doing those things for herself, or the medication or the illness that caused her to lose her self-care skills. After this hospitalisation I found a local carers support group, who have given me lots of information and help.

More recently I've been told by the disability support service that Beth has a psychosocial disability, whatever that means, and that she might be eligible for the NDIS due to the severity of her disability. What makes applying for the NDIS difficult is that Beth has no idea she has any disability let alone a psychosocial one. We have collected her medical history, and have filled out the NDIA's Access Request Form. I am also writing this letter to show how much support Beth needs, as she would not be able to communicate this information herself.

Beth sometimes thinks that she has a special task force to look after her. During these times Beth does not recognise me as her real mum to the point that she doesn't like leaving the house and gets quite anxious because she doesn't want to miss her 'real' mum who is coming to pick her up and take her to England. She can be quite suspicious of me at these times and it takes a lot of effort to stay supportive and upbeat. On really bad days she does not realise that she has to look after herself; she doesn't eat, shower, brush her teeth, get out of bed or change her clothes without a lot of prompting from me. Sometimes she doesn't do these things even with prompting from me! We get visits from the psychologist, Dr Fink, regularly, but Beth doesn't realise why Dr Fink is there and doesn't really engage with him.

I don't argue with her when she thinks I'm not her mother and instead try to distract her by talking about things she enjoys and then bringing up the topic again when she's in a good mood. Beth has

hopes to one day move out, as well as be more part of the community and raise chickens. I am hoping that with support from the NDIS, Beth will be able to become more independent and achieve some of these dreams. I love Beth and want the best for her.

If Beth is able to get into the NDIS, she will need my help as her nominee. I would have to be there throughout the planning process to make sure she gets to supports she needs.

#### Areas Beth needs support in:

**Communication:** Beth finds it difficult to follow directions and is easily distracted, and doesn't feel confident communicating with people she doesn't know. Because of this she can't really use public transport or get to appointments without assistance, so I have to drive her to all appointments. Beth would benefit from support which will allow her to improve her ability to follow directions and confidence in communicating her needs with people she doesn't know.

Beth needs support to attend medical appointments as she doesn't believe she has a mental health condition so I have to attend weekly medical appointments and tell the doctor what has been happening. This is about an hour a week.

Beth will not listen to me or follow instructions when she is really unwell as she does not recognise me as her mother. I find this very upsetting and am increasingly struggling to remain calm and supportive. I need outside help; I can't continue to do this on my own.

**Self-Care:** Beth struggles with her self-care and when she is unwell she needs to be constantly reminded to look after her personal hygiene. Beth is currently unable to live independently because she needs prompting to take care of herself, switch off the cooker, lock the doors and keep the house clean.

I spend about 18 hours a week on Beth's self-care. Some weeks when she is unwell her support needs are very high and I need to prompt her to eat, shower, brush her teeth, get out of bed or change her clothes. Beth would benefit from additional supports to help her build a routine to look after herself, as well as time with a physiotherapist to help her walk around

**Self-Management:** Beth relies heavily me for all her daily support needs. I manage all Beth's appointments and complete most of the daily activities in the home such as cooking or doing the laundry. This is about 40 hours per week. Beth can take her own medication as well as undertake basic tasks such as taking out the rubbish, however, she has to be reminded. Beth identifies that she often feels bored and she does not currently have the skills to find and get to groups and activities that interest her.

Beth relies on me to buy her prescriptions, manage her money, monitor medications as she doesn't understand what they are for or why she needs to take them, and ensure her weekly routines are consistent to build her skills and hopefully require less prompting in future.

Beth would benefit from some in-home assistance at least three times a week to build independent living skills and create a routine – such as cooking, washing and cleaning the home. She would also benefit from support which to attend activities in the community that interest her, such as going to the movies.

**Mobility:** Beth and I are both anxious about Beth leaving the house independently as she has trouble with her leg due to her brain injury. At the moment I am doing too many tasks at home to walk her around the neighbourhood, so she needs extra support to get out and become more confident getting around the neighbourhood. When she is unwell Beth needs increased support, especially to get to appointments as public transport is not an option due to her anxiety and difficulty with her leg. Beth does not drive. I spend at least six hours driving Beth around a week. Beth would benefit from physiotherapy support to improve mobility in her leg.

Beth is severely affected by her anxiety which can lead to repetitive questioning and behaviours to calm her down. If her rituals get interrupted she has to start again or she gets very angry so sometimes it takes hours to get out of the house and we often miss scheduled appointments. Without support I will not be able to keep up this high level of support.

**Learning:** Beth has expressed an interest in learning about sustainable living and ultimately working in this area through the Australian Farms and Community Gardens Network. Beth is very enthusiastic about this as one of her long term goals is to raise chickens. She has spent a lot of time researching chickens, and would like to continue with her studies to own and raise chickens. Beth would like to volunteer at the city farm project but has been unable to engage with the local farm by herself as she feels very anxious and worried that people will reject her ideas. At the moment I am not able to find the time to take her to this volunteer role.

She feels that with support she can achieve these goals: people to support her to access the city farm project and community gardens network; however, I'm exhausted thinking about the effort that it will require getting her to these activities. Additional support to the support I can provide would be necessary to help Beth achieve these goals.

**Social Interaction:** Beth has become very socially isolated with limited connection to the world outside her home. Beth states that she feels overwhelmed and very anxious when meeting new people - she has the desire to make friends, but does not have the skills and confidence to do so.

Beth hopes that volunteer work with city farm project as will help her meet new people as well as build her confidence. Beth would benefit from support at such activities to help her improve her skills and confidence when meeting new people.

I am Beth's main social interaction and this puts us both under considerable strain. I am incredibly isolated too as I can't work and have limited energy to meet up with friends and spend most of my time with her. I would like nothing more than for her to be able to move out of home and live independently, find work, have friends and enjoyable things to do and be able to spend time with me when she wants to hang out with her mum. At present this is impossible due to the high levels of support she requires to do the basic tasks of daily living.

#### Impact on me as a carer

I have my own health problems and am getting treatment for depression and anxiety which my doctor tells me is likely a consequence of long-term stress. Beth's physical, mental health and psychosocial disabilities require a lot of attention every single day and I don't have a lot left to take care of myself at the end of the day. I have very little saved for retirement as I haven't been able to work much throughout Beth's life. I worry about what the future brings for me and Beth if I can't get full time work.

As part of Beth's NDIS plan it would be good to have coordination of supports included. At the moment I feel like I am not able to fully understand what is needed to manage NDIS plans as I am so stressed and overtired from looking after Beth. I want to continue looking after Beth as I love her, but I need help in supporting her because I am becoming more and more frustrated with her and feeling more and more alone. Sometimes I can't give her the best support, as I don't have the energy, no do I have any idea of how to help her improve her life skills – I've tried everything!

In home support for Beth's activities of daily living to work toward her goal of living independently and support for her to access the community to make friends and work toward her goal of raising chickens would also give me the opportunity to look for work and restore my energy so I can keep supporting Beth in her wellbeing.

Thank you for taking the time to read this,

*Gillian Darcy*