

Families for Change

Promoting and defending
the rights and interests
of people with
developmental disability.

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A D V O C A C Y

Life After School...An Opportunity For Work, Growth and Dreams

As the end of high school approaches, Family Advocacy hears from many families who are gripped with anxiety. With school coming to an end the future is filled with great uncertainty. When should they start planning? What could be possible? Who do they need to speak to? What do they need to do?

Inspired by this articulated need from families to get more information, Family Advocacy developed a workshop – *After school – what then?* This workshop provides an overview of the post school landscape and offers examples of what young people with disability are achieving in their post school years.

The workshop encourages families to think about what sort of life they want for their son or daughter, to start planning early, to gather information and to take control of the direction the future might take. It also encourages them to have high expectations and dream big dreams.

There is significant research going back many years to show that all people can engage in meaningful work, or work related activities, irrespective of the level of disability.

For people with very high support needs, the intervention and assistance given will, of course, take more time and require more intensity, but we hear many stories of young people with very significant disability pursuing work roles. A person we know grows fresh flowers in her garden and has a small business providing restaurants with fresh posies of flowers. Another young person is running a postal pick-

up and delivery business. Both these individuals need people to support them at all times. Neither can drive, nor can they speak. They both have very high support needs in all acts of daily living and in personal care. Stories such as these demonstrate what is possible

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when families hold a strong, positive and inclusive vision for their son or daughter and believe that they can make real contributions to their community. Young people with disability around Australia are achieving their individual dreams via a range of avenues that offer inspiration and strategies and this issue of *Families for Change* will share some stories of what can be possible.

In *Let's get Working*, you will hear from Helen Parkes about the path to work that students with disability may take and the supports that may be available. In *Taking Control*, Sylvana Mahmic provides insights into her son Karim's first months of post school life and how his world is changing for the better. Sylvana provides frank insights into her initial apprehension, the challenges and the rewards of Karim forging a life that is opening up all kinds of unknowable possibilities. *A New Vision* provides insights into the post school life of Clare Hooper, who is two years out of school. The article

discusses specific tools used by the Hooper family to support Clare to be an active member of her community and considers the road ahead. In *University Days*, Miriam High shares her daughter Rachel's experience of auditing university courses in Adelaide and the rich and varied experiences that have resulted. Rachel was supported via the Up the Hill Project that facilitates the participation of people with intellectual disabilities in the social and educational life of the Flinders University. The Up the Hill project is the only one of its type in an Australian University although individual families have negotiated with universities so that students with disability can audit courses of their choosing.

This is not yet a commonplace occurrence here in Australia, but in Canada and elsewhere, young adults with developmental disabilities have been successfully and fully included in both university and colleges for almost 20 years. It gives us something to aspire to.

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Let's Get Working

Helen Parkes

Helen Parkes is an Assistant Manager with Jobsupport Inc's Transition Program. Helen has been working with Jobsupport for four years and continues to feel great satisfaction when the young people supported achieve their goals and good job matches take place. Helen provides an insight into the journey from student to worker, including what goes on behind the scenes.

People with disability leaving school and seeking employment may go directly to employment or training or they may be supported via a program or service specifically intended to help people with disability move into a work role.

Jobsupport's Transition Program is intended to give school leavers with a disability extra help *before* they attempt paid employment, by providing them with individual training within real work settings and by addressing issues that are preventing their acceptance into an open employment environment. All transition services offer different models and parents and students should talk to service providers to ascertain which service will best suit their individual needs. Transition to Work programs (TTW) are funded by the NSW Department of Ageing, Disability and Home Care (DADHC). This program essentially offers training that will lead to paid work.

In contrast, the Disability Employment Network (DEN) is funded by the Commonwealth Department of Education, Employment and Workplace Relations (DEEWR) and provides support to people with disability needing ongoing support to find and keep paid employment in the open market.

For some students the journey from school to work can be a very stressful and difficult time trying to find the right service to best suit the individual needs of the student. For others they may have very clear and specific ideas about what direction they have in mind. They may even have started some work experience when at high school that has helped to provide tangible experiences and opportunities.

Transition services should provide guidance to assist in this transition and develop realistic and practical training methods to assist the student on the pathway to employment.

Families may first come into contact with services offering work related support during the school years – directly

via school meetings, at information afternoons and at expos. Some families just contact organisations directly to ask questions about what could be possible.

Families find out in October each year the type of service funding the student has been granted. After this time families can then choose and register with a service provider before December but, it is preferable to have started the planning process before then.

The feedback from the employer and the young man has been fantastic.

All transition services operate differently, however, it is useful to start gathering background information and assessing potential school leavers as early as year 10. This information is gathered from a variety of sources, including families and schools, to help obtain a clear picture of the young person. What does he or she like? What are his or her past experiences? What courses have already been completed? What travel skills does the person have? What social networks does the young person enjoy? What are the dreams and aspirations of the young person and his or her family? An initial meeting with the student and family, observation of the student in their school work experience placement, and/or a work trial in another setting, is also part of the assessment process.

Once this information is gathered an assessment summary is completed, with any gaps identified in terms of skills, knowledge or experience.

A meeting is then organised between the service provider and the young person and his or her family. Families are provided with a copy of the summary in advance so that they can meaningfully contribute to the discussion and be actively involved in decisions and development of the plan.

Even though social networks may not be an obvious consideration, social skills are an important part of work life and it

may be that suggestions are made about where possible connections could be explored relative to the interests of the young person.

There is not really a typical day in the Transition to Work Program. What happens depends on the goals and support needs of the young person being supported. There may be intensive concentration on a skill that is providing an obstacle to employment or there may be experience in a work setting. Travel training is one skill that may be worked on to ensure that a young person can reach that important hurdle of travelling independently to and from work.

Many young people start with a wide range of ideas of where they may like to work in the future and part of the role of the organisation providing support is to help the young person think laterally about where a job may take place. For example, if someone is keen to pursue a future in food preparation there may be a whole range of contexts in which this could take place beyond a cafe or restaurant.

One young man who entered the Transition to Work Program expressing a desire to be a chef ended up gaining employment in the open market, in an office role. During his time in the Transition to Work Program he tried a range of roles in food preparation and an office context. When he was accepted by the Open Employment team (DEN) and a chance for a job in a large office came up, he grabbed the opportunity. He loves the environment and working in a work place with more than 2000 staff. The feedback from the employer and the young man has been fantastic. He received intensive work place training and support for the first four to six weeks, with support reducing as the job was mastered. Support continues for the life of the young person's job/career and, who knows where he will end up working, but the possibilities for this young man, and the many other young people pursuing their dreams, is bright!

Taking Control

Sylvana Mahmic

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.

In this article Sylvana shares Karim's initial steps into post school life.

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.

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.

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.

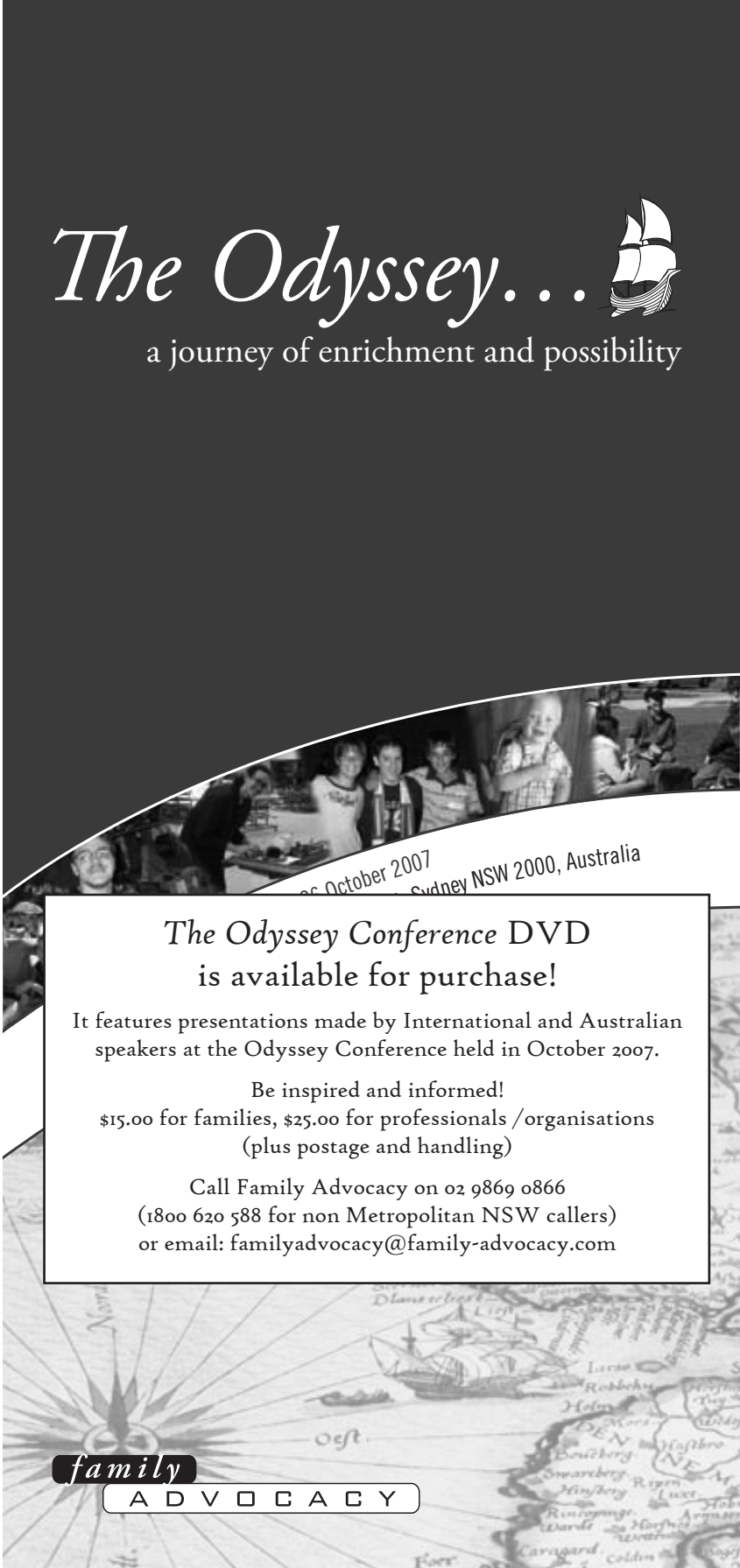
With no experience of the self managed option, we looked to our agency for information and support to help us start the program. They have provided this through a combination of telephone and face to face meetings. I have also found email contact helpful, especially around administrative matters. Our 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 Roadshow*. 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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family ADVOCACY

A New Vision

Helen Hooper

Helen Hooper is a mother of three children who lives in Drummoyne, Sydney.

My mother always said there was no such word as 'CAN'T'. It is true, we no longer say, "I can't" or, "We can't". Now we say, "I can" or, "We can".

How did our new vision begin?

It seems that a major set back is often a wonderful stimulus to jolt people's minds, actions and enthusiasm. After the wheels fell off with a provider who was supporting our daughter, our family was forced to re-examine the situation and to start thinking about how to operate individually, rather than collectively.

Fortuitously, at about that time, Family Advocacy held a conference, *The Odyssey*, where there was a wide presentation of papers from both overseas and Australia that were inspiring, educational and motivational.

The timing was very appropriate as a new option called Self Managed Community Participation had just been launched and we were the first family accepted into the program.

Our first task was to establish a 'circle of friends' for our daughter, as we felt that this would allow us to think very broadly about the many pathways we could venture into and allow some very necessary lateral thinking. The selection process around who would be in the circle was left to my daughter, as it was important that she was comfortable with the circle. She selected some of her peers, her sister and family friends.

At our first meeting we attached posters around the room on which we scribed under the following headings.

- ✓ What interests me and what is great about me?
- ✓ My community and the services I use.
- ✓ What I like about where I live.
- ✓ Activities I like doing in my community.
- ✓ What sort of jobs would I like to do in my community?

From this very lively, happy and very fruitful meeting we ran with a number of successful ideas.

Firstly, our daughter has always been a very good artist, so it was decided that

she should work with an artist one day a week. This led into the production of occasion cards, Christmas cards, art competitions and exhibitions.

There was a need to improve fitness and lose a few kilos so, a personal trainer was employed! The one-on-one experience and doing something that many other young people were up to in the local park resulted in a good 10kg coming off in a short period of time. This was also assisted by joining a weight loss program, another 'circle of friends' initiative.

She is an artist, an office worker, volunteer, weight watcher, a citizen, trainer, commuter and valued community member.

The 'circle of friends' was very keen to see our daughter as a strong member of her community. It was thought that volunteering would help her establish this standing. We developed a flyer saying 'Help a local out'. This was distributed to businesses in the working locality. A number of responses arose from this, one in a real estate office where she delivered, with a support worker, the 'For Sale' flyers in the local streets. This not only offered exercise, but a chance to 'chit chat' with the neighbourhood.

Another opportunity arose in an architect's office where she was able to carry out general office duties two hours per week. She enjoyed this contact, the feeling of importance within an organisation, plus an opportunity to learn many new skills.

The 'circle of friends' meets every 6-8 weeks at a local coffee shop to evaluate our daughter's progress, suggest new ideas and enjoy successes.

Over a very short period of time we have achieved a lot and moved from a very sad, non functioning situation to a happy, active and successful program. Through these activities that are growing, changing and developing, our daughter has valued physical and social roles. She is an artist, an office worker, volunteer, weight

watcher, a citizen, trainer, commuter and valued community member. In less than two years our daughter has grown in confidence, is included in her community both socially and in the workforce.

The success of the self managed program is allowing us to embrace the idea of independent living. We are able to discuss the idea of leaving the family home and beginning a new existence close by, hopefully with a companion.

As Darcy Elks, a speaker I heard recently says, "Always examine the gifts people with disability can bring to the world and how these gifts can enrich us all as well as open up possibilities of a full inclusive life within community."

How do you build a vision?

1. To find information on building a vision, go to www.family-advocacy.com
2. On the Home page go to 'I want to know about....' and click on the down arrow. You will be given a selection of topics. Click on 'BUILDING A VISION' from the drop down box.

The page that opens provides links to:-

Building A Vision [Articles]:

- No. 11218 *Clarity of Vision: A Compass for the Journey* by Wendy Stroeve. This paper was presented at the Family Advocacy Conference *The Odyssey*...
- No. 11113 *Developing a Vision* by Colleen Tomko
- No. 11222 *Planning for now, tomorrow and the future* by Jeremy Ward, another paper presented at our conference *The Odyssey*. (See opposite page for info about how to order your copy of *The Odyssey* DVD.)

Also, under that topic, see:

- What's in our Library
- Links to Useful Websites
- Further Information

Prefer to receive hard copies of articles or want to know how to borrow books from our Inclusion Collection Library? Please ring Family Advocacy on 02 9869 0866 or freecall 1800 620 588 (NSW non-metro callers).

University Days

Miriam High

Miriam High has been a tireless campaigner for 30 years in the field of Early Intervention, Parent Empowerment, Inclusion, Housing, Carer Support and the Arts. Miriam lives in Adelaide with her husband and only daughter, 32 year old Rachel.

At 21 years old, Rachel completed the Gold level of the Duke of Edinburgh Award Scheme. On receiving her Gold Award, Rachel was asked by the Director of the scheme what she would do next and if she had considered applying for the Up the Hill Project.

The Up the Hill Project facilitates the participation of people with intellectual disabilities in the social and educational life of the Flinders University in South Australia. Eligible participants are assisted to select and audit topics of their choice and are supported by mentors to access and enjoy the services and experiences the university has to offer.

Rachel is an only child and therefore had no siblings who could have introduced her to this university experience, so the idea was completely new and she did not really appreciate what it all meant but was eager to consider it.

Once Rachel had applied, we, as a family, were invited by the Project to attend lunch at the Flinders University. We were to meet other people interested in attending and some of the current participants.

A casual conversation took place over lunch with the friendly Director of the Project. Rachel was encouraged to talk about her interests and how she thought she might benefit if she attended university. Little did any of us appreciate it, but this had been her interview and to her delight a letter soon came saying she had been awarded a place in the project.

The first day of term came and Rachel was introduced to a young student in Disability Studies. This student was to become a mentor to Rachel and remain her companion during the first semester.

Rachel needed first of all to know how to get to Uni on the bus, unaided. How to catch the bus from home, change buses in the city and where to get off when she had arrived at the university. After only a few weeks of training, Rachel was managing this well on her own. On one occasion,

when she did get off the bus at the wrong stop, Rachel walked the remainder of the journey following the bus route and met up with the mentor a little late but in the right place. Rachel had now proved she could learn this lesson so we felt more confident all would be well.

The relationship she had built up with this group of people at university was, as with most other university students, influencing her future.

Supported by the mentor, Rachel registered as an Auditing Student and collected her, all important, student card. Together, they met up with the lecturers of the subjects she had chosen and negotiated for her attendance at the lectures. Once accepted, she paid her auditing fee and registered for the subject.

The role of the mentor is not one of personal carer or, to keep all the Up the Hill participants together, but more to allow the individual participants to completely disappear in to the community of the university. They introduce the participant to as many aspects of university life as possible: to include them, without specific reference to any special needs, to the facilities offered to other students on the campus. This includes use of the library, access to a computer and use of the gym as well as access to any social activities organised by the students.

From here, Rachel was like any other student. She and her new friend attended the lectures together. She bought and ate her meals in the 'Decaf' (university café) with all the other students, attended student activities and visited the halls of residence. The hall of residence was very attractive to Rachel and she would happily have left home and gone to live there.

As time went by, she became just another person on campus and she was reveling in it. On one occasion, I was concerned that she was wearing older clothes. I asked her if it might be a good idea to wear something smarter to Uni. Her reply was to say, "If I do that Mum I would look different to everyone else, most people wear old clothes".

One of the first subjects Rachel selected was Film Appreciation. In Film Appreciation, she learnt much about the techniques and the language of film making as well as the exploration of different genres.

As each semester went by, Rachel became more comfortable at Uni and attended two days a week which gave her the opportunity of taking more than just the one subject. Each time, with the assistance of her mentor, she was required to negotiate with the lecturer for admittance to the subject. Over her three years she chose a variety of topics.

During her studies of English, she completed some of the assignments set for the students and presented them for comment by the lecturer. Auditing Students don't receive a mark for their work, but this lecturer was very happy to comment on Rachel's efforts and she was delighted.

Another subject Rachel undertook was Drama. This was a very difficult subject to get in to. She did, however, attend the lectures and in this setting was introduced to some fine plays and acting by students. The lecturer later commented how Rachel always came down to the front of the class when a performance was over to congratulate the actors on their work, something other students seemed not to do.

Screen Studies followed on well from the Drama and Film Appreciation. In the first year of Screen Studies, Rachel was totally included in the class. Here she was able to form part of a discussion group, which had been given the task of making a short film. Many of her

contributions were well received and she enjoyed being part of the team. The class eventually went on location and made a short film. Rachel assisted with the camera work, the lighting, and provided the voice over in the film.

Life was full and rich for Rachel at Uni and she had many adventures with the students. She has a group of friends from her growing number of mentors and often went on social outings with them. There was the occasion when Rachel asked if she could go to the karaoke night. There was concern both from the mentor and the Director about this request. The students at the karaoke had a reputation for being extremely hard on people who dared to take the microphone. They did not know how Rachel would accept this challenge and felt very protective. As it happened, they all took the chance, in line with the philosophy of the project and took Rachel to the karaoke evening. She did sing, she did get heckled with all the others, she did enjoy it and, she did get genuine praise from the organisers for her performance. So all were grateful for the decision they had made.

The end of the three years came all too soon and, to her delight, Rachel graduated from university in the same manner as that of her peers, in that she dressed in a black gown and mortar board and crossed the stage to be formally presented with her certificate of

attendance to the applause of the student body. Now, four years after Uni, Rachel is still in contact with some of the tutors and students who became part of her life. One major and lasting event which has come out of her time at Flinders University is the ongoing relationship she developed with the Screen Studies lecturer. She impressed him to such an extent, that he and his family maintain a relationship with us as a family.

Rachel's interest in script writing did not go unnoticed and the lecturer suggested to Rachel they make one of her scripts into a film. This idea grew with great momentum and the lecturer then supported and mentored Rachel through two years of film production. Between them they devoted a lot of time refining it to make it in to a shooting script. He would give Rachel challenging projects to achieve by a certain date and she would in turn set to and do the task. These were real tasks - like compiling the background of characters, costumes, background music, finding shooting sites, or finding actors to play her roles. The film "Brown the Dirt" came to fruition at the end of last year, 2008.

The opportunity to again work on a project with the lecturer and some of the students she had been with at university took her knowledge to a greater depth along with the many people who offered to take part in the making of the film.

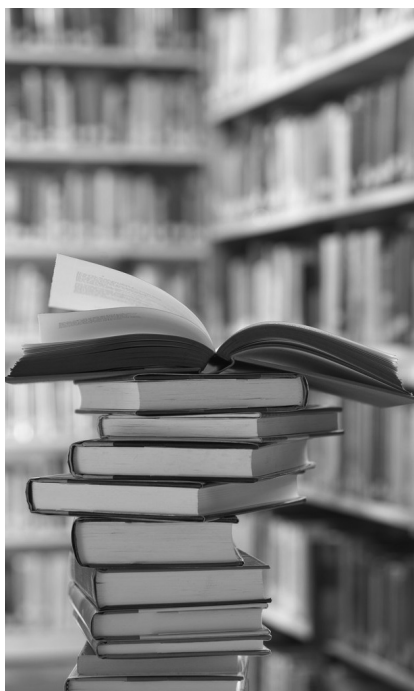
The relationship she had built up with this group of people at university was, as with most other university students, influencing her future.

We are very grateful to the Up the Hill Project and appreciate that our daughter has been very fortunate. We are well aware this experience is one which is mostly denied to people with an intellectual disability.

Rachel's time with the Up the Hill Project had offered her more than just the opportunity to tell her friends and family that she was a university student. She found self confidence and personal security. She has been offered an opportunity to gain new knowledge as well as the acceptance and respect of other students; students, who were, in turn, eager to know her and share her knowledge.

For Rachel, her three years at university has been a full and exciting time. It has been a deeply enriching experience, which will have a lasting effect on Rachel's life.

Postscript – we have just received the exciting news that Rachel and Miriam leave for Dublin in the middle of August for Rachel to present this information, from her own perspective, at an international conference!



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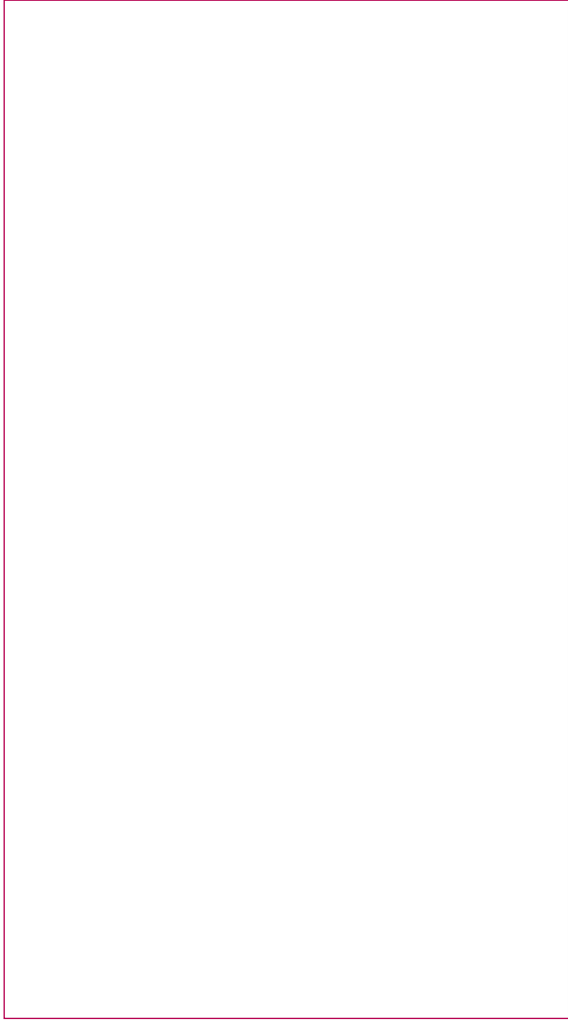
Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

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