

Submission

No 32

INQUIRY INTO CHILDREN AND YOUNG PEOPLE 9-14 YEARS IN NSW

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Development

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**Family Advocacy Submission
to the
Inquiry into Children and Young
People 9-14 in NSW**

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Executive Summary and Recommendations

Children and young people with disability are first and foremost children and young people who need to be valued, to belong, to form an identity as a teenager and to have increasing opportunities and support for independence. Unfortunately these fundamental needs are sometimes overlooked in a system designed to ‘fix’ their deficits and relieve their families of the ‘burden’ of their care.

A framework of promoting wellbeing has been used in this submission to argue for Government policies and services to be focused on the best interest of the child or young person and work to minimise exposure to risk factors and maximise exposure to protective factors.

At the most fundamental level, children and young people with disability need:

- their family to have an understanding of their disability in a way that contributes to a positive vision of them as a full member of the family and community;
- to grow up in a family that is properly supported. If the birth family is unwilling or unable, for whatever reason, the child needs a alternate family;
- families that are supported to develop patterns of everyday life that actively include, rather than exclude, the child with disability;
- support from people who are encouraged to form attachments;
- inclusion in local generic places where all children and young people belong;
- support to develop friendships;
- high expectations by all who know them.

Key messages that must underpin any service response for children and young people with disability include a belief in, and an acceptance that:

- The way in which we view children and young people with disability and our expectations of them have the most profound impact on their lives.
- Children and young people with disability have the same fundamental needs as their peers – the need to belong, to have friendships, to grow in independence and to be valued. They need additional support to meet these needs and to have an ordinary life as a child or young person.
- Disability exposes many children or young people to increased risk factors. These include:
 - child risk factors – low self esteem, poor social skills, poor problem solving, difficult temperament and early school leaving;
 - school context factors – school failure, bullying, peer rejection and poor attachment to school;
 - community and cultural factors – lack of support services and social and cultural discrimination.
- Children and young people with disability are increasingly members of the regular class of local neighbourhood schools but many schools continue to struggle to provide a welcoming environment that embraces physical, social and curricular inclusion.

- Children and young people with disability are less likely to attend before and after school and vacation programs.
- Children and young people with disability and their families often need help from systems that characterise them in a deficit mode, focusing either in ‘fixing’ their deficits or relieving their families of the ‘burden’ of their care. These messages are profoundly detrimental for a young person’s emerging sense of self and contribute to low self esteem.
- For those reliant on the specialist disability service system, their opportunities for the rough and tumble of an ordinary life are restricted because of conservative understandings of OHS, the discriminatory attitude of some programs and the lack of support for their participation.
- It is never too late to build protective factors in children and young people with disability and their families. Changed expectations and opportunities can have a profound impact (Smart: 2003).

Recommendations

Family Advocacy recommends that Government take action to implement policies and fund programs that enable and support:

1. All children and young people with disability to be welcomed and educated in the regular class of local neighbourhood school with supports.

To facilitate physical, social and curricular inclusion, it is recommended that the NSW Department of Education and Training (DET):

- Provide a skilled and experienced specialist teacher in every school. This specialist teacher will provide direct support to students with additional needs and simultaneously strengthen the capacity of teachers to support all students.

This can be achieved by re-focusing the role of existing school based staff for students with low support needs and repositioning many of the area and regional based staff.

- Implement peer support mechanisms for students with disability.
- Implement effective transition processes that address social, personal, curricular, pedagogical and learning management issues for students with disability entering secondary school.

2. The reorientation of specialist disability services from the current deficit crisis model to focus on enhancing exposure to protective factors that build the resilience of children, young people and their families.

Significant service development is necessary to build capacity to offer services that focus on these fundamental needs of children, young people with disability and their families. An effective proposal would be designed to be transformational for:

- individuals and families - making a difference in their lives;

- specialist disability and generic organisations - developing skills to respond in different ways and the capacity to generalise what they have learned to other people and families;
- the broader system - in the longer-term bringing about practices to meet changed expectations and which, in turn, will influence policy.

Family Advocacy seeks to be involved in the implementation of any service development proposals that are taken forward from this Inquiry.

3. Children and young people with disability to be active members of their local community including active participation in before and after school and vacation programs, community and cultural groups and activities.

To facilitate community inclusion requires:

- an increase in resources to provide individual support (through both State and Commonwealth programs);
- the development of individualised support arrangements to enable teenagers with disability to participate in after school and vacation activities with their friends;
- an increase in the competence of support workers to build and enhance friendships between children and young people with disability and their peers rather than providing a 'paid' friendship.

4. Family friendly practices in workplaces

To support parents of children and young people with disability to rejoin and remain in the workforce, family friendly work practices are required.

5. Eligibility for Centrelink payments

The Work Participation Legislation that requires mothers in receipt of Parenting Payment to look for at least 15 hours a week work once their youngest child turns 7 needs to be reviewed to take greater account of the unpredictable and time consuming demands on parents of people with disability.

Issue: The needs of children and young people in the middle years

“Every child wants to believe in himself or herself as a successful person; every youngster wants to be liked and respected; every youngster wants physical exercise and freedom to move; and youngsters want life to be just”. (Stevenson: 1992)

Like all children and young people in this cohort, those with disability need:

- to belong – to be like everybody else;
- to form an identity as a teenager;
- to have increasing opportunities and support for independence.

Context

Children and young people with disability are embedded in research statistics (Mission Australia: 2005) that documents the fact that:

- Young Australians live in a diversity of family types including intact couple families, step, blended and one parent families.
- Parental participation in the labour force increases quite significantly, particularly for mothers, once their youngest goes to school. This will pose more difficulties for families with a child with disability.

Research confirms the existence of identifiable factors that impact on wellbeing and promote or inhibit resilience, the ability to bounce back or recover after adversity or hard times. These are reported as:

- risk factors that increase the likelihood of a poor outcome;
- protective factors that increase the likelihood of a positive outcome and help promote resilience.

Mission Australia (2005) provides a valuable framework in which to consider the most useful ways to intervene to promote wellbeing in children and young people. The factors are summarized in Table 1.

In addition, new research confirms that developmental pathways can change. Children who exhibit ‘difficult’ characteristics during childhood do not necessarily become ‘problem’ adolescents – and such change is common (Smart: 2003).

This submission

This submission will argue that children and young people with disability are first and foremost children and young people whose fundamental needs are sometimes overlooked in a system designed to ‘fix’ their deficits and relieve their families of the ‘burden’ of their care.

This submission will use the framework of promoting wellbeing to argue for government policies and services to be focused on the best interest of the child or young person and work to minimise exposure to risk factors and maximise exposure to protective factors.

Table 1: Factors impacting on wellbeing

Risk factors				
Child factors	Family factors	School context	Life events	Community and cultural factors
Low self esteem Poor social skills Poor problem solving Difficult temperament Lack of empathy Homelessness Early school leaving	Family violence Poor supervision Harsh or inconsistent discipline Lack of warmth and affection Abuse and neglect	School failure Bullying Peer rejection Poor attachment to school Deviant peer group	Divorce and family breakup Death of a family member	Neighbourhood violence and crime Lack of support services Social and cultural discrimination Community norms concerning violence
Protective factors				
Child factors	Family factors	School context	Life events	Community and cultural factors
Social competence Attachment to family Empathy Problem solving Optimism School achievement Easy temperament Good coping style	Supportive caring parents Family harmony Secure and stable family Supportive relationships with other adult Strong family norms and morality	Positive school climate Pro-social peer group Sense of belonging Opportunities for some success at school and recognition of achievement School norms re violence	Meeting significant person Moving to new area Opportunities at critical turning points or major life transitions	Access to support services Community networking Attachment to the community Participation in community group Community cultural norms against violence Strong cultural identity / ethnic pride

Mission Australia, 2005 *“Developing resilience at every stage of a young person’s life” Snapshot 2005*

Issue: The extent to which the needs of children and young people in the middle years vary according to age, gender and level of disadvantage

“It is the theory that decides what can be observed” (Albert Einstein)

The answer to this issue depends on the question we ask. Our society tends to frame children, young people and adults with disability in a deficit model and as a result asks the fundamental question, “What services do people need?” The utilisation of these services tends to generate the need for further paid supports.

An alternate question is ‘What is a good life?’ This leads to a more fundamental exploration of what is important in life and only secondarily to an examination of the role services could play in supporting a child or young person with disability to gain a good life. The question, ‘What is a good life?’ throws relief on the fundamental needs to belong, have friendships and have a positive image of one’s self. It demonstrates that the fundamental needs of children and young people with disability are no different from those of their peers without disability. What is different is the support they need to be able to participate.

Parents of children with disability are often starved of the natural opportunities to enjoy parenthood and develop local networks of support. From the earliest age of their child, they are forced into a different path from that used by other local families as they seek to understand and fix their child’s difficulties. By the middle years, many children and young people with disability are quite disconnected from opportunities in their local communities.

Appendix 1 provides a story of Alex, a young person who was able to move away from the ‘therapy treadmill’ to establish ‘a real life, with real friends, real interests and real achievements’, even though he has very significant support needs. Alex’s parents report that the things which were most critical in making the change to Alex’s life were:

- finding a strong, positive vision of his future;
- insisting on his right to the same ordinary, everyday dreams other parents have for their children;
- knowing that families can make a difference.

Similarly, in the book "Educating All Students in the Mainstream of Regular Education" Jeff and Cindy Strully wrote a chapter on friendships as an educational goal. In this chapter they point out how people often describe children and dream about their futures. They gave the following examples:

A description of two daughters		
Description	<p>Beautiful brown eyes and brown hair</p> <p>Favourite musicians and musical groups are: Bruce Springsteen, Tiffany, U2, Bangles and Madonna.</p> <p>She will wear clothes with the following labels only: Guess® and Esprit®</p> <p>Her favourite movie stars are: Rob Lowe, Matt Dillon and Matthew Broderick.</p> <p>She is a sophomore at Arapahoe High School. She tried out for cheerleaders, but didn't like it.</p> <p>She works part-time at Sound Warehouse.</p> <p>She "hangs out" in shopping malls, at Burger King and 7 Eleven Store, the gym and anywhere there are boys!</p> <p>She spends time on the phone talking to friends. Friends are very important to her.</p> <p>She loves swimming and getting a tan.</p> <p>She loves to decorate her room, including the ceiling with posters.</p> <p>Extracurricular activities have included signs and posters, gourmet cooking, Girl Scouts, and the high school newspaper.</p> <p>She is caring, bright, and very typical. When you ask her friends to describe her they say: happy, exciting, pretty, silly, normal, wonderful, intriguing, engaging, unique, fun, enjoyable, stubborn, great, laughable, caring, annoying, energetic, picky, fickle, affectionate, pushy, loveable, decisive, sensitive, strong-willed, temperamental, spontaneous, diplomatic, terrific</p>	<p>Severely/profoundly mentally retarded</p> <p>Hearing impaired, Visually impaired</p> <p>Has cerebral Palsy</p> <p>Myoclonic seizures</p> <p>Does not chew her food and sometimes chokes</p> <p>Is not toilet trained</p> <p>No verbal communication</p> <p>No reliable gestural communication</p> <p>If given the chance, will self-stimulate, mainly hand in eye and hand in mouth</p> <p>If given a developmental checklist, would "top out" at 17-24 months</p> <p>Loves Fisher Price® toys</p> <p>Loves music – "Row, Row, Row Your Boat, "Three Blind Mice", "London Bridge"</p>
Desirable future	<p>Hardly a day goes by without our thinking about the kind of future that we would like for our daughter. Our dreams for her are much like those outlined by her friends, including in their own words:</p> <p>Living with someone who cares about her</p> <p>Doing something during the day that she likes to do</p> <p>Having lots of friends to do things with</p> <p>Living in her own condo. Having an active life</p> <p>Being around people who want to be with her</p> <p>Having friends over everyday to do "stuff" with. Being happy</p> <p>Going to college</p> <p>Modeling for a fashion magazine</p> <p>Working in a job that she likes and that makes money</p>	<p>Thinking about a desirable future for our second daughter is more difficult for most people. They might dream about her future in the following ways.</p> <p>Group home with six or eight other people</p> <p>Sheltered workshop – day activity centre</p> <p>Special Olympics</p> <p>Volunteers to "work" with her</p> <p>Need for programming</p> <p>Group field trips</p> <p>Friends like to be with her who are just "like" her</p>

Strully concludes that "These two children are the same person, our daughter Shawntell."

At the most fundamental level, children and young people with disability need:

- their family to have an understanding of their disability in a way that contributes to a positive vision of them as a full member of the family and community;
- to grow up in a family that is properly supported. If the birth family is unwilling or unable, for whatever reason, the child needs a alternate family;
- families that are supported to develop patterns of everyday life that actively include, rather than exclude the child with disability;
- support from people who are encouraged to form attachments;
- inclusion in local generic places where all children and young people belong;
- support to develop friendships;
- high expectations by all who know them.

What do we know about the life situation of children and young people 9-14 who have a disability?

They have had less opportunity for inclusion in early childhood services than their peers with out disability

In school

- Increasing numbers are in the regular class: 73% in primary school; 43% in secondary school and 61% over the whole NSW State school system. Negotiating the supports they need, however, would probably not have been a smooth path for their parents and would have added to family stress. Conversely however, 27% remain in support classes and SSPs with poor role models and experiencing limited curricula.
- Anecdotal evidence suggests that many children and young people with disability are suspended from school for issues related to their behaviour. Contrary to the DET Suspension and Expulsion Procedures, they return to school without appropriate planning and support to minimize the probability of incidents recurring. (Guideline 5.0.2 indicates that “Suspension allows time for school personnel to plan appropriate support for the student to assist with successful re-entry. This may include the access to appropriate support staff such as ... support teacher behaviour”). The refusal of the DET to disaggregate suspension data means that there is no reliable data on suspension of students with disability.

They are less likely to attend before and after school care, vacation care and other sporting and community activities for children and young people

Whilst increasingly community activities for children seek to include children with disability, on a practical level, many lack the resources to support children with disability to take an active role in their activity and so the experience may be one of marginalisation.

Some activities for children continue to exclude children with disability on the basis of their disability. A recent email to Family Advocacy indicated:

“Many activities & services still exclude children with special needs. My daughter attends the only Girl Guides in our area that will accept girls with special needs. There needs to be support/funding for small sports and activities based groups that cater to children, so that they are able to support children with additional needs.”

Critically, there are very few organised after school and holiday programs for high school students. This leads to isolation for young people with disability at the time when their peers are gaining confidence as a result of increased independence. This issue will be discussed under the impact of changing workplace practices.

If their families are struggling with life’s challenges and are reliant on the specialist disability service system for support, they will find a variable response

The increased provision of services through *Stronger Together* within a more coherent policy framework means that there are more options on the ground where families live. However:

- The so called ‘flexible respite’ has become more rigid and hence less responsive to the interests of both the young person with disability and his/her family.
- Behaviour management support is of variable quality and many children and young people with autism but without intellectual disability are not even eligible.
- Services for children and young people either focus on ‘fixing’ the child or on minding the child or young person to give their parents a break.
- The high intensity supports, particularly intensive family support, alternate family care and shared care are seldom available when required. This places families under untenable stress and puts children and young people at risk.
- In addition, the media attention to the crisis situation of families endangers good Government policy that “Children belong in families”. The lack of readily available intensive family support and family based out-of-home care options means that families who are unable or unwilling to care for their child with disability have no publicly funded options that are coherent with the best interests of the child. The policy is attacked as unviable whereas it is the level of resources devoted to its implementation that ought to come under attack.
- If the child or young person with disability enters out-of-home care through the child protection system, they are unlikely to be accommodated close to their family putting family contact and reunification at risk.

For children and young people in voluntary out-of-home care

They remain unlikely to live in family based options with little or no emphasis given to restoration to their birth family.

Many children and young people with disability in voluntary out-of-home care live in boarding school type situations in which they are cared for by rostered staff with little opportunity to meet their fundamental needs.

Key messages in relation to children and young people with disability

- The way in which we view children and young people with disability and our expectations of them have the most profound impact on their lives.
- Children and young people with disability have the same fundamental needs as their peers – the need to belong, to have friendships, to grow in independence and to be valued. They need additional support to meet these needs and to have an ordinary life as a child or young person.
- Disability exposes many children or young people to increased risk factors. These include:
 - child risk factors – low self esteem, poor social skills, poor problem solving, difficult temperament, early school leaving;
 - school context factors – school failure, bullying, peer rejection, poor attachment to school;
 - community and cultural factors – lack of support services and social and cultural discrimination.
- Children and young people with disability are increasingly members of the regular class of local neighbourhood schools but many schools continue to struggle to provide a welcoming environment that embraces physical, social and curricular inclusion.
- Children and young people with disability are less likely to attend before and after school and vacation programs.
- Children and young people with disability and their families often need help from systems that characterise them in a deficit mode, focusing either in ‘fixing’ their deficits or relieving their families of the ‘burden’ of their care. These messages are profoundly detrimental for a young person’s emerging sense of self and contribute to low self esteem.
- For those reliant on the specialist disability service system, their opportunities for the rough and tumble of an ordinary life are restricted because of conservative understandings of OHS, the discriminatory attitude of some programs and the lack of support for their participation.
- It is never too late to build protective factors in children and young people with disability and their families. Changed expectations and opportunities can have a profound impact (Smart: 2003).

Issue: Activities, services and support which provide opportunities for children and young people in the middle years to develop resilience

Catalano (2002) describes resilience as the individual's capacity to successfully adapt to change and stressful events in healthy and constructive ways. It is a dynamic process involving an interaction between both risk and protective processes that act to modify the effect of an adverse life event (Rutter:1985). In this context, resilience implies an ability to recover from negative events (Garmezy: 1991).

Important research gives encouragement that it is never too late to build protective factors. Research by Smart (2003) showed that one third of children identified as 'high risk' of anti social behaviour at age 11-12, did not subsequently engage in such behaviour at age 17. This resilient group seems to have benefited by exposure to protective factors including more positive parent-child relationships, fewer anti social peer friendships and more attachments and positive attitudes to school.

The critical point is that the increase in protective factors was shown to minimise the impact of risk factors, building resilience in the child or young person and leading to more positive outcomes.

Table 2 looks at ways to enhance protective factors in children and young people with disability.

Factors and strategies that enhance wellbeing		
Factor	Focus for intervention: Strategies to enhance	Implications for services
Child protective factors	Social competence, Communication skills Relationships with peers Identity as a teenager Increased opportunities for independence School achievement	Timely quality behaviour management and therapy support Age appropriate role models (inclusion) Physical, social and curricular inclusion in school Support for inclusion in local community activities with peers Inclusion support focused on building relationships with peers
	Attachment to family	Supports to reduce family stress - increased availability of flexible support under control of family
Family factors	Supportive relationships	Increased availability of flexible support under control of family Assist families to develop natural support networks in their own communities
	Appropriate work/family balance	
School factors	Positive school climate	Policies and strategies to develop inclusive school communities
	Effective transition planning	Implementation of DET processes
	Relationships between students with and without disability Sense of belonging	Peer support and mentoring programs
	Opportunities for success at school and recognition of achievement	Effective curricular inclusion with appropriate rewards for achievement
Community and cultural factors	Inclusion into local and cultural peer groups	Support for young people to actively participate with their peers
	Inclusion into age appropriate community activities	Cross age and peer support mechanisms

Implications for services for children and young people with disability

- 1. Services need to focus on the real issues for children and young people.** The vogue in service provision for children and young people with disability is to be ‘child-centred, family focused’. Anecdotal evidence, however, suggests that specialist disability services have little knowledge and skills in, for example increasing the social competence of a child or young person, enhancing friendships, enhancing the child’s problem solving, optimism or coping style.
- 2. Services need to be underpinned by a value base** that sees children and young people with disability as children first and has high expectations for them.
- 3. Services need to see their role** as building resilient children (rather than fixing deficits or minding burdens) and building or enhancing natural networks for families and for children and young people
- 4. Services need more resources and must deliver services through generic settings** rather than pulling children, young people and their families away from their local community. This includes services required to address specific developmental needs of children and young people with disability such as quality behaviour support, special education and therapies. In addition, the families must be given authority to make major decisions about resources directed at their support.
- 5. Services need to provide support tailored to each child, young person and their family through a mix of formal and informal support with investment in developing informal support.** If people remain reliant of the specialist disability service system, their lives will lurch from crisis to crisis because unmet demand will always be with us and one night in a respite house usually only creates demand for another. Policy and service practice must help families to become more resilient and less reliant on disability services. Services need to help families call forth and validate the involvement of family and friends. Services need to focus on helping children and young people to be actively included in their local communities.

Case study:

A NSW agency extended the notion of respite by having the main focus on supporting children and young people with disability to do what they enjoy and participate in community life. The program provides practical assistance to enable a child or young person to become a member of a group, a team or undertake a valued role such as a volunteer. The focus for the support worker is to facilitate relationships between the child or young person with disability and other members of the group.

The value added from this type of support is that it facilitates opportunities for children and young people with disability and their families to increase the number of people they know and who know them and such connections have greater likelihood of developing freely given relationships leading to friendships. Half a day in a respite house, an outing with other people with disability or even with an individual support worker where it is ‘paid friendship’ will only lead to a demand for more of the same. Support to be included, to be a ‘member’ has the opportunity to deliver much more.

Working in this way, families gain the benefit of ‘respite’ (by having a break), explore new opportunities for their sons and daughters and take a greater role in planning for the future. In addition, the active participation of each individual helps change the community expectations of people with disability from dependent burdens to contributing members.

6. Services need technical assistance to change their orientation to more contemporary supports that build connections for children and young people.

It is unrealistic to expect a major culture shift in services without significant support for the change process. Technical assistance through a service development unit would work with services to change practice and culture including reorientation of service provision to:

- undertake authentic person-centred planning and assist young people to develop valued social roles.
- provide support tailored to each child, young person and their family through a mix of formal and informal support with investment in developing informal support.
- recognise the importance of attachments and support the same type of relationships that parents want when they seek a private babysitter. The practice of flexible respite providers deliberately changing support workers lest a relationship develops is anathema to the best interests of the child or young person. The key is to have that support worker understand that his or her role is about facilitating the young person’s relationships with peers, not being a ‘paid friend’.
- provide support that contributes to patterns of everyday family life that do not exclude the child with disability.
- look beyond the specialist disability service system for resources and opportunities.

Implications for generic services for children and young people

Generic services and social and community activities for children and young people need to understand the vulnerability of children and young people with disability and take steps to ensure they are actively included and properly supported. Part of the issue is resources and part is competence in building natural networks amongst children and young people with and without disability. The technical assistance identified above could assist.

Implications for schools

The importance of inclusive education

“One of the greatest problems facing the world today is the growing number of persons who are excluded from meaningful participation in the economic, social, political and cultural life of their communities. Such a society is neither efficient nor safe.”

This is the lead paragraph to the UNESCO Paper on Overcoming Exclusion through Inclusive Approaches in Education (2001). The paper documents the way in which current strategies and programs have largely been insufficient or inappropriate with regards to the needs of children and youth who are vulnerable to marginalization and exclusion. Where programs targeting various marginalized and excluded groups do exist, they have functioned outside the mainstream through special program, specialized institutions and specialist educators. Notwithstanding the best intentions, too often the result has been exclusion: second rate educational opportunities that do not guarantee the possibility to continue studies, or differentiation becoming a form of discrimination, leaving children with various needs outside the mainstream of school life and later, as adults, outside community social and cultural life in general.

The solution, promoted by UNESCO (2001):

“regular schools with inclusive orientation are the most effective means of combating discrimination, creating welcoming communities, building an inclusive society and achieving education for all”.

Defining inclusion

Wills and Jackson (2001) describe inclusion as having 3 components:

- Physical inclusion: Physical inclusion means attending the local neighbourhood school, playing in the same playground, being in the same classrooms as well as having access to opportunities offered by the school at the same time as same aged peers without disability.

If a child is not present, then clearly he/she cannot be included. Unfortunately the landscape of our typical schools is such that even minor mobility or self care issues can play havoc with just being there.

- Social Inclusion: Whilst physical presence of children in regular classrooms is a prerequisite to social inclusion, the personal and social welcoming of children within the social milieu of the school is a vital part of school life.

One can be rejected and lonely even in a crowded classroom as many children will know. Recommending segregation to prevent this sort of rejection, however, is clearly illogical. Social inclusion involves policies and practices to promote a welcoming social environment for ALL students including promoting personal friendships, caring for one another, discouraging and addressing teasing and all other forms of social isolation of students.

- Curricular inclusion: Curricular inclusion is the involvement of the student in the regular curriculum of the school. Of all the aspects of inclusion, this is probably the hardest and most controversial. It is increasingly being recognized that every child is special, with individual skills and needs and that this has to be addressed by the teacher. The child with the disability highlights this issue for all children.

Experience of students with disability in schools

Students with disability are more likely to:

- experience the risk factors associated with school such as school failure, bullying, peer rejection, poor attachment to school and to have a deviant peer group.;
- experience an uncertain transition to high school ;
- be taught by teachers who feel ill prepared for the challenge.

Lessons from US educational reform

Three important themes have emerged from high school reform in the US as guiding principles: they are rigor, relevance and relationships (Bill and Melinda Gates Foundation: 2004).

This work has relevance for students with disability.

First, the rigor of the curriculum is seen as critical. All students should have access to rigorous curriculum. Teachers should hold high expectations for every student, design learning experiences that challenge students to achieve their potential, provide supports students to succeed and remove barriers to engagement and achievement.

Second, all students should have access to school experiences that have relevance to their lives. Instruction must be engaging, draw upon students' interests and equip them with the life skills they will need to be active and contributing citizens.

Third, schools should be deliberate about fostering meaningful relationships for all students. A sense of belonging, positive relationships with peers and access to personalized supports are all known to contribute to students' success in school and overall quality of life.

High schools that emphasise these three elements – rigour, relevance and relationships are presumed to offer a more engaging and motivating place for youth to learn.

Improving curricular inclusion for students with disability

Carter et al (2008) argues that rigour, relevance and relationships are just as essential and beneficial for youth with severe disability, yet a visit to most high schools in the US (and in Australia) would reveal that the majority of students with severe disability are not getting these things.

“It is the quality of pedagogy that most directly and powerfully affects the quality of learning” (Quality Teaching in NSW Public School, 2003)

Enhancing teacher competence and backing it with specialist resources is critical to improve the quality of inclusion offered in NSW schools.

Assistance currently available for students with moderate to high support needs in the regular class is mainly drawn from the Funding Support program. Most of the resources on Teachers' Aides Special who provide a valuable contribution but are the least skilled members of the school staff team.

Specialist staff located in area and regional offices provide some assistance, but the delay in accessing support can be great leading to:

- increased frustration on the part of the student and the teacher;
- missed opportunities to develop capacity in the teacher;

- the consolidation of poor practice in the classroom;
- increased likelihood of the student being suspended.

Part time, school based experts are only available to assist students with low support needs in literacy and numeracy. Area and regionally based itinerant staff assist in targeted areas of student need. This silo effect produces artificial barriers and reduces the opportunity for timely support for teachers and students.

What is needed is a more school based approach. Students and teachers need expert assistance in a timely fashion. Teachers need support to improve their knowledge, skills and capacity to teach all students.

Research confirms that teachers do not change their teaching practice without exposure to:

- what teaching actually looks like when it is done differently; and
- someone who can help them understand the difference between what they are doing and what they aspire to (Ainscrow:2005).

The use of coaching and mentoring by skilled school based colleagues is a highly valued professional learning strategy.

Every school needs a skilled and experienced specialist teacher who is able to provide direct support to students with additional needs and simultaneously strengthen the capacity of teachers to support all students. This can be achieved by refocusing the role of existing school based staff for students with low support needs and repositioning of many of the area and regional based staff.

Social inclusion

Inclusion in school is quite different from integration. In attempting to clarify the differences between integration and inclusion, Loreman (1999) draws the distinction as

“... integration involves coming from the outside. Integration programs aim to ... help a child to fit into a pre existing model of schooling. Inclusion differs in that it assumes that children are a part of the regular school system from the start.”

Inclusion assumes that the school has a responsibility to make adjustments to enable all students to belong. This requires attention at the system and school level to adjust school processes and culture to build inclusive school communities.

The value of peer support mechanisms

Giangreco & Broer (2007) argue that the widespread use of individually assigned paraprofessionals suggests that more deliberate reflection is needed on the strategies used to support high school inclusion. Indeed, heavy reliance on adult delivered supports to promote inclusion may not be yielding the social and academic benefits that educational teams intend (Carter & Kennedy, 2006). Increasingly, calls are being issued for schools to consider alternative approaches for supporting the inclusion of students with severe disability.

Carter (2008) argues that peer support arrangements are one promising approach for promoting access to rigorous, relevant learning experiences and expanding opportunities for students to establish new relationships with their peers. These intervention strategies involve inviting one or more peers without disability to provide ongoing social and

academic support to their classmates with severe disability. Key to success is the provision of ongoing mentoring, feedback and assistance to peers and their partners as needed; and the shift of the role of the paraprofessionals to a broader social role within the classroom through which they assist all students as directed by the teacher.

The US experience and anecdotal evidence from Australia shows that peers can be quite adept at supporting their classmates and that a number of academic and social benefits are available to participating students with and without disability (Carter et al:2005) Although concerns are sometimes raised that peers may fall behind academically by serving in this support role, research in fact suggests the opposite (Cushing & Kennedy. 1997). The additional feedback and assistance peers receive from adults coupled with the experience of teaching to someone else, may partially explain the academic benefits.

Transition to high school

In recent years the DET processes for transition to high school have improved significantly. Table 2 provides an outline of the broad based longitudinal process that is considered good practice.

Table 2

DET Transition processes				
Area/phase	Preparation	Transfer	Induction	Consolidation
Administrative				
Social and personal				
Curriculum				
Pedagogy				
Learning management				

Unfortunately, a significant number of students with disability do not get passed the administrative processes in the preparation phase prior to the end of term 4 year 6. What is necessary is the application of generalist broad based process used for transition of all students, to be implemented with students with disability.

Issue: The extent to which changing workplace practices have impacted on children and young people in the middle years, including possible workplace practices which have the potential to benefit children and young people in the middle years

A recent email to Family Advocacy addressed many of the issues families face.

The Work Participation Legislation that requires mothers in receipt of Parenting Payment to look for at least 15 hours a week work once their youngest child turns 7, disadvantages parents who have a child with a disability, as their criteria for exemption is almost impossible to get. Either a letter from your doctor or school stating that you must be available at all times to care for your child.

There is no flexibility or exemption for the fact that our children get sick more often, or our need to attend workshops and training, while our child is at school, to equip us for catering to our child's special needs. Furthermore you cannot get an exemption on the grounds that you can't get childcare or OOSH care, which in this area is near impossible, as some services will not take our children and there is a long wait for funding.

The workplace is still not a family friendly environment, especially in high unemployment areas like the Mid North Coast. Workplaces will not give flexibility in hours to cater for school hours, sick children or specialist appointments.

Furthermore OOSH services are only funded for children up to 12 years. What happens to these children while their parents are at work, are they out vandalising or walking the streets with their friends? If your child has special needs, then working no longer becomes an option.

Families of children and young people with disability continue to experience enormous barriers to workforce participation. As the email comments the rigid requirements for income support, the lack of availability of outside school hours and vacation care for primary school students and its complete absence for secondary school students with disability and the lack of family friendly policies in many workplaces makes work a dream for many parents.

The Commonwealth Government seems to be scoping work in relation to vacation care for young people with disability but seems to be focusing on models that group young people with disability which would be unacceptable for a significant majority of families. Opportunities for support to 'hang out' with local friends needs to be considered in any Government program targeted at this need.

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Appendix 1

Alex's life: from the therapy treadmill to a real life

From the beginning, Alex's life was dominated by lots of visits to doctors, specialists, trips to Sydney. They used all sorts of jargon like "vision impairment", "electro-retinograms", "CT scans", "developmental delay", "autism", "intellectual disability", "cerebral palsy", "epilepsy", "severe" this and "severe" that. In short, Alex acquired a list of labels and perceived 'deficits' as long as your arm. He was not expected to walk or to talk.

Alex's parents hopped on what they call the "therapy treadmill", where their lives seemed to revolve around therapies and interventions recommended by professionals. These interventions, it seemed to the parents, were aimed at 'fixing' Alex, and they began to feel much of what was done only really served to highlight the many ways he was seen by others to be 'not right'.

Alex's parents remember that while other parents were actively enjoying their new babies, they were never given the impression by anyone that they would **ever** find anything to enjoy about theirs. They began to feel the prospect of the ordinary joys of parenting children slipping away from them and they actively avoided thinking about the future, as it seemed full of negative things.

Alex's life now is very different from those early expectations!

Alex is still the child that was being described with all the labels. I say these next things because it is important not to jump to the conclusion that his disability has disappeared or become less significant in its impact. Alex still has very limited communication. He does not make eye contact with people, or follow instructions. He likes to put objects into his mouth, he dribbles, he is not toilet trained, uses a wheelchair etc.

Yet he also has a REAL life, with REAL friends, REAL interests and REAL achievements. His life is far richer than anyone would have expected when he was little.

The things which were most critical in making the change to Alex's life were:

- finding a strong, positive vision of his future;
- insisting on his right to the same ordinary, everyday dreams Emma's parents have for her;
- knowing that families can make a difference.

These three things guided the choices that have been made for Alex. His early life, as described, had become a very limited, segregated life, centred on interventions, therapies and medical investigations. He was a long way from the things other children his age were doing. The first step in bringing his life back to the direction it is now headed in was finding the vision.

The family sat down and decided what they did and did not want for Alex. Here are a few of the points to give you a bit of an idea what they were thinking about.

- We want Alex to be involved with lots of different people.
- We don't want him to be lonely or isolated, but to have friends and acquaintances, like other people.
- For this to happen, we think he will have to be 'out there' doing things and becoming known by people in his local community.

- We want Alex to have a safe place to live with people who know or care about him. We don't want him to live among strangers and paid workers.
- We don't want him to spend his life 'filling in time' or having to be involved in activities chosen for him by others.
- We want school and early life to help him develop his skills and explore his interests and strengths.
- If there is anything we wouldn't want in our lives, then it's not good enough for him either. We think that we have nothing to lose by aiming high. We know what we'll get if we don't.

Developing a vision has provided Alex's family with a guide, when faced with difficult choices... 'Does this choice fit with our family's vision for Alex?' If yes, then go ahead. If no, don't touch it! Or at least, if you really have no choice, know that it is temporary.