

Kitty O'Sullivan & Andrew Klose

## NDIS Capability and Culture Submission

We are the parents of Olivia (Livvy) Klose, our second of three daughters. We knew of Livvy's Down Syndrome diagnosis before she was born and withstood substantial pressure from several doctors to end the pregnancy. We were more than happy to join the disability community and give our second daughter the same opportunities afforded to her two sisters, and we are extremely grateful for the government assistance we have received over the last 24 years.

Unfortunately, with the advent of COVID 19, like so many others in the community, Livvy's mental and physical health spiralled out of control. Her violent self-harming, non-compliant behaviour, anxiety and weight gain meant caring for her in the home was becoming increasingly more difficult to manage. We both have demanding careers, and, despite our best efforts, we felt that every member of our family was struggling with Livvy's very unhappy situation. An insightful psychiatrist suggested that Livvy might be trying to tell us she wanted to live more independently in a highly supported setting (specialist disability accommodation [SDA]). Over time, we decided to explore this SDA option for her. So began our incredibly stressful and protracted NDIS SDA journey.

November 2020

As a trial, Livvy accessed STA (Short Term Accommodation) for 8 weeks and absolutely loved it. Her numerous behaviours of concern ceased immediately, and she began to lose weight and generally feel happier within herself. Unfortunately, the cost was so prohibitive (approximately \$42K per month) that we had to bring her home, as our NDIS plan didn't allow for such exorbitant costs.

We engaged with a Support Coordinator who started the SDA application process so we could find a more long-term accommodation solution.

January 2021

With input from us, an SDA application was submitted to the NDIS SDA panel (which only meets once a month).

April 2021

After 3 months, Livvy's SDA application was reviewed by the SDA panel and immediately rejected, as not only did it contain her old NDIS goals of "continuing to live in the family home", but also several pages of documents relating to another participant altogether! We were absolutely devastated to hear this, as was the NDIS officer who made this discovery. We received a phone call from the NDIS to say our application had been rejected, but we were never officially informed in writing or encouraged to reapply for this funding.

Meanwhile our Support Coordinator (SC) left the organisation she was with, so we were assigned to another SC who was even more incompetent than his predecessor. After weeks of hounding him, we finally submitted a new SDA application which we basically wrote ourselves.

August 2021

Finally, 3 months later, SDA funding was approved and thankfully the room in the fabulous highly-supported house nearby was still vacant and available for Livvy. However, it still took another 7 months until March 2022 for the accommodation providers to complete the roster of care and Supported Independent Living (SIL) funding to be submitted and approved by the NDIS.

Now Livvy is thriving and finally able to enjoy the same basic rights as others to live a more independent adult life. She absolutely adores her 3 female housemates and dedicated support workers and has lost more than 25 kilos! She happily participates in her day program, dance classes and regular discos (complete with the occasional cheeky "hook up"! ). Her mischievous sense of humour and infectious laughter have returned, and she tells us all the time how happy she now is. As her doting parents, we could ask for nothing more, but we are still reeling from the amount of effort and persistence it took to secure this new life for our daughter.

We firmly believe that this drawn out and incredibly traumatic process should never have taken this long (16 months). Time and time again we encountered NDIS staff who simply had no idea what they were doing. Had it not been for our dogged persistence and determination, our daughter would still be languishing at home living a far from fulfilled life.

We are happy to make our experience public so that other families do not have to face the disheartening hurdles that we encountered at every turn.



GPO Box 700  
CANBERRA ACT 2601  
1800 800 110

Olivia Klose

Friday, 26 May 2023

Re: Your Change of Circumstances Request for Home and Living Supports

NDIS Participant Number: 430370239

Dear Olivia,

I am writing to let you know the National Disability Insurance Agency (NDIA) has made a decision about your change of circumstances request. I have assessed your request needs based on information submitted to the NDIA. The evidence I have reviewed in making this decision is:

- Request for Home and Living Supports, (A.Klose), (30.01.2023)
- Change of circumstance form, (A.Klose), (01.02.2023)
- Occupational Therapy Functional Report, (J.Caplan), (18.01.2023)
- Behavioural Outcome Report and Plan Recommendations, (S.Guiliani), (15.12.2022)
- Behaviour Incident Log, (21 Dec 2021 to February 2023)

I have made a decision based on available evidence that at this time that you do not require a specialised home and living decision. I have approved a new statement of funded supports, which will give effect to this decision.

The reason and justification for my decision is as below:

You have requested additional 1:1 supports to meet your personal care needs and assist you in managing your emotional regulation.

\* [ As stated in the Occupational Therapy report written by J.Caplan on 18.01.2023, it is noted that you are independent in getting ready for the day.

\* [ As evidenced in the Behavioural Incident Log, you may require support with your emotional regulation. At this time further evidence such as detailed incident reports and positive behaviour reports are recommended. As evidenced in this report and the Behavioural Outcome Report, it is stated that you require prompting for aspects of your personal care. However, there is no evidence to support what this prompting may look like. Further explanation of this is encouraged. This will assist the home and living team to better understand your circumstances.

Your current Behavioural supports are:

**Daily Routine and Structure:**

Livvy wakes up in the morning and is assisted to complete her self-care tasks. Then depending on the day she will either be driven to the day program or have a support worker for community access. In the afternoon, she will engage in activities at the SDA home with the other residents.

**Showering:** Livvy requires 1 X physical assistance to shower every morning. Although she may be able to complete the movements, she does not wash herself effectively and therefore the support workers will ensure that all areas are washed functionally. Livvy is able to dry parts of her body, however requires a support worker to dry under her skin folds to reduce the risk of pressure injuries.

**Toileting:** Livvy requires prompting to use the toilet regularly. She requires lots of encouragement to go, which should be provided between tasks, otherwise it is unlikely that Livvy will stop engaging in a task to go. Livvy requires supervision when on the toilet to ensure that she remains on the toilet and has her hygiene attended to. Livvy has a history of getting up from the toilet without managing her hygiene and pulling up her pants. A support worker is required to manage her hygiene following bladder and bowel movements. Livvy wears pull ups during the night as she is urine incontinent. She requires physical assistance in the morning to manage this nighttime incontinence.

**Bedroom/ Dressing:**

Livvy requires 1 X physical assistance with putting on her bra and picking appropriate clothing for the weather. Livvy is able to independently dress herself and don her socks and shoes.

**Eating/ Drinking**

Livvy has a mealtime profile following an incident where she choked on food and the ambulance was called. She requires supervision when eating as her swallowing ability can fluctuate. Livvy requires food to be cut up in small pieces to reduce this risk. Meg reports that Livvy may eat slowly in the morning and has been late to the day program as they are waiting for her to finish her food.

safety issue  
\*  
]

**Meal preparation:**

Once a week, Livvy will assist in meal preparation for the house. She will pick what she wants to make and assist with supervision in chopping, grating and is able to make a cup of tea and put her toast in the toaster. Livvy enjoys making tacos for the other residents.

**Housework:**

Livvy does not complete household tasks. All tasks are provided by the staff.

**Community Access and Participation**

Livvy requires supervision when accessing the community due to her poor safety skills and fluctuating physical capacity. She accesses the community regularly with a support worker and enjoys attending dance groups and other activities regularly as she is a very social individual. Livvy should continue to receive funding from a support worker to engage and explore community access tasks in areas of interest.