

Parliamentary enquiry into the NDIS

The NDIS has been very good for our family. Our son Carl, who is now 20, was diagnosed with high-functioning autism just before his fourth birthday. He has been an NDIS participant since May 2015 and the control and choice that self-managing our NDIS funding has made possible, has been instrumental in helping us start to realise our family's vision for a good life for Carl. We share our story in the hope that it helps others to understand what can be possible when people with a disability and their families develop a strong vision for the future and self-direct their supports.

This is a summary of our vision for Carl:

Our vision for Carl is that he has the best possible chances of attaining the good things of life: good relationships with family and friends, meaningful work and financial security, a good education and opportunities for self-development, valued participation in his community, good health and a home in the true sense of the word.

Carl's autism is part of him but it doesn't define who he is and it shouldn't limit anyone's vision for what Carl might achieve or where he might belong. So in envisioning Carl's future, our guiding principle is to reach out for the typical opportunities that are available to young people with similar interests and aspirations, even though Carl may sometimes need an atypical path to realise those opportunities.

In spite of some signs to the contrary, I have chosen to remain hopeful that a key principle articulated by Rhonda Galbally, one of the architects of the NDIS, still underlies the opaque planning processes of the scheme: "People with a disability share the ordinary aspirations of their peers without a disability but need reasonable and necessary NDIS support to achieve them".

When you ask people across different cultures to name the 5 or 6 most essential components of a good life, i.e. the things they most aspire to attain or keep hold of, their answers are remarkably similar and look very much like the good things of life we have described in Carl's vision. But we all know that people with a disability are much more risk than the general population of missing out on attaining the good things of life.

The most important thing that I have learnt about planning for Carl's future is that in order to get the good things of life, he needs to be able to have **valued social roles** (think employee, student, crew member, runner, neighbour, friend, radio cohost, film maker). Research in the social sciences tells us this, but so does simply looking at our own lives. Holding valued social roles sets up a virtuous cycle in our lives where our valued participation leads to greater social connection and that in turn leads to more opportunities to contribute and connect and become truly enmeshed in the fabric of our community. Holding valued roles is clearly the most powerful protective factor against the marginalisation that many people with a disability face. But traditional methods of support have tended to limit people with a disability to token roles with limited expectations and opportunities for valued contribution. **For us, the most valuable aspect of the NDIS is self-management because this makes it so much more possible to support people with a disability to take on valued social roles in the typical community spaces where their interests would take them.**

The first time we used our NDIS funding was to support Carl to undertake an internship in radio production at 2XXfm, a community radio station in Canberra. [The Intern](#) is a short video that tells the story of the internship. Please watch the video because it will help to make the next points more salient. Self-managing allows us to employ people from across the ACT community, not just NDIS registered services. Firstly, this means that we have a much wider talent pool to draw on to find really enabling support for Carl than if we were agency managed. Secondly, it allows us to support Carl in typical community spaces such

as 2XXfm using people who are already part of that community. A key reason that Sophie, the manager at 2XXfm, was confident to propose the internship was that she could use Jenni, a team member whose capabilities and strengths she knew well, to support Carl. Thirdly, and probably most importantly, employing Jenni to support Carl, meant that he was able to develop genuine skills and make a valued contribution to the station. Carl has developed a degree of confidence and competence in a sound studio that he had not previously had in any other environment. If we had only been able to employ a support person from an NDIS-registered service, what would have been the chances that they would have had any radio skills to impart or that they would have been able to support Carl to take on anything more than a token role at the station? Since the internship, Carl has been producing and co-hosting a weekly radio show on 2XXfm.

The most significant impacts of Carl's autism are sensory sensitivity and anxiety. Even though Carl liked school, for students like him, who are situated towards the outer tips of the bell curve, it can be a difficult place to thrive. School can be an overwhelming sensory environment and Carl found tests and assessments very anxiety provoking and had a very limited output. So he finished school having absorbed a lot of information but also with a very limited sense of what he could be capable of. Statistics relating to the long term life outcomes for people on the autism spectrum show that only a relatively small numbers of them thrive in adult life and many of them are languishing on the Disability Support Pension. Experiences like the 2XXfm internship, where Carl could work one-on-one and without assessment, have shown us that adjustments can change a situation where Carl struggles into a situation where he can grow. We've experienced a lot of goodwill in the school system and the Canberra Institute of Technology Media Department but they only have limited scope for adjustments. **This is where we see the insurance function of the NDIS working in the interests of Carl and the Australian tax payer. We are investing some of our NDIS funding in a bespoke training pathway in media production, Carl's**

chosen area of professional development, in order to maximise his achievements and his prospects for gaining meaningful work and a career in this field. We hope that with a few more years of investment in this training pathway, Carl will never have to rely on the DSP. There is a growing open-mindedness about autism amongst employers and an appreciation of the value of the attention to detail and other traits that are common among people on the spectrum and this also makes us more optimistic about Carl's employment future.

For the last two years, Carl has been developing his film production skills through one-on-one mentoring with Daniel Sanguineti, a local film-maker and proprietor of Sanguineti Media, as well as through studying media at CIT. We are using our NDIS funding to pay for Daniel's time. Daniel is assisting Carl to write, direct and produce a 16 minute stop-frame animated film based on Carl's original concept, using the same processes, software and technology that are used in the film industry. I have included as part of this submission, a copy of Daniel's letter to the NDIA, written for our plan review in May 2017, that describes the progress that Carl has made in the first 10 months of their collaboration (see below). Carl has now developed a level of technical skill that means there are likely to be opportunities for him to assist Daniel on a paid basis with his client work this year (Carl has also enjoyed opportunities to assist on film sets for some pro bono projects that Daniel has been involved with, such as "Balloon Man" that was a finalist in the 2017 Lights, Canberra, Action film festival). Sanguineti Media recently relocated to the new film-making hub at the Canberra Technology Park, along with Screen Canberra and several other film production companies. Monica Penders, the director of Screen Canberra, has got to know Carl and has had a look at the completed scenes from his film. She advised us recently that she thought that it would be the sort of content that ABC iView would be interested in hosting.

We have developed a good relationship with CIT staff but we find that Carl requires different support to undertake assessments than what CIT provides through their disability

support services, which tend to focus on learning difficulties, whereas Carl's real challenge is debilitating anxiety in the face of assessment. Our ultimate aim is that he will be able to complete CIT work, or any other tertiary course work, without assistance but we are still in the process of untangling that connection between assessment and anxiety through the input of CIT teachers, Daniel and Carl's psychologist. His teachers are providing detailed breakdowns of tasks to give Carl a high degree of certainty about what is being asked and Carl is working on tasks with Daniel alongside to provide guidance and reassurance to help him get started and persist. Carl and Daniel recently "rehearsed" an in class assessment to help Carl prepare. On the day, some of the technical requirements were different and Carl felt flustered for a while but was able to work his way through his anxiety, rather than shutdown, and completed the task successfully. This is a sign that Carl is beginning to have faith in his own abilities and his capacity to solve unexpected problems on his own and won't always require so much one-on-one guidance in order to flourish.

Our last plan review was a sobering experience. Firstly, we had to focus on describing Carl's functional impairments, rather than goals, in order to determine funding. Once again, he was being defined according to his disability, and not by his aspirations, as his typical peers would be. At that time, Carl's main goal was to get into part-time employment as well as study part-time - which is very typical for someone his age. The planner suggested that we apply for Newstart allowance, the requirements of which aren't very conducive to an autistic person succeeding, but he did include \$1000.00 in the plan towards employment (\$6000 was included in our previous plan for employment). The planner also rewrote our plan goals and put completing media studies at CIT as the main goal. It seems, from our experience and those of other young people we know, the NDIS had decided that young people with a disability are either looking for full-time work or undertaking full-time study.

Although we had emphasised how useful our capacity building funding had been in the previous year, all our current funding was put into the core section of Carl's plan (apart

from some funding for occupational therapy). We were concerned that Carl might have to give up film mentoring with Daniel because it was essentially a capacity building support. Carl suggested that he go down to the local shopping centre with a sign saying "The NDIS sent me here". We spoke with staff at the Braddon NDIS office and they confirmed that we could still use our funding to pay Daniel because we are self-managing our funding.

We were also unable to access our NDIS funding for 4 months after the new portal came online. In the end we had to resort to contacting our 3 Federal Government representatives in order to get action to fix the problem. Senator Katy Gallagher's office responded to us immediately and contacted the NDIS on our behalf, which resulted in Ms Gill Marsh, from the Braddon office, contacting us shortly after to look more closely into why we didn't have access to Carl's plan through the portal. Over a period of about 2 weeks, we spent several hours on the phone and Ms Marsh spent many more hours outside of those calls in working with NDIS IT staff to fix the problem. We were very appreciative of her doggedness in solving the problem.

Finally, we wish to lend our support to Ms Gay Von Ess's submission in regard to the Early Intervention Preschools that operated in the ACT prior to the introduction of the NDIS. Carl was able to access the Chisholm Early Intervention Preschool from the age of 3 and a half, a few months prior to him receiving a diagnosis of autism. This was such a valuable resource for us. The small group setting and specialist skills of the staff helped Carl to learn many of the social and language skills that allowed him to successfully transition to our local preschool the following year. For us as parents, it was a great relief to see Carl be able to access a setting where some of his evident developmental challenges could be addressed, even though we didn't yet have an overarching label for them. We were also able to get advice from the staff that helped us to engage and communicate with Carl more successfully at home and this helped to make home life easier and more enjoyable. While we found one-on-one therapy very important for Carl's development, it couldn't provide the

scaffolded socialisation in the role of "student" that helped Carl to have a positive transition to mainstream preschool and school.

May 10th, 2017

Dear Adriene,

I am writing to you to appraise and report on Carl's progress during the last 10 months I have been providing mentorship and guidance to Carl in film production and theory.

I am incredibly pleased to see how far Carl has grown from our first meeting. I have endeavoured to provide Carl a welcoming and patient environment, that works at the pace he feels most comfortable and where he ultimately has had the control of how our time is spent together. In return, Carl has shown is tenacity to work to his absolute best, aspiring for a sense of professionalism in the content he has created and displayed a passion for film and storytelling. Even though Carl needs a slightly different approach when it comes to learning a topic or being explained a task required to complete, he has shown that he is able to do a number of different tasks related to the preparation and production of a film or video.

The main project we decided that we would work on together was a Lego Animation short film. But instead of simply jumping into the fun part, making the lego pieces and then taking some photos to see how it all turned out, we have spent the majority of the time, carefully planning and developing his film, much like how films are developed within the industry.

We first brainstormed the ideas around the film. We wrote keywords down and developed ideas from those keywords. We outlined a wish list of characters and scenarios and possible back stories. From there we worked on the three key elements of the film, the beginning, the middle and the end. Once we identified these story points, a mid-point crisis was identified - all the characters were to be captured by a villain. This allowed us to develop a story from these four plot points, which then we expanded into a full film script, currently titled "The Hasaid Maneuver." Scene action was written and dialogue that suited each character was experimented with until Carl was satisfied with how it sounded on the page. Even though I was writing the words onto the computer, Carl was responsible for those words, such as crafting what the characters were to do next, what they were to say in response to the current situation, and how the story was to come to an end.

From the script, each scene and shot were drawn into a storyboard. Through these storyboards Carl was able to begin visualizing his film. Over 140 storyboards were drawn to capture the entire script, each frame representing a shot from the film..

The next stage involved casting the voice actors to play each of the characters. An audition line was sent out to Canberra's actors, and Carl received a number of audition pieces. Carl listened to all the pieces and selected which actor's voices suited his vision best. Following on from the casting, each actor came in to do the voice recording. Before each recording session, Carl wrote directing notes to give the actor for each line of dialogue. During the recording Carl referred to those notes, and providing explanation and direction to the actor of how he envisioned the line to be performed. Carl used the notes to ensure he was consistent in describing his vision to the actor.

Following the dialogue recording, Carl listened to the entire raw audio of each performer and cut out all the takes and excess audio to leave a simply audio track of the best performance of the required lines from the script. He repeated this for each actor's recording. Next came the dialogue assembly. While referring to script, Carl located the correct pieces of dialogue and edited the basic structure of the film. Following this, he began adding in the storyboard images to produce an animatic of the entire film. This animatic will dictate how long each shot will need to be when we begin the stop motion animation. Carl has also begun adding sound effects and temp music to help develop a mood and feel for each of the scenes.

Together, Carl and I have agreed we would be looking for shortcuts in the stop motion animation process. An example is for some dialogue scene, we will be taking a single photo of the character instead of twenty five photos per second. Then the animation will be done using computer software, to animate the mouth moving or move the camera using keyframe animation. We have done some experimenting with keyframe animation and I believe Carl will be able to complete this short cut quite effectively.

As a result of this work on his short film, Carl has now gained experience using a number of different software programs synonymous with those working professionally in the industry.

We worked through the functions and utilities in Apple's Final Cut Pro X. In this program we produced a short intro video using keyframe animation, graphic shapes and text elements. Carl went on to complete a rough cut for a professional music video, of which became the scaffold for the final completed and delivered edit to the client.

We also have worked with Adobe's suite of software. We used Adobe Story to write the script to Carl's short film. We used Adobe Sketch on an iPad Pro using a stylus pen to draw the storyboard frames. He has used Audacity to edit his audio recording and Adobe Premiere to edit his audio and assembly his animatic. He has also used Adobe Photoshop to assembly his storyboard frames and prepare them for insertion into the Adobe Premiere timeline.

I think Carl's biggest realisation over this time has been about how long the filmmaking process can take, as there are quite a number of different steps and processes. He has completely come on board on the idea that taking our time to get each little element correct and working well, has benefited his understanding of a bigger picture process that belongs in the media industry. Currently we still have the stop motion animation to begin, but in some ways, the film is already coming to life through the dialogue edit, temp music and sound effects, and the storyboards. He has shown he has aptitude to complete repetitive tasks efficiently and accurately.

There is a number of directions we can continue working on together. Obviously, we need to finish the stop motion animation. This will continue to be a focus for upcoming sessions. Beyond that, there is a room for us to work on shorter content to continue help building a portfolio of work for Carl. An idea that I have put to Carl is involving him in more in my client's projects. This could involve editing work for review by a client, or attending client shoots as an assistant. As Carl's confidence in his work continues to grow, I believe this could be a great way to build his skill base and resume.

Carl has a clear passion for film, is hard working and very professional in his approach, and it has been a real pleasure for me to provide him with guidance and mentorship over the last several months, and I look forward to the opportunity to continue working with him onward.

Kind regards,
Dan Sanguineti



Producer, Writer, Filmmaker