

## Taking Control

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*Sylvana Mahmic lives in Sydney with her family of three sons. Sylvana 's interest in disability began 19 years ago when her first child was diagnosed with a disability. Her interest has led her to work in this field.*

We have spent the last three years planning what our son would do after the HSC and, in that time, we never imagined that we would choose a post school option that included the capacity for us to self manage his support. But here we are, three months into it, and it's working out well for him and our whole family.

We first read about the self managed option in the DADHC post school options book, which we received after applying for entry into a post school program. Our son, Karim, was eligible for the Community Participation Program. It sounded interesting: you organize your own activities and prepare plans for how you will use your DADHC Community Participation funding. We mentioned the option to a few people involved with Karim, but they weren't very positive about the idea. According to them, it was a complex option, available to a tiny number of people. That hasn't been our experience.

Shortly after receiving this booklet, we attended a school leaver's expo, organized by post school service providers. I asked about the self managed option at the DADHC booth and received encouragement to contact the agencies who were providing the packages. I gave one agency a call and since then everything has fallen into place and we are really happy with our son's post school life.

Like me, you may be wondering what the self managed option is all about. Your son or daughter, along with your family (and others if you wish to include them), make all the decisions about how the program will meet your son or daughter's needs. Together, you decide what it is your family member wants to do and when they want to do it. You have the assistance of an organisation to help you through this process. Every program is individual and starts with your child's strengths and interests. The self managed approach is about thinking,

planning and developing skills, so that your son or daughter is seen as a valued member of the community.

For our family, this flexible and individual focus was appealing. We had spent years trying to fit our son into other programs. Due to the nature of his disability and additional health problems, this has been a constant challenge. Now, he could be at the centre of everything, and the program would work around his needs. He didn't have to fit in with what was being planned for the majority: it was all about him.

When I first read about the self managed package I imagined that it would be a huge amount of work for the family to organize. After all, we are 'managing' our son's community participation money for the year. Actually, it hasn't been as time intensive as I had imagined. I haven't had to take time off from my full time work to help start our son's program. The first three months have been less intense than I expected.

The financial side is managed by the agency. They receive the money from DADHC and do the administration associated with our son's staff and manage the yearly funding allocation. They pay the staff and organize all other payroll matters. Our family's main administrative task is to check and then email our staff time sheets to the office so that their pays can be processed.

Recruiting the staff is probably the family's biggest challenge. A significant task for our family has been to induct new staff. While this has taken a significant amount of time, the benefit has been that I now share a lot of knowledge about my son that, up until now, I have been the 'keeper' of. I feel a tremendous load off my shoulders, as we now have some systems in place, to help people get to know him and some of the important things about his health, safety, strengths and interests.

With no experience of the self managed option, we looked to our agency for information and support to help us start the program. They have provided this through a combination of telephone and face to face meetings. I have also found email contact helpful, especially around administrative matters. Our experience has been that the staff are very respectful of our family and that they work sensitively with us to support our skills in managing the program. Initially, we scheduled monthly meetings and talked on the phone fortnightly. Now, we are meeting every three to four weeks and I feel I can phone whenever I need to. There is an expectation that we are working in partnership with the organisation, but that my son and our family, lead the program.

A typical day is guided by our plan. Karim is assisted to complete the things most people take for granted every day, as independently as possible. His daily routine starts with breakfast,

grooming and some housekeeping responsibilities. He has help to participate in these activities and our long term aim is that he becomes more independent in some of these. In a busy household, we had lost sight of this, as it was easier and faster to do things for him. Now we have someone fresh, whose job it is to take him through these routines, with the aim of teaching him to be more independent. He is enrolled in a computer course through TAFE outreach, which he really enjoys, as he knows more about how to use the computer than everyone else there! We are talking about ways to continue to develop his interest and skills in computers: maybe a course on developing his own blog? He goes to the local gym once a week to start focusing on how to get fit. We hope that we can get a personal trainer to work with his physiotherapist, to make sure he does this safely. On Fridays, he goes to prayers at the mosque, just like other adult Muslim men. Surprisingly, he really loves this day of the week (the sermons are short!). Based on his interests, we have several more things we are trying to set up: he wants to do karate; we are looking for ways to incorporate his passion for cricket and football; he wants to learn how to use the phone (not an easy task as he cannot talk very much at all!) and he loves antiques and the Antiques Road show. I think I see him visiting the local auctions and who knows what can develop from there.

So, just over three months into the program, what has all this meant for Karim? He is happy! That is really our number one concern. He has a say in what he does every day. He has greater control over his life. He is directly involved in making decisions about what he does. If he enjoys it, we carry on, if he doesn't, we will make changes. He is trying new things and gaining confidence in learning from these experiences. He is communicating more, not surprising when I think about it, as he is happy about his choices. His program starts each day, when he is ready, as we are not running to someone else's timetable. He is more relaxed. And so are we.

If your son or daughter is approaching the senior years in high school, start looking around at the options available in your area. Talk to your school and check out the information provided by DADHC. Attend a few expos, start visiting some organisations and give the self managed option some consideration. The benefit of this approach is its flexibility. Our service stated that they would work with us to enable our son to 'pursue a lifestyle that is personally meaningful, relevant and entwined in the life of the broader community'. So far, the self managed approach has met our son's unique needs and placed him at the centre of building a meaningful adult life.

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