

**INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS
WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR
FAMILIES**

Organisation: Family Advocacy

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About Family Advocacy

Family Advocacy is a state-wide advocacy organisation which promotes and protects the rights and interests of children and adults with developmental disability. The organisation has a high presence and profile across the State:

- building the capacity of families to undertake an advocacy role;
- developing leadership skills in families;
- making representations to Government regarding legislation, policy, funding, monitoring and practice and the extent to which they reflect the needs of people with developmental disability;
- providing advocacy related information and advice.

Introduction

“Families need much more support to make the right decisions for their child. I have the education, persistence and although I work, the flexibility to visit schools, meet with people during the day, take a workshop, etc. However, still it is a daunting task and emotionally pretty scary to think your child is leaving where he/she has been sheltered and is so familiar with. I can easily see how many other parents, whether they be from non-English speaking backgrounds, or who have no flexibility with their own job, would have a very, very difficult time with all this. It can be quite complex to understand and navigate, but is a very, very important decision.” –Parent in NSW, July 2011

This statement, reported to Family Advocacy from a parent of a child with disability, eloquently depicts the multifaceted pressures families face as they try to navigate what is currently a highly fragmented and complex system.

Family Advocacy is well placed to respond to the terms of reference of this inquiry given its ongoing connection and interaction with families across NSW. Family Advocacy sought feedback from families about their experiences of making transitions in education to ascertain: what types of support they received, what supports they found helpful or unhelpful and what support they would have liked to have received. Within 48 hours we had received over 35 responses from families, demonstrating the pertinence of this inquiry. Drawing from the feedback of these families as well as research and literature, three key themes have been identified as significant across all stages of transition. These themes are:

- accessing information and resources;
- building ongoing partnerships with families; and
- early planning and preparation.

Other issues relating to specific points of transition that will be discussed in this submission include:

- IQ testing;
- adequacy of transport; and
- the transition to adult life.

Theme 1: Accessing information and resources

Lack of a consistent approach to distributing information and resources

Many families emphasised the importance of accessible information and resources to promote a clear understanding of the steps and processes involved in undertaking a transition, as well as the support available throughout the transition period and beyond. This information must be accessible in two ways: it must be easy for families to initially obtain and it must be in a clear and easy to read format, not as one parent put it, in “government speak”.

Families reported to Family Advocacy that they tended to stumble upon information in ad-hoc ways such as through a recommendation from a friend, an internet search or by happening upon a service or individual that could guide them in the right direction.

“We were not really supported at all. We were terrified. However we were able to independently find out about a transition to school program [a service] was running in Jan, so we took [my son] to this...nobody had advised us about it we just found out by our own research. [The service] was wonderful, but I feel that any help we get is very piecemeal. Who knows what other programs are out there that may have helped?”

“Further on down the track when [my son] was in Year 10, I attended – without the intervention or suggestion from the school – a 2-day Positive Partnerships workshop run by [a service] and supported by the Department of Education. This was absolutely key for me because I connected with a wonderful person from the Catholic Education Office who put me onto a Transitions worker who could work with [my son] in the school. It is incredible to me still to this day that the school never put him forward for her caseload, and I had to go to this workshop to actually find out about her. This is something that the school should have been helping us with.”

Families lamented the lack of a consistent approach to distributing information and resources about transitions. One parent suggested:

“There needs to be a pooling of ideas and resources and somewhere to report the successes of how transitioning worked in a particular case. Take out the elements that worked and add this to the knowledge we have in one place – there are hours of time lost just trying to find the answers to one problem that may have already been overcome by another school.”

The value of stories and insights from other families

A number of families reported that the most valuable information that best shed light on transitions came from the insights and stories of other families who had already undergone the process. They suggested that a mechanism for sharing success stories and their experiences would be an extremely useful tool.

“The best information I received was hearing the experience of a former student through his parent. The key message for me is to hear the experience of other parents who have (recently) gone before, and to provide checklists so that parents and older students are prepared to make informed choices.”

“It would be great if there was a way of spreading and receiving great tips and support with other Australian families outside of the existing online forums and also to be able to receive and give mentoring to others who have been through, are going through or gone through similar issues.”

The value of a well informed guide

Having a well-informed person to guide families through the process was seen to be the kind of support that would be extremely helpful for families. This person would ideally be situated within the community or local school, giving them the ability to develop an intimate knowledge of the local landscape, foster networks and partnerships with members of the community, and work closely with families to facilitate access to individualised supports.

“I definitely see a need to have a person, not necessarily a special ed trained teacher, but someone who has some background in disability in general to be available to the schools who are transitioning children into the main stream setting. It is so often just a lack of knowledge that makes a situation look so bleak and not doable. This person should ideally be able to give the schools the tools they need to have a successful transition happen. Even to the point of being able to give them a time line of what should be happening at each stage within the time frame they have. I think it would be very important that there is support not only for the school but also the parents as well. There should be more of a team approach than everyone doing their own thing.”

“It is still early days for us, but I believe that managing school transitions are made much easier when the school and family are able to lead the process, tailoring the transition to the child, as they are the ones who need help. These transitions can be a highly stressful time for families of children with special needs, and it is the people on the ground - teachers, aides, and other students - who make a difference, not department representatives who visit the school every six months.”

Informed decision making

Supporting families to make informed decisions requires families to have a comprehensive knowledge of the wide range of options that are available to their family member and an understanding of the implications these may have for the future. Families have reported that information about inclusive options is often withheld because someone has decided the option is not in the best interest of their family member.

For example, one mother whose son left high school in 2010 told us of a conversation she had with a transition support teacher at a local school who actively withheld

information about the self-managed model in post-school options stating: “we don’t promote self-managed to any of our families” under the assumption that families wouldn’t have the capacity to cope in this option.

Another parent told us of attending a post-school options expo called “Enhancing the Links” organised by the National Disability Coordination Officer at which the options presented were very limited. For people with very low support needs information was given on options such as attending University or undertaking an apprenticeship (with no mention of support being available for either), and for those with higher support needs, attending a centre-based program was recommended. The parent remarked “if you wanted to find out about self-managed options you would have left knowing next to nothing.”

One family said they would like to have received:

“Proper discussion of options – not just ‘there’s a place in this IO class’ or ‘there will be a place in this special needs school next year’...I nearly had to leave work to home school due to lack of options at one point.”

Findings of the NSW Ombudsman

The NSW Ombudsman Report “Consultations with families of children with disabilities on access to service and support” (June 2011: 3-4) reported receiving very similar responses from families to those Family Advocacy received. The following extracts are particularly illuminating:

“Our consultations highlighted that families need better information and support and they need it sooner. It is difficult for families to obtain basic information about what supports are available, what they may be eligible for, and how to get necessary services.

“Our consultations indicate that families currently rely heavily on other families and the internet to obtain information about disability services and support.

“Families said that it is often difficult to get clear and accurate information, even through direct contact with service providers. We hear repeatedly from families that services expect them to know what they want without providing them with sufficient information to know what exists, what is available, and what would be suitable.”

Our recommendations draw strongly on the needs of families identified as by the Ombudsman.

Recommendations

Family Advocacy recommends that:

- The Department of Education and Communities (DEC) develops a central place where regularly updated clear information and resources can be accessed by families.
- DEC works with service providers associated with children and families as well as schools to ensure families are connected to this central place as early as possible.
- Given that transition is more effective when parents are supported to partner with the school, it is recommended that DEC funds non-government organisations (NGOs) to provide personalised guidance and support during times of transition to help families:
 - access relevant information and resources;
 - develop a clear and in depth understanding of all available options so that they are able to make informed decisions; and
 - connect with other families who have undertaken similar transitions and can share advice, experiences and success stories.

Theme 2: Building ongoing partnerships with families

Effective partnerships and relationships between families, schools, service providers and members of the local community are the essential foundations upon which transitions are built. This is acknowledged in an article entitled “Current Research” published on the DEC website about transitions to schools (Pigott, 2008). In the “10 Guidelines for effective transition to school programs”, developed by leading Australian researchers, number one in the list is centred on this theme: “Establish positive relationships between the children, parents and educators”. Under this heading Pigott elaborates:

“While transition programs may focus on developing children’s knowledge, understanding and skills, they have as their key function, a commitment to facilitating positive social interactions and relationships. Effective transition programs encourage all participants to regard themselves, and their co-participants, as valued members of the school community.”

Fundamental to authentic partnerships is supporting families to have meaningful participation in decision making and planning and to have their deep understanding and knowledge respected and drawn upon throughout the transition process. This will lead to decisions and support that are appropriately tailored to meet the individual needs of the person transitioning. Of equal importance is implementing measures to maintain positive partnerships beyond the transition period to enhance the likelihood of ongoing support continuing to be suitable and effective.

The difficulties families reported to Family Advocacy were reflected in a literature review conducted by SCOPE (2011) for the Victorian government Department of Education and Early Childhood. These included, lack of participation in decisions about the child’s education, not feeling welcome by the service provider or school, difficulty establishing new support networks and lack of communication with school.

The power of relationship building and positive partnerships

One particularly positive story that Family Advocacy received from a family demonstrates the importance of actively building ongoing partnerships and relationships between the family and other people who will be involved during the person’s time of transition and beyond.

Julie* told us of her positive experience transitioning Adam with very high support needs from pre-school to primary school based on the established networks and relationships the family had in their community and the willingness of the school to work in partnership with the family under the assumption that “the family knows best”.

* Names have been changed

Julie intentionally built relationships and networks within the community right from Adam's birth which she remarked "removed a lot of the fear factor" for other parents, teachers and students about including him in the regular class. Of critical importance was the relationship she had with a DEC representative who had known Adam for six years and was instrumental in helping him make the transition to school, and continues to provide support years afterwards. Similarly, Julie and her family had developed a relationship with a teacher at the local school - a family member's neighbour - who gladly took Adam into her class.

Adam attended the school's three orientation days, the first accompanied by Julie, and the second two with the support worker he had been using for a number of years throughout pre-school. Julie recounted how for the other children starting kindergarten (many of whom had a long-established relationship with Adam from day care and preschool) the presence of this support worker was common place. These measures enabled all members involved in the transition including Julie and her family, other parents and children, the school and teachers and most importantly Adam himself to feel comfortable and confident in the transition to primary school. Currently, Julie is working in partnership with Adam's school to teach Adam to communicate with his feet using Morse-code and developing a training course so that Adam's peers can get their "drivers license" and push Adam's wheel chair in the playground.

Julie's confidence and the support of her tight knit community contributed to her son's successful transition and ongoing inclusion in their local primary school. Many other families who do not have Julie's confidence or live in small communities would need assistance to intentionally develop networks and relationships around their family member.

Non government organisations are best placed to assist families to build a vision for their family member with disability and to develop the relationships that make for a good life. Such organisations are also well placed to support parents to develop effective partnerships with the many organisations, including schools with whom they will need to partner over time. *Resourcing Families*, an initiative of Family Advocacy provides families with information, strategies and support around building networks and relationships.

<http://resourcingfamilies.org.au/index.php/building-support-networks.html>

Effective partnerships in decision making and planning

Family involvement in the planning and decision making process is particularly vital during times of transition where decisions that are taken lay the ground-work for future directions and prospects for the person with disability. It is essential that families (they know the needs and strengths of their family better than anyone) are at the centre of this decision-making and that support is available to bolster the family and turn their decisions into reality.

Families reported feeling that they were not able to make meaningful contributions to decision making and planning about their family member - a particularly common experience for families working with schools and their learning support team.

Common examples reported by families include:

- meetings being arranged without checking the families availability;
- families being given essential documents such as funding support applications or the meeting's agenda during the meeting - giving them no time to prepare or have an understanding of the issues at hand; and
- families feeling intimidated and outnumbered by a high ratio of professionals and staff who may present as being on a united front.

These experiences lead to families feeling disempowered, having to fight to have their views heard, and decisions being made that are not appropriately tailored to suit the individual needs of the person with disability because they were made without adequate input from the family.

Recognising the natural authority of families

Families believe that the transition process would be far smoother and less stressful if the natural authority of families, who have the deepest understanding of the person with disability, was respected and deferred to. Families report having to battle to take the path they feel is in the best interest of their family member against professionals who present as knowing more about the person with disability and what is good for them than the family.

“Unfortunately, we have had problems throughout [my son’s] schooling with staff being ill-equipped and untrained to understand and deal with his needs (this continues to this day), and unbelievably, argumentative with his parents about how best to assist him.”

“Eyebrows were raised/comments made when I insisted that [my daughter] also participate in the mainstream orientation program...The key message I have is that parents should be supported in their decisions.”

*“Our journey is ongoing. To date we have seen remarkable progress in our son but it has not been an easy road. I have felt isolated, bullied and stressed not because of his disability but because of the inadequacies of the systems and people in place supposed to help. I am a determined, tertiary educated person who is able to challenge and deal with problems, if I wasn’t I suspect the outcome for our son would not be as good as it is. I sometimes think if I had allowed myself to be bullied and pressured by those who wanted me to put our son in a special class and suggested I was making a very bad decision for him by insisting he be integrated into mainstream schooling what a terrible outcome that would have been. **So finally recognition of the “expert” knowledge most parents have about their own children and being able to have more input into programs that assist would be of maximum assistance.**” [bold formatting added]*

Welcoming attitude of schools

Recurrent feedback from families suggests that schools and the DEC often advise families to send their family member with disability to a special school or special class when the families

preferred option is inclusion in the regular class at the local school. Families reported that finding a welcoming school, in the transition from preschool to primary or primary to secondary, is fragmented and inconsistent and relies heavily on the attitude of the principal and executive of the school.

“My first port of call was [my local] Public School, where the then principal made it clear that she would be delighted to have [my daughter] attend the school. I looked at several other nearby public schools but none were so welcoming. I also contacted the department of education and a representative visited [my daughter] at pre-school to assess her needs. From then on I felt that the department were constantly pushing me to visit schools with special needs units and consider sending [my daughter] to one of these schools. Once she started school, every time we had a meeting with the department to discuss the education plan, the department representative would ask if I had considered a school with a special needs unit.”

“We did not choose our local state system school because both schools were very definite that she would go to the special needs class. The special needs class environments were NOTHING like [what] we had envisaged for her after mainstreaming her throughout primary school. The schools both stated that they couldn’t guarantee her safety out in the big bad world of mainstream children and seemed less than keen to pursue ideas on how to make sure she was safe if mainstreamed. I find this amazing considering how much extra funding [my daughter] would get in the state system compared to how much she gets in the independent system (who subsidise the costs to keep her there and seem to do it very happily and graciously). [My daughter’s] safety at the independent school has NEVER been in doubt.”

The importance of ongoing support

Families reported a lack of ongoing support following the end of a transition period. Sustaining support for families, students and schools is vital to ensure that positive partnerships and outcomes are maintained for all involved and minimising tension and stress. Having additional staff within schools who have an expertise in the area of supporting students with additional and complex needs would bolster teachers’ capacity to teach all students in their classroom, in effect facilitating effective ongoing support.

“Whilst the transition to school was fantastic and term one went well too, term 2 and now term 3 are not starting off so good. Seems there is a recognition there is a lot of support needed for transition but equally this is needed all the way through. Our daughter is experiencing anxiety and we feel very stressed and worried about her.”

“We would have loved to have received more direct assistance at the school after the start of kindy. Lifestart did offer assistance for Term 1 but it was mainly a couple of phone calls when they were asked a question. I would have loved regular scheduled visits of a special educator to the school. Despite excellent preparation, [my daughter]

has had a hard transition and it has taken her a good 6 months to settle in – with a variety of quite unpleasant and largely avoidable dramas along the way.

“Teachers are busy and even if they are provided with resources and strategies, I have found them to be largely ‘reactionary’ to problems and that often doesn’t solve root issues. I am sure they feel very unsupported in the classroom and if they had a regular visiting professional who could offer support and strategies on how to resolve issues, I’m sure that would go a long way. I have in the main had to take that role which has and continues to be very stressful. As the teacher dumps problems my child has ‘caused’ when I pick her up in the afternoon, I have to go home, put aside my emotional response to these things, and see if I can input something helpful to the teacher so that what has happened can be worked through/prevented next time.”

Family Advocacy considers the DEC’s recently trialled School Learning Support Program (SLSP) to be an effective way to ensure ongoing support in schools is provided. The SLSP aims to establish a specialist teacher presence in government schools to provide ongoing support to students with disability and their classroom teachers, with a particular focus on building the capacity of teachers to teach *all* students in the classroom. Alongside providing direct support to students with disability and timely professional advice and mentoring to teachers, the role of the specialist teachers is also to facilitate effective working partnerships between schools and families.

Family Advocacy does, however, argue that in order to provide adequate support to schools, the current allocation of 0.4 and 0.1 full-time equivalent specialist teachers needs to be increased.

The Department of Education and Communities

The DEC is obviously aware of the significance of family involvement in decision making, respecting the natural authority of families, the (un)welcoming attitude of schools and the gaps in support for families, students and schools in the post transition period.

This is evident in reports and articles produced by the DEC including:

- Five guidelines for effective transition programs identified by international research cited by Pigott (2008) on the DEC website which are: foster relationships as resources, promote continuity, focus on family strengths, tailor practices to individual needs, and form collaborative relationships.
- A “Transition Project” commissioned by the then NSW Department of Education and Training (2005) conducted by a team of researchers from the University of Western Sydney which highlighted the importance of relationships, focusing on strengths and competencies rather than deficits, promoting inclusivity rather than exclusivity, responsiveness to local communities and the need for dedicated support and resources.

Given this, many of the following recommendations emphasise the *implementation* of established DEC rhetoric.

Recommendations

Family Advocacy recommends that:

- DEC develops strategies to challenge the deeply ingrained expert culture of education staff and emphasises the importance of:
 - respecting the natural authority of families;
 - facilitating families to meaningfully participate in planning and decision-making; and
 - having a welcoming attitude to students with disability.

- DEC implements the School Learning Support Program state-wide and increases resources so that no school receives less than 0.4 full-time equivalent specialist teacher and no specialist teacher support more than two schools.

Theme 3: Early planning and preparation

Whole of life approach

Family Advocacy is of the view that families are far more likely to have successful transitions when a “whole-of-life” approach is taken to planning from a very early age. Supporting families to develop a vision and long-term goals based on the strengths and interests of the person with disability helps to guide and clarify decisions made in the short-term – from what subjects are chosen at primary and secondary school to the type of work experience undertaken in year 10.

Transitions in education are more effective when families have been assisted to develop a vision and long-term goals for/with their family member. A small number of non government organisations assist families in this way

The Tasmanian Department of Education and Training has also developed numerous useful resources for schools to support families to plan for the short and the long term transitions and life of their family member. They also act as a tool to build effective partnerships between families and schools.

These resources can be accessed online via the following link:

<http://www.education.tas.gov.au/curriculum/needs/disabilities/transitionplanning/templates>

Preparing as early as possible

During specific times of transition, families need to be supported to begin planning and preparing as early as possible. Feedback from families indicates that an effective approach to preparing all parties in a transition is to facilitate the person transitioning to experience the new environment over a period of time long before the actual transition takes place.

“I would like there to be more of a transition to school where [my son]’s support worker would work alongside his new teachers to minimise the change and maximise his potential. It would be great if programs such as [the transition to school] one was longer than 4 x 2 hour sessions in January, but perhaps working with the school for a few months prior to starting and just after starting.”

“We will be pursuing Self Managed funding as our Post school funding...and I would very much like to begin organising our plans for her now. Unfortunately it’s just too early to talk to the relevant services etc, TAFE don’t want to talk to us, the local [Community Participation] programs aren’t willing to talk with us until next year...Nobody thinks that pre planning has any merit at all and I am seriously concerned that [our daughter] is going to drift into the segregated disability system because no-one is productively helping us work through the system”.

“I visited several providers when she was in year 11 and 12 and her transition teacher came with me to 1 of them. When we chose a provider... her school provided 3 days of her teacher’s time to go to the new place with my daughter for 3-4 hours each time so that [my daughter] could have a bit of a transition prior to leaving school. We were very

worried about how she would cope with this new situation, but she has done very well and likes the new program.”

Individualised approach to transition

Other families reported that they would have liked there to have been a more thoughtful and individualised approach to the transition, enabling the person transitioning and family to enhance their competencies and confidence over a period of time in preparation for the transition.

“Our son has down syndrome and I must say that now that I look back the transitioning that he received was totally inadequate for his entrance into the mainstream setting at school from preschool. Their idea of transitioning was to sit all the preschoolers at desks like they were at school and do some colouring in for about an hour a week for a month before the end of the year. The primary school that we were going to had 4 sessions where you brought your child up to the school where the children perhaps cut and pasted or sang songs and danced. There was absolutely no structure or forethought in to how [our son] was being supported and how much he actually knew what was going on.”

The following account from a parent details the positive experience she had with a transition support provider that supported the family to tailor a transition plan suitable for their family member, allowing adequate time for the child to be immersed in the new environment and build his competencies in relevant areas. A positive partnership was also fostered between the school and family founded on their son’s strengths and needs (not his deficits), strengthening the possibility of a positive school experience into the future.

“In his second year at pre-school [our son] also attended Lifestart Prep for School group. This group ... gave all the children involved the opportunity to learn crucial skills and experience "Big School" so that they could make a successful transition to school . They were specifically taught skills essential to success at school and in the playground, that other children without special needs would just pick up. Towards the end of Term 3 Lifestart was available to support parents in their decisions about the most appropriate placement for each child. Lifestart was available to support parents at Interviews with prospective schools and with advice from their years of experience.

As part of the enrolment process Lifestart staff attended meetings with the Principal, the Head of the Support Learning Team, School Counselor and ourselves. This helped us to understand what we could expect from the school. During [our son's] orientation to the school the Lifestart staff observed [our son's] interaction with his potential teacher and new class, they then gave suggestions to the school and the teacher about what might be issues for [our son]. They suggested strategies for overcoming potential problems for us as a family and for the school. When [our son] started school Lifestart provided a detailed portfolio of [our son's] strengths and needs and examples of his work which was invaluable in helping staff get to know [our son] and to look past the label. Once [our son] went to school even though he was no longer in the Lifestart Program there was a

follow up visit and recommendations for strategies to solve any problems. When problems arose Lifestart was still there to support our family. This kind of program is the kind of exemplary practice that all children with special needs should have access to.”

This type of support for families is particularly needed in the transition from preschool to primary school when families do not have established connections with the DEC.

Transition resources for schools developed by the DEC

The DEC has developed a number of resources that can be used by schools to facilitate successful transitions from primary to secondary school. Planning frameworks (Appendix 1) provide a structure for schools to ensure that all aspects of the transition process are considered and that preparation begins well in advance of the actual transition. Feedback from families indicates that more work is needed around implementing this existing DEC infrastructure.

Recommendations

Family Advocacy recommends that:

- DEC funds NGOs to support families in the process of transition. Such support could be provided individually, through workshops and through the development of family friendly resources.
- DEC develops and utilises existing planning frameworks for schools and develops a strategy to ensure all schools and their principals are trained in utilising and implementing such frameworks.

Issues relating to particular points of transition

IQ testing for confirmation of intellectual disability

The requirement that children undertake an IQ assessment to confirm their disability has the potential to act as a barrier to a child's transition from preschool to primary school on a number of levels.

There is an immediate potential for conflict between the school and parents if the parents refuse to have their child take the test. Parents are concerned about IQ testing as the results of these test often misrepresent the child's actual abilities and strengths, do not correlate to the support needs of the student, reinforce negative labelling of the student and set up a pattern of lowered expectations from teachers. If this conflict arises, it may be one of the very first interactions between the school and the parents, inhibiting the development of a constructive partnership.

"My message is: we should not have to oppose the system and refuse IQ testing. There should not be a requirement to justify need for support with IQ testing in the first place but rather, where there is already an identified disability, be granted support without our kids having to be tested for levels of intellect or prove their disability further."

Families report that if a child's IQ is known, teachers and DEC staff sometimes pressure families to send their son or daughter to a special school or special class. Indeed, Family Advocacy is aware of schools that were successfully including children with disability in the regular class that, upon receiving the results of an IQ test, have done a rapid turn around and insist that their school does not have the resources or capacity to teach the child.

"On attempting to enroll in the local primary school our son was given an IQ test by a school counselor in a way that was completely inappropriate for a child with aspergers. From the predictably bad results of the way this test was administered the counselor decided that our son had borderline mental retardation (sorry I forget her exact term) and I was then pressured by her and a member of the education department staff – told that I was doing my son harm by insisting that he attend mainstream school and that he would be better served by going to a special school. I knew full well that my son was extremely intelligent and having assessed the special class knew that it would be completely inappropriate for him. I insisted that he attend the local school but was made to feel that I was doing him a terrible disservice."

Recommendations

Family Advocacy recommends that:

- The DEC removes IQ assessment as the basis of confirmation of intellectual disability and replaces it with a functional assessment.

Transport to and from school

A number of families reported that a lack of appropriate transport acted as a barrier to the successful transition of their child from preschool to primary and primary to secondary school. Families recounted that in the absence of DEC eligibility guidelines about applying for special transport, they were left feeling uncertain about what criteria they were expected to meet and on what grounds they were refused transport or a transport subsidy (especially if they had been receiving it previously).

“I had major problems transitioning [my daughter] from primary school to the high school. It was particularly bad as, at this crucial time, the Student Special Transport Unit (SSTU) decided in December 2009 (just before my daughter was due to start high school) that my daughter was no longer eligible for the taxi. This was despite there being no change in our family circumstances and the application letter being almost identical to the original one when I had applied 2 ½ years earlier. The loss of the taxi was a huge blow and caused very major problems for us. I immediately appealed the taxi decision but it took 4 appeals over several months, before the taxi service was fully re-instated. In the meantime my daughter had to be dragged (literally) from our vehicle and carried by 4 adult staff while she kicked and screamed. This was an extremely undignified start to the school day and caused enormous distress to her and me. This, no doubt, was a huge reason why she had trouble settling in to the high school and why she was suspended 3 times in her first 6 weeks at the school, despite never having had any trouble of this sort in the primary school.

The high school were very slow to respond to the obvious distress of my child. They should have pressured the special transport unit to get the taxi service operating immediately. It took weeks before they finally wrote a letter asking for the taxi and then it was only resumed in the morning and I had the bother of further appealing to get the service resumed in the afternoon. When the SSTU had knocked back my first appeal I rang them and begged them to re-instate it for just a couple of weeks to help with her transition to high school but their response was very cold-hearted. They said ‘no’.”

Recommendations

Family Advocacy recommends that:

- The DEC develops and releases eligibility guidelines for special transport applications to ensure transparency and accountability in assessment.

- The DEC develops a mechanism to fast-track families’ applications for transport during crucial times of transition until, if necessary, alternative arrangements can be made.

Transition to adult life

A number of families reported feeling very unsupported in the transition out of school. Families felt that they were not supported to begin planning well in advance of leaving school (see example under “preparing as early as possible” p.11), were unable to make informed decisions due to information being withheld (see examples under “informed decision making” pages 3-4) or were not included in the planning and decision making process but instead were allocated an option.

“Post school transitioning consisted of a meeting with the then ADHC person for Post school options, paperwork completed & then the wait to see what funding she was eligible for. She got Transition to Work which only provided enough funding for 2 years.”

Family Advocacy has found that successful transitions out of school require the following two essential ingredients which fit within a whole-of-life framework:

- High expectations (from others and of self)
- Early planning and preparation

High expectations

It is not uncommon for service provider and DEC staff to believe (consciously or unconsciously) that people with disability, especially those with higher support needs, are unable to hold valued roles and meaningfully contribute to our communities. These low expectations often become self-fulfilling prophecies: being unable to imagine people with high support needs having jobs, volunteering or having other socially valued roles, prevents these avenues from ever being considered let alone pursued.

Family Advocacy is in contact with numerous families whose vision of a meaningful life embedded in community for their family member (many of whom have high support needs) has led to them holding full-time or part-time jobs, successfully running their own small businesses and volunteering in the community.

Early planning and preparation

Families need to be supported to begin developing a vision of the post-school possibilities as early as possible in order to begin laying the ground work for this vision to be realised. Family Advocacy believes that families should be supported to undertake more specific planning around the post school period in years 9 and 10 to allow families time to develop an in depth understanding of the options available, talk to other families who have undergone the transition out of school, and support their family member to develop networks, build their competencies and have as many experiences as possible. These experiences may include visiting different types of businesses, volunteering, taking a part-time job, and getting involved in activities and clubs outside of school.

Recommendations

Family Advocacy recommends that:

- DEC train relevant staff to begin supporting families to plan and prepare for adult life in year 9 and 10 at the latest.

Summary of Recommendations

Family Advocacy recommends that:

Accessing information and resources

- The Department of Education and Communities (DEC) develops a central place where regularly updated clear information and resources can be accessed by families.
- DEC works with service providers associated with children and families as well as schools to ensure families are connected to this central place of information as early as possible.
- Transition is more effective when families have received support to partner effectively with their school. Family Advocacy thereby recommends that DEC funds non-government organisations (NGOs) to provide personalised guidance and support during times of transition to help families:
 - access relevant information and resources;
 - develop a clear and in depth understanding of all available options so that they are able to make informed decisions; and
 - connect with other families who have undertaken similar transitions and can share advice, experiences and success stories.

Building ongoing partnerships with families

- DEC develops strategies to challenge the deeply ingrained expert culture of education staff and emphasises the importance of:
 - respecting the natural authority of families;
 - facilitating families to meaningfully participate in planning and decision-making; and
 - having a welcoming attitude to students with disability.
- DEC implements the School Learning Support Program state-wide and increases resources so that no school receives less than 0.4 full-time equivalent specialist teacher and no specialist teacher support more than two schools.

Early Planning and Preparation

- DEC funds NGOs to support families in the process of transition. Such support could be provided individually, through workshops and through the development of family friendly resources.
- DEC develops and utilises existing planning frameworks for schools and develops a strategy to ensure all schools and their principals are trained in utilising and implementing such frameworks.

IQ testing for confirmation of intellectual disability

- DEC removes IQ assessment as the basis of confirmation of intellectual disability and replaces it with a functional assessment.

Transport to school

- DEC develops and releases eligibility guidelines for special transport applications to ensure transparency and accountability in assessment.
- DEC develops a mechanism to fast-track families' applications for transport during crucial times of transition until, if necessary, alternative arrangements can be made.

Transition to adult life

- The DEC trains relevant staff to begin supporting families to plan and prepare for adult life in year 9 and 10 at the latest.

References

Pigott, S., (2008) *Current Research*, available on the DEC website at:

<http://www.schools.nsw.edu.au/media/downloads/schoolsweb/gotoschool/primary/transition/yr2008/research.pdf>

NSW Department of Education and Training, (2005) *Transition Project - Sydney Region*

NSW Ombudsman, (June 2011) *Consultations with families of children with disabilities on access to services and support – Final Report*

SCOPE, (2010) *Transition to school for children with disabilities: A review of the literature*

Table 1A: Blank grid to identify transition activities and strategies

| Area \ Phase | Preparation | Transfer | Induction | Consolidation |
|-------------------------------|-------------|----------|-----------|---------------|
| Administrative | | | | |
| Social and personal | | | | |
| Curriculum | | | | |
| Pedagogy | | | | |
| Management of learning | | | | |

Table 2: Example of a final set of activities selected for inclusion in a transition program

| Area \ Phase | Preparation | Transfer | Induction | Consolidation |
|-------------------------------|--|---|--|---|
| Administrative | <ul style="list-style-type: none"> Transition team meetings begin Year 7 adviser meets with primary school teachers Speak at student/parent meetings | <ul style="list-style-type: none"> Transition team meetings* Speak at primary schools' parent information evenings Exchange of student data Special needs students – interviews and orientation | <ul style="list-style-type: none"> Transition team meetings* Joint primary–secondary teacher meetings to discuss student progress and issues | <ul style="list-style-type: none"> Transition team meetings* Joint primary–secondary meetings to discuss student progress and issues* Evaluate student/parent information on the secondary school web site |
| Social and personal | <ul style="list-style-type: none"> Year 5/6 attend secondary school musical production Year 5/6 students/parents attend secondary school open day during Education Week Year 7/8 students perform at primary schools' gala day | <ul style="list-style-type: none"> Year 6 student/parent open day, including orientation tour and 'taster' lessons Year 6 orientation day, with Year 6 students in Year 7 class groups plus 'taster' lessons Year 7 students visit old school | <ul style="list-style-type: none"> Year 7 welcome assembly Year 7 orientation program Year 7/10 peer support program Year 7 health and fitness day Year 7 camp | <ul style="list-style-type: none"> Peer tutoring for Year 7/8 students Year 8 camp |
| Curriculum | <ul style="list-style-type: none"> Gifted and talented program, including collaborative Internet project* Students use secondary school specialist facilities* Joint school development day on pedagogy and curriculum Establish team to develop a curriculum framework statement for technology 5–8 | <ul style="list-style-type: none"> Gifted and talented program, including collaborative Internet project* Students use secondary school specialist facilities* 5–8 curriculum meetings* Technology 5–8 curriculum framework completed | <ul style="list-style-type: none"> Gifted and talented program, including collaborative Internet project* 5–8 curriculum meetings* Technology 5–8 curriculum framework implemented | <ul style="list-style-type: none"> Gifted and talented program, including collaborative Internet project* 5–8 curriculum meetings* Technology 5–8 curriculum framework implemented* |
| Pedagogy | <ul style="list-style-type: none"> Joint primary–secondary school development day on pedagogy and curriculum Teacher observations | <ul style="list-style-type: none"> 5–8 pedagogy meetings – Quality Teaching* Teacher observations, cooperative teaching | <ul style="list-style-type: none"> 5–8 pedagogy meetings – Quality Teaching* Teacher observations, cooperative teaching* | <ul style="list-style-type: none"> 5–8 pedagogy meetings – Quality Teaching* Cooperative teaching* |
| Management of learning | <ul style="list-style-type: none"> Lessons and directed activities in the development of study skills, problem-solving, time management, decision making, thinking skills, social skills | <ul style="list-style-type: none"> Year 6 'focus on learning' mornings Student choice within classroom units of work | <ul style="list-style-type: none"> Year 7 'focus on learning' days Student choice within units of work and assessment Teacher meetings and student interviews to address progress Year 7 parent evening about 'Helping your child learn' | <ul style="list-style-type: none"> Year 8 'focus on learning' days Student choice within units of work and assessment Academic support for struggling students Year 8 parent evening about 'Helping your child learn' |

* Ongoing program or activity