

Hello,

I wanted to let you know about some changes that we've had with BuddyBoy, to take into account when preparing his NDIS plan. After your visit in May, we decided to increase his Support Worker hours from 3 hours to 5-8 hours per day depending on worker availability. Obviously this made life much easier for myself and the rest of the family, but it also had a huge effect on BuddyBoy. Within the first week of having so much undivided attention, BuddyBoy absolutely blossomed. He started using the potty or the toilet, and this continued until it became consistent. He was talking a lot more – both echolalia and scripting, but also for actual communication, including answering questions with “no” or “okay”. He was engaging a great deal more with his workers and us, and was tolerating the noise of his siblings and their presence much more. His OCD and anxiety decreased as did his constant need to shred. He was much, much happier – smiling most of the time, laughing and singing, and going to sleep at a more regular time. He was even trying new foods!

When the rest of the family went away for the weekend from 9-11 June, BuddyBoy was at home with 1 or 2 support workers giving him constant attention. The reports we got back from them and my mum who visited on a regular basis, was that BuddyBoy was extremely happy and cheerful, he was not shredding at all (a miracle in itself), he was playing lots with workers (another miracle) and everyone was having a marvellous time. He was extremely cheery when we arrived home on 11th and still on the 12th on which day we had no support workers. He is used to having one day a week (Sundays) with no workers, so that didn't worry him. As from 12th June however we cut support worker hours back to 3 hours per day as we were concerned that if his NDIS plan does not provide for sufficient funding for the workers, we would then have to pay the bill, which we cannot afford to do. From 13th June around lunchtime, BuddyBoy literally started looking for his support workers. He was used to having workers here from 11am or 12pm, and I could see that he was obviously missing them. This was the first time he's ever looked for someone other than me! For that week, he would go to the window when I would tell him which worker was coming that day, to see if they were here yet. He started becoming less happy and more on edge.

By Sunday 18th, he had started not using the potty all the time but doing a wee on the floor quite often or flinging poo. He was no longer eating and drinking properly. His speech changed back to just being scripting, not even echolalia. He was no longer happy, not engaging much with us or his workers, and he started shredding paper and destroying anything he could get his hands on again. By Tuesday 20th, we were not allowed to use the microwave, the kitchen tap, the kettle, the toaster or open the fridge, or he would fling himself at us and harm us or himself. I have a cleaning lady coming every week who does what I cannot do while I'm monitoring BuddyBoy – for the first time ever he couldn't tolerate the noise of the vacuum cleaner. He ended up self-harming to an extent I have not seen since he was on medication, as well as attacking me quite viciously. He spent all that evening just crying and screaming and throwing himself onto the floor.

On Wednesday morning I contacted Interchange as I was simply unable to continue like this, and we now have support workers coming 6 hours a day again. Yesterday and today he used the potty consistently all day. He's eating and drinking more again, and today he started singing and using echolalia again. He has been happier

again the last two days, and I hope that with continued additional support worker hours, he will continue to improve. There have been no other changes in his environment other than the changes for the support workers' hours. The extreme changes in behaviour — to so much better, and then regressing severely, I can only attribute to the extra attention he was receiving with the support workers being there for him exclusively.

I would like to make sure that this is taken into account when developing his NDIS plan, as I can see that he would be so much more able to learn, grow and engage with others again, if he has that constant support which he obviously needs.

Many thanks,
Martina