

Appendix 4: Documentation: Consultations, Written Feedback and Individual Stories

(a) Reporting On Community Consultations: May 23-25th, 2005

Consultations were conducted on May 23rd-25th, 2005. This included two evening consultations and a one mid-day consultation. In total approximately 55 people participated in these three sessions. While participants were primarily parents of students or adults with disabilities, a number of service providers and special education teachers also took advantage of the opportunity to contribute.

The purpose of the consultations was to gather comment and advice on the types of opportunities that were suggested in the Opportunities Paper and circulated through the ACT community.

The comments received are documented below, and are organised with respect to the individual opportunities that were presented. It is important to note, however, that where comments appear somewhat disjointed, this is a reflection of the general 'dialogue' which emerged between participants and the fact that some participants were primarily concerned with clarifying their understandings.

Despite these limitations, and the lack of any clear themes, the comments do reflect the types of experience and concerns of participants, and in particular a broader concern about whether, and how, implementation might roll out.

1. Overall Feedback

- Very good paper ... some specific comments ... generally what we have been talking about with Government for years is captured in it.
- Similar I think, one observation however, I don't think we cast the map wide enough, lack of clarity of what the 'scheme' is about. Looking at a system from school to established-in-life... one thing missing ... transitioning people to independent living ... transitioning into areas like their brothers and sisters.
- Overall positive, it includes the things that we have been talking about for ages. But what is different this time?

2. Opportunity 1: Enhancing the Quality of Work Experience, Traineeships and School Base New Apprenticeship Program

- Excellent ... it's fine. How much will it cost in the ACT to put this in place?
- Regarding work experience with employers, as soon as you mention 'intellectual disability' shutters go up. Students in my special class could undertake some work experience.
- Employers are worried by insurance.
- So would the 'fee for service' agencies, find the jobs / work experience? That is not made explicit in the paper.
- Special needs teacher reports that it has now been suggested that the coming together, of the ILP and Student Pathway Planning is now to be integral.
- Parents reported that their daughter with Downs Syndrome is doing work experience at Kmart. It's great. She visits when not on shift and staff are pushing for her to get a job there.

- Definitely this needs to happen, with the support of specialised employment agencies, but not on top of what they are doing already, they need to be funded to do this.
- Personal experience ... I was put in touch with an employment agency and now, 18 months down the track, still no work. Regarding work experience, school problems, and insurance issues still haven't been overcome. Most of the work experiences arranged by schools are in 'childcare', and this is problematic because of the support issues for PWD in the workplace. I struggle to see how this is going to work?
- Insurance liabilities are a risk employers are not willing to take whether a myth or not. Insurance for PWD doing work experience is illegal.
- Industrial and OH&S legislation is relevant to employment. The requirements of Industrial law cannot be met with work experience arrangements.

3. Opportunity 2: Enhance Access to Quality Career Education

- Should career advisors and employment agencies be different? Let's not delude ourselves of getting more careers advisors.
- I think this is a good thing, however, the knowledge that the careers advisors need to know is scarce. It's not like acquiring information because you are interested in it. Who would jump at it?
- Where do the careers advisors come from, how does it assist the non-government schools?
- The opportunity such as this is to be across the board, not just to the government system.
- Personal experience ...parent reported that when she went to school it was 'careers advisors' not 'career counsellors', does this imply problems?
- Teacher report that Individual Learning Plans vary, life skills aren't always included. Individual Learning Plans happen in isolation from Student Pathways planning, Individual Learning Plans are driven by curriculum decisions.

4. Opportunity 3: Timely Decision-Making and Planning to Reduce Anxiety

- There is also the problem transition period when students are in Year 10 needing to plan what college will be appropriate.
- Early transition planning is obvious, but Government hasn't been persuaded in the past. Another, impact on planning, is that you really don't have to decide to the end of the year if and when PSO funding becomes available. This is a problem – I don't understand the thinking.
- Learning Plans as an enjoyable experience: Probably, but only with the speech pathologist. I find it amusing that we have to go through music, maths, English, when our son can't read or write.
- Learning plans ... useful, a lot of it isn't, teachers do listen to what you say, but it is difficult to get them to move from what they have set for the student to do.
- This is all about education, careers ... more options ... is ridiculous ... focus money on specific services. Forget choices. Daughter goes to Sharing Places, her group, her social life. Why don't students leave (Sharing Places) ... I don't want my daughter anywhere else ... she will be there all her life! I don't want anything else. It's getting that way with the government that you have to go out and be the 'town crier' to get funding. I don't mind options ... one time we used ACE or CAPS

who drove my daughter around town all day. PWD do not need a great choice ... there's not enough money ... options wastes money in administration.

- I was lucky I got an ISP package, my daughter can keep going to Sharing Place, other parents didn't get funding. Now these parents, who both work, now have no funding and have the Federal disability-to-work dilemma, too.
- The government knows the number of students; yes I agree plan early so parents don't have to scramble ... there is not enough services out there!
- We've just been through ISPs ...no money for ACT fire fighters ... so no extra money for ISPs. What is the Federal government or ACT Government going to do about this?
- ... planning is happening to an extent, IEP were designed to support my daughter out of school. When leaving school an extra 20 kids applied for support PSO funding that the Department did not expect. It's not that the schools aren't active; there is a 'fallout' between school and post school.
- Government needs to know government and non-government numbers to prevent the 'fallout'.
- The planning decision needs to be informed, a student's interest that may not flow onto paid employment. Supporting unrealistic notions, reinforced over 5 years, can be hard to turn around and be disappointing.
- Pre-planning creates the opportunity to discuss realistic expectations and job design.
- You're referring to IP for students to start in Grade 10-12. IP fall along the curriculum, and therefore has students are directed along academic lines, not necessarily their interest.
- Yes, there is the employment outcome, but what about further education and training. Students with disabilities, like mainstream students, need further education and training too.
- We'd like to get our students out to work experience but curriculum demands make it difficult to make the time.

5. Opportunity 4: Day Providers and Community Access – More than a casual experience

- When kids leave school there is nothing out there, its fragmented, nothing beyond 3pm, it's a big culture change that needs to be stated with some force, they have been talking for years, they are not listening.
- Reframe, we don't know the unmet demand, to we don't want to know the unmet demand. Government will be shocked by the answer.
- Transport is an issue, at school, they are picked up and delivered. Currently, post school transport is totally unreliable.
- Special education teacher reports that she relies on taxis and they are unbelievable, a 2:15 pm pickup arrived at 4:15 pm. ACT Taxis give many excuses, taxi has broken down, however, they don't like disability jobs.
- With wheelchair buses, there is no evidence, but taxi will not pick up from a known disability agency, they will skip the job on their screen and leave it for someone else. It's because of OH&S, and less money, takes more time.
- We need another taxi company. Competition, improved service delivery.

- Day services, (eg. CAPS) are not funded for transport in their service provision, only available transport is the taxi subsidy scheme. You might have a day activity but you can't get there on time.
- You need two vouchers to go through town because if the trip fare is over \$35.00 you pay the full fair. Chris Johnson, will break a trip in two if this is likely.
- Transport is a huge cost.
- Will the good recommendations actually be funded?
- I think, in the ACT parents don't have choices. A student leaves school, goes to Centerlink, and looks for employment. When unsuccessful the only option for families is day activities. It is the only option to get people with disabilities into the community. Graduating students have lost their community that was school. Further, parents are having the best success at finding the work experience; insurance is again the issue at times.
- With regard to 'access' you don't want your child to sit at home. Community access is the only opportunity to keeps my daughters social skill up to speed, sitting at home, sees her loosing confidence and self-esteem.
- Now that the community in general is looking a work life balance, access activities should also consider real connection opportunities, not just the 9-3 pm or 9-5 pm to cover the parents working hours, or to just be out of the home. People with disabilities may have health concerns that do not allow full time employment or day activity. Let's think much broadly when considering this.

6. Opportunity 5: Increasing the range of employment opportunities through job design.

- How do we go about this? The broader community is quite, unaware (about job design).
- You suggested a joint venture DEWR and DHCS, given the schools and silos, should the joint venture with the whole ACT Government?
- Transport should be involved; whole of government makes it a government responsibility.
- Regarding job design, I am quite supportive of that; currently the only assistance for employers is to offer a discounted wage ... job design should lead to no need for wage discounting.

7. Opportunity 6: Increased access to business services

- We need more business services; some of the services are almost closed because of waiting lists.
- The Federal government initiative is to open employment, so why increase business services?
- There is a lot more pressure on business services to be a viable business. In order to achieve this I don't see the business taking their best workers and transition them to open employment. If these barriers didn't exist for business services then this opportunity in the paper would be good.
- Let's push the barriers out, by doing the paper. We are in the best opportunity time to look at this.
- Some of us feel that we will walk out of here and nothing will be different.
- The paper doesn't say what you have just said; the opportunity as current written in the paper appears regressive. Opportunity 6 as it is written is not thinking outside the square.
- We need to be a bit careful; there is a risk of people with intellectual disability being put in more vulnerable situations. Pushing people with disabilities, DEWR would see people with disabilities falling through the gaps. Further, in order to provide genuine assistance to people with disabilities

to assist them to 'create a life' we need to look at 'how' it is made to happen, not 'why' it happens. Let's thing outside the square.

8. Opportunity 7: Enhancing Access to Information

- It was suggested that there should be some form of 'community access', one body, one government service. Everyone needs to be told where one stop shop is.
- There is an Access / Eligibility /Funding Working Group. Have you spoken with them?
- With regard to information, you can be well informed and because of waiting lists, there are still no options.
- My daughter is in Year 11, and I thought this was an information session about PSO. My daughter's aspirations cycle from McDonalds to counting money in the bank. It's hard to know ...
- Its about finding the right person for advice, the school is excellent, but teachers move on, if information isn't consistent, who is the right person to talk to; government should employ a person with the authority to know.
- Regarding data, I've never found a shortage of government data. One issue is Centrelink ... three different answers on one question ... quantity of data, is different to quality of data.
- Prefer information in written and verbal form. Two understandings can come out of the same verbal information.
- Organisations don't promote because funding bodies have in the past told them that they are not to create demand by promoting their business – 'demand creation'.

9. Opportunity 8: Enhancing Access to Transitional Support for Adults with Disabilities

- I thought it was an extension of the schools (not clear that it was for adults in clearly post school).
- The Client Guardian Forum was funded by Department to do PATH planning workshops. This planning is done with agencies and parents, a 5 years plan of a PWD life.
- With the PATH planning process you start at the end, with the vision of the life you want to achieve for the young person. You then work on the path, back to the present day, identifying the services you need, and the barriers you may experience. You have the vision and work in small steps towards achieving it.
- No matter how much planning, if there is no money or services to support it the plan doesn't go anywhere.
- It's about valuing people with disabilities, if they were valued, then we shouldn't have to go through this.
- All the way through school the government spends more on a student with a disability than a mainstream student, when this stops at 18 - skills are lost, the money is wasted.

10. Opportunity 9: Access to individual funding support

- Have any other models been tried, is there anything we can canvass from them? Participant reported that she has seen other models, and was impressed with the idea that you can 'create a life' for your son or daughter, and that the ACT seems to be stuck in a 'service based model', out of school into a service. Creating a life as you might for your other sons and daughters.

- The only criticism of the paper is that it didn't include accommodation and transport, transition is also about moving out of home.
- The second paragraph of the paper is missing, the paragraph that explains what the system is about, what is its underlying philosophy? What are post school options – what is its aim in the world?
- We need a context for the project / helps us understand the 'scheme' we are in at the moment.
- My daughter is about to do work experience, unsupported for a week. It hasn't been arranged through school. I am extremely nervous.
- The ACT Department of Education, Training and Adult Education Branch hosts the Student to Industry Program (SIPS). SIPS arrange work experience placements for students in Year 11 and 12. Only now students with a disability are getting more attention. However management suggests that workers need to 'deal with special needs, fit it in around your current duties'. (Suggestion SIPS to be included in the teams that come together as suggested in Opportunity 1).

(b) Summary of Individual Written Responses to Options Paper

1. General Comments

Response 2:

The paper expresses many important ideas which I do agree with and have not attempted to comment on.

Response 3:

It was good to read this paper and note that it has highlighted many of the issues and especially the barriers for people with disabilities already experience in attempting to find let alone get and keep long term work placements. It was also encouraging to read S & S Consultants had given some constructive thought to Post School Options (or lack of) and current issues regarding the access, funding of both services and programs.

Whilst in agreement with some of the issues raised in the paper – we at the Woden School have been pro-active and put in place flexible programs (teaching and learning) to overcome the glaring gaps. This way we are minimising the risks and enhancing the possibilities for our students' futures.

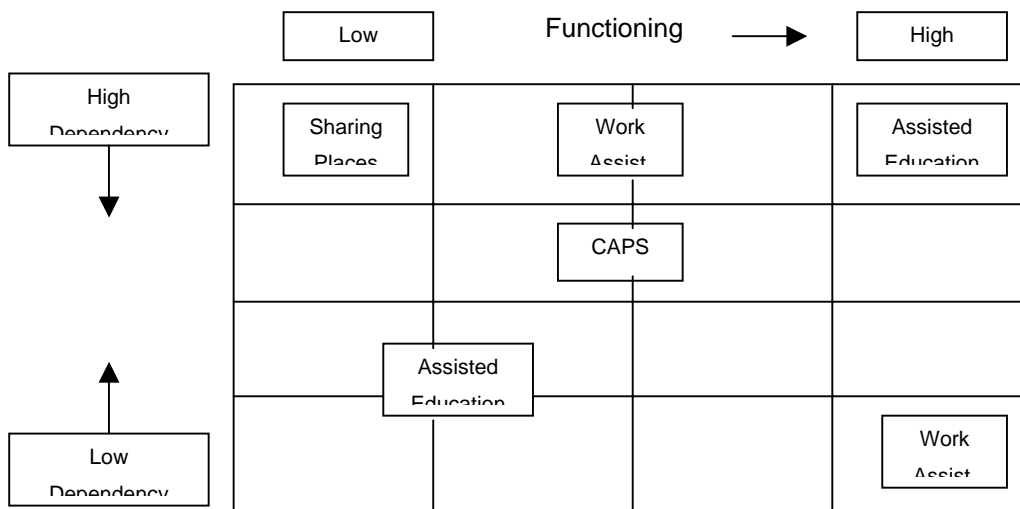
We at the Woden School are already leading the way in piloting a partnership program with a service provider to overcome some of the issues addressed in this paper. It is our experience that leads us to recommend Transition Planning , training and support should be provided much earlier in the young person's student life – in Years 9 and 10 – in partnership with High Schools, students, parents / carers and service providers/businesses.

The education and training of businesses and employers is also vital in any successful placement into work. Extra funding to support teachers (schools) to carry out this role, the relationship building, networking, nurturing of businesses is needed.

Teachers need to visit potential employers and support them to allay fears/barriers to ensure the successful outcome of work experiences for students with a disability. This builds and opens the opportunity door for the future. Later it is the service provider that can carry on this role /service.

Response 5:

Need to do a matrix of opportunities against a spectrum of disability status from low to high functioning, high dependency to independent, and what each option provides in terms of meeting need.



2. Opportunity 1: Enhancing the Quality of Work Experience, Traineeships and School Base New Apprenticeship Program

Response 1:

It needs to be said explicitly that the organisation managing work experience has to create or find the appropriate jobs. This is a very challenging part of the management of work experience.

Response 2:

Suggest say explicitly that the organisation managing work experience has to create or find the appropriate jobs. This is a very challenging part of the management of work experience. Can you offer any advice on how to do it well?

Response 3:

The Woden (Special) School in the ACT is already doing this. Since 2002 some of our Year 10 students are leaving our high school with Traineeships and one student with an Apprenticeship and some to work.

Response 4: Agree

Response 5:

Yes, Think planning needs to start in year 10 to be in place by end of year 11 and budgeted by mid year 12 for start in year 13.

3. Opportunity 2: Enhance Access to Quality Career Education

Response 3:

Who will do this? Have not in our experience found outside agencies whist well meaning with the necessary levels of expertise nor the depth of background or knowledge in education (the teaching and ways of learning) to develop the necessary support for people with disabilities. Teachers/schools are would be best placed to work in partnership. Where is the accountability? Who will ensure the student's needs are being met? Teachers in special schools have both knowledge and expertise. *(Editorial note: As noted in the paper, this was an option around career advise within the education system not external to it. The respondent may have misunderstood this.)*

Response 4:

The members of such a team would have to be very knowledgeable about options for it to be effective. The team should be familiar with funding processes.

Response 5:

Not just career opportunities, but also access and personal development programs.

4. Opportunity 3: Timely Decision-Making and Planning to Reduce Anxiety

Response 1:

Any implementation will require teamwork and this needs to be emphasised. Experience would suggest that it is hard for any on service to focus on getting its act together on just the job it performs let alone have a good understanding of the of the bigger picture for any client. Potentially people will visit three sets of 'experts' for help in different but very closely linked aspects of their post school lives. How will families decide the right path – employment path, community access or both and who will be

responsible for this function? Transport – there are huge difficulties – and costs – in arranging for transport to activities. It is not recognised how much time and effort and cost is involved here.

It is not explicitly discussed about the fact that transition from school to work or other community activities does not follow a three year schedule as DACT's program seems to assume. Many of our parents have been involved every year in pointing this out especially as each three year period expires. Obviously transition cannot fully occur until the person is established independently in work, home etc. While your brief does not include accommodation we urge that your paper point out that full transition - and full adherence to the oft-stated mantra of 'independent living', let alone the 'Vision and values' statements - cannot be achieved by throwing a bit of money at three years worth of some post school options scenarios. We are not going to settle for the option of us as parents/carers looking after our disabled adults full time except for some work and access options until the day we die - unless that's the option we want to choose. Unless one has money there is currently little future for the disabled adult outside of the family home.

In the past PSO support didn't start until February but they finish school in November/December - does the department think that the family can just take 2 months off work? We believe it that the outcome of funding assessments should be announced much earlier than they are currently.

Response 2:

Opps 1,2 & 8. You said tonight that the implementers of these three ideas would have to work as a team. I suggest the paper say this explicitly, as well as ideas you have for the coordination. Without good teamwork we shall have people potentially visiting three sets of "experts" for help in different but very closely linked aspects of their post school lives.

Who do you think would have responsibility for helping families to decide whether to focus on an employment path, or a community access path, or find the right balance of both? I think many families have found it difficult to think this through, and they receive uncoordinated and even conflicting advice about what would be best.

A number of people drew attention tonight to the difficulties of arranging and paying for transport to the person's activities.

I don't recall anyone saying it tonight (but we should have) that transition from school to work or other community activities does not follow a nice three year schedule as DACT's current PSO program assumes. In fact full "transition" usually cannot occur until the person is established in his/her own independent (but often closely supported) adult home. Someone did say that your paper doesn't tackle accommodation issues, and I think you pointed out that is beyond your brief. But at that point one of us parents should have pointed out that in many cases more than three years of transition support will be needed.

Response 3:

We at the Woden School begin in Years 7 and 8 with pre work skills and build on into year 9 with students beginning for example the CIT hospitality course cycling through to completion of the course in year 10 combining this with Work Experience. We explicitly teach social skills which become the foundation of the skills of work under enterprise education. Years 11 and 12 are far too late to introduce this! It must begin earlier and with more flexibility to real work experience engaging with future employers. Where will the \$\$\$ come from? And where is the accountability to ensure the young people's needs are being met – in real work and real long-term jobs as real outcomes???

Response 4: Agree

Response 5:

Need definite process and time to ensure continuity.

5. Opportunity 4: Day Providers and Community Access – More than a casual experience

Response 1

We would also like to see the notion that services stop at 3pm to be challenged. This is 'post-school' - school hours do not apply! Other notions need challenging: when someone reaches 25 years of age many services end - what if the person involved doesn't work 5 days per week 9 til 5?

Response 2

Could you challenge some more of the erroneous "traditional" ideas that surround transition services, eg. that it is OK for services to stop at 3 pm, as school does

Response 3:

Who is going to be sensitive enough to develop this to meet such a range of aptitudes and needs? This will/does need long term commitment and serious funding – not babysitting! It has to be relevant and meaningful programs that values the individual and treats them with respect.

Response 4:

Sharing Places provides programs which are structured, have continuity⁶ with community inclusion/social experience. The participants have individual program plans, which are reviewed annually with participants, families, carers, guardians and Sharing Places staff. While there may be a need for additional services such as Sharing Places, especially after 3 pm and during the weekends, the greatest obstacle is funding. Sharing Places can expand if an individual has funding. Post School Options and ISP funding does not always cover the increasing organisational costs of services.

Response 5:

Yes, absolutely

6. Opportunity 5: Increasing the range of employment opportunities through job design.

Response 3

Agree but it is hard enough now to find Work Experience places for students with an intellectual disability, let alone the idea of part or full-time work! Here at Woden School we are already finding real work for real students having successfully designed our whole school teaching and learning to meet this outcomes. The private/public sector needs educating too. Who is there to develop the job design? Teachers in special education are the rich untapped resource that could provide for the benefit for all.

Response 5:

Yes, also very important for education and assistance at TAFE, e.g. IT/software industry.

7. Opportunity 6: Increased access to business services

Response 3

Agree but it is hard enough now to find Work Experience places for students with an intellectual disability, let alone the idea of part or full-time work . Not tokenism (or risk of meaningless activities, contrived and risk of unfair treatment and abuse) but real work for real people! Businesses need to be educated – but who will do that well? Cost time and \$\$\$! Competition and the triple bottom line and profits get in the way. We need partnerships Who will monitor?

Response 4:

This again has implications for sufficient funding to support service infrastructure. Need for block and for hybrid funding process.

Response 5:

Yes, Need mentoring program if business is to really succeed for a lot of people.

8. Opportunity 7: Enhancing Access to Information

Response 2:

I agree with what you say in principle, but I think it is very difficult to implement it in full. It is a big ask to expect each NGO to know about the services, funding situation and prioritisation process of all its peers, and to accurately disseminate this to its frontline staff and keep it up to date. But having said that, doubtless we can work together better. Do you have knowledge of how this has been successfully tackled in other places?

Response 3

Schools need more information and access to valid up to date information as they are in direct contact on a regular basis to students and their families. They are natural partners that need to be in the information loop and not be sidelined.

Whilst they may have more information to and of the workplace/business it is high schools (teachers) that have the knowledge and expertise of students and their teaching and learning needs. It is in Years 9 and 10 that 'futures' planning is happening well before years 11 & 12.

The Woden School is already leading Australia in enterprise education and in developing a partnership with a core service provider. This current pilot model (action research) will we believe, will provide an exemplar 'best practice' model for other service providers to follow.

Response 4: Agreed

Response 5:

Somewhat, There is lots of information provided, no shortage of it in fact. Problem is getting specific data and consistent data in response to a specific question, eg Centrelink have given 3 different answers on our son's eligibility for a particular allowance. Finding out what criteria apply is often difficult.

9. Opportunity 8: Enhancing Access to Transitional Support for Adults with Disabilities

Response 1:

We believe it is impractical to implement the kind of transitional planning at the agency level you have suggested. For each NGO to know about the services, funding situation and prioritisation process of all services - and keep all staff in their organisation up to speed - is frankly next to impossible for all sorts of reasons, not the least being the difficulty in attracting the level of staff that might be required for the salaries available. The CGF believes that planning has been a major lack in disability services and that the department must take responsibility in ensuring that proper planning is put in place - and that does not mean passing off responsibility to everyone else in the sector.

Response 3:

Mothers / parents/ carers are the ones left mainly with the responsibility. To assist adults they need plans that reflect the range and nature of disability – flexibility to respond to on-going health and mental health issues of individuals. Who really is able to provide the consistency and commitment required for whole of life long-term options? Who really cares? This costs \$\$\$ Who cares if they have a social life or access to recreational activities? The cry from mothers is that they cannot do it alone. They need the community to care enough to do it for the person with a disability.

Response 4: Agreed

Response 5:

Yes, provide clear templates and examples and a reviewing, verification, advice service.

10. Opportunity 9: Access to individual funding support

Response 2:

Could you challenge some more of the erroneous "traditional" ideas that surround transition services, eg: that post school support needn't start till end of the following January, rather than when school finishes AND that informing parents of the financial support they will have from the government need not happen till the end of the year. (You have of course strongly featured the need to start planning the post school future two years out, and I think DACT will readily agree with that, but I would like to see them have explicit advice about announcing the outcome of funding assessments much earlier than now. I have argued that August/September is about the right time.

Response 3:

Will they (?) be doing an "appraisal of Need" of individuals for fairness and equity to the assistance providers? Who will monitor this? And who delivers the transparency and accountability? How will it be ensured that the people with disabilities real needs are being met?

Response 4: Agreed

(c) Individual Consultations – Personal Journeys

Keith's Journey – From School to Work

Lauren has a 20 year old son, Keith, who has an intellectual disability. He completed college approximately 18 months ago. Lauren's son participated in special education programs from primary school through college and had quite mixed experiences. This up and down experience has continued since he completed schooling and transitioned to work. Her son's experience has been highly demanding on the family and Lauren continues to need to provide a high level of support to her son, although he is living independently.

Keith's school experiences have not always been supportive of his personal growth.

Keith's primary school experience was positive, with a high degree of mentoring, involvement in mainstream physical education, and promotion of independence. However when Keith moved to high school, Keith had limited opportunities to mix with non-special education students, was excluded from literacy and numeracy classes, having been assessed as a non reader. He was not encouraged to participate in any area other than sport. When Keith transitioned to college he was able to develop some skills, is articulate and has a wide range of general knowledge. While he does not have strong reading skills, he is able to cope with every day literacy requirements. However, much of Keith's achievements, in knowledge and skill, came from the strong family support and encouragement, rather than from the school environment.

Keith's Employment Experience has demonstrated his commitment and capacity, in the face of quite challenging circumstances.

Following completion of school, Keith registered at an employment assistance agency that was able to place him with the organisation in which he had previously done work experience, for one day per week. This evolved to five days per week, of which four were unpaid. Some of the work was not for the agency with which he had been placed, but rather a 'side business' of one of the other employees. Ultimately concerned about the situation, Lauren contacted the employment assistance service. The agency reported that Keith's records had been lost, which is why no follow up was done. Keith was removed from this employment, generally it was agreed that he had been exploited.

After a period in which no work was found, Keith sought the assistance of another employment assistance service. No work was found, with the placement person indicating that she had some 85 other clients to help as well.

Keith was then referred to a third service that was able to find Keith work through the general classifieds, working three days a week. This lasted nearly 6 months, when economic circumstances led to the loss of the position. This was no reflection of Keith's skills or abilities. This was followed by a short-term placement, and now three-day a week part time employment in a new industry. Keith is coping well with all these opportunities. The challenge will be, however, finding a sustainable stable employment. The movement in and out of work will become increasingly difficult, given the anticipated changes to the DSP requirements and Lauren is very concerned about Keith's long-term prospects.

Keith has also started a CIT course, but has found it lacks challenge and is working at a level far beneath his capacity. Many in the class have more significant disabilities and the course has been centred on this.

Getting assistance to support independent living is an ongoing problem.

Keith lives independently, with considerable support from Lauren. She spent the first year sleeping each night with Keith at his home. He is now able to stay alone 7 nights a week. However he does need ongoing assistance with house cleaning, some grocery shopping and living skills. Basic equipment like a lawn mower and vacuum are needed.

Although Keith had received a small grant from Disability ACT, which is managed by Community Connections, he has not been able to get the benefit he needs. Attending life skill classes is not what he needs. He needs someone to work with him in his own home, and this could not be arranged. He also needs financial assistance to buy basic equipment which he needs in his own home. Again this is not provided for within the parameters of grant funding

Lauren will not be able to continue to provide this level of support on an ongoing basis. She needs urgently to find a way to get Keith help with housekeeping and maintenance, but does not know where she can get this. She has returned now to Community Connections to make a last chance for help. If she is unable to get help, Lauren doesn't feel Keith's current arrangements will be sustainable.

Shelly's Experience – Reflections from a transitional perspective

Shelly has a son in grade 12 who has been involved in special education in the ACT since pre-school. She made contact to share her experience, and that of her son, to help reflect on the issues for young people with disabilities in ACT schools.

Information is hard to access and getting in a timely manner requires parents to find it themselves.

Access to information has been an ongoing problem, but more so recently as the end of college approaches. Shelly was aware that Canberra College has an expo, although this is not the college which her son attends. She indicated to the teacher that she was interested in attending and was eager for advice on when it was to be on. It was only in the last day (over a week since it was held) that Shelly found out that she and her son had missed the expo. This is seen as an important lost opportunity to speak with people about what the post-school options might be and what services might be most appropriate to her son's needs.

This has been consistent, with virtually no communication to parents about what should be done, such as registering a student with an employment assistance service while they are still in grade 12. She has only just found out that this should be done this year. Shelly suggested that Centrelink should send out a notice to young people when they turn 18, and their parents, about how they should proceed to plan for transitioning from school, their entitlements and how to apply.

School culture is not inclusive, rarely encourages young people with disabilities to work to their potential or extend themselves.

While the initial philosophy behind special education units in the school, high school and college was to promote integration in social and educational pursuits, this rarely happens in practice. Young people with disabilities in special education units are often excluded in mainstream options, are kept in the same room with a single teacher (as in a primary school) and not pushed to be integrated within the school. This creates a real disadvantage in terms of learning social skills, which they will be able to take with them when they leave school.

Exclusion is often encouraged by both teachers in charge of special education units who do not encourage students to mingle, and mainstream teachers who are not informed or skilled in teaching young people with disabilities. This is equally true of career advisers who have no knowledge of disability or its implications for career planning.

When a new special education unit is formed in a school, mainstream students are not encouraged to accept the new students. Teachers, who take a blind eye to school yard bullying, exacerbate this. No preparation is done to prepare school body, teachers of parents, to clear the way for the students.

Similarly schools / colleges rarely recognise the achievements of students with a disability in special education unit. For example, any sporting achievements as in the Special Olympics, are not acknowledged, nor are achievements in vocational education or training. This can create a real self-esteem problem as well as reflecting the existing negative perceptions of the school community.

Despite the theory, planning processes are inclusive in theory rather than practice.

As parent, Shelly was invited to attend a discussion on curriculum planning (ILP). In practice, Shelly was told what had been planned for her son, and to question this is frowned upon. Equally parents are not always prepared to ask the 'right questions' and the school team does not put itself out to generate questions or address potential issues. A parent is made to feel that he/she should simply be thankful and that any suggestions are rejected on the basis of 'limited resources'. In short, teachers take on board a role to tell parents what is best for their own child – there is no real dialogue about this.

Pathway planning with students has also been a negative experience for Shelly's son. When he was unable to identify a specific career choice, this was turned against him as a 'failure' and he was further interrogated as to why he was even in school.

Participation in Recreation and Sport Programs has been an important part of life

Shelly's son is a good athlete and participates in a range of sporting pursuits. He has won awards and medals, none of which have been recognised by the school. However he competes inter-state as well as in international competitions. There is room however for mainstream sport and recreation groups to be more inclusive, rather than being limited to 'special' or disability recreation pursuits.

Aadesh, His Wife and Son – Imaging a Difficult Future

Aadesh has a 23 year old son, Ram, who lives at home with Aadesh and his wife. Ram has Downs Syndrome and requires considerable medical attention. He has no literacy skills.

Lack of structured activity has led to increasing frustration and violent behaviours that are impacting on the whole family. To date, Ram has had a mixture of activities including some Life Skills through Gunghalin Community Services, participation in a pottery course, and two days work in a business service. However he spends most of his time at home all day and has no social. Although his parents have tried to provide Ram with some guidance, he can be very difficult and resists any such advice. The combination of inactivity and lack of friends, has a significant impact on Ram behaviour. He is getting increasingly frustrated and this is expressed through violent behaviour towards his parents. This in turn is contributing to significant stress on his parents' relationship.

While an application for funding has been sought to enable Ram to get involved in other activities, Ram parents are concerned that if they are not successful, they will not be able to afford for Ram to participate in any other options.

Ram's parents are now approaching retirement age and feel that they are not able to cope with this situation. However they have been unable to access any assistance with housing and support, which would allow Ram to leave the family home. Ultimately, Ram and his wife realise that they will not be able to care for Ram in the long term. They have sought advice on accessing a suitable accommodation arrangement for their son, but have been told that there is nothing available.

Ram has need for a coordinated accommodation, support and meaningful activity. Given the current situation, Aadesh feels that the future is very bleak. He is unsure how much longer they will be able to cope, and is desperate for assistance with accommodation, support and helping Ram to get involved in structured activity. He is now simply hoping to get some funding so something can happen.