

8. Education

1. “Breaking into” a new school or educational setting may be problematic/difficult;

To assist in the move from one educational setting to another (e.g. pre-primary to primary school or primary to high school, and then TAFE or University) the following suggestions, although adapted from an American journal¹, can be applied, and or adapted to Australian educational settings.

- a. Start planning early. This includes not only ensuring physical access is possible, and specific support needs are complied with, but also academic and social aspects are examined. E.g. what educational strategies have been effective, what are the student’s learning styles, preferences, and dislikes? Planning early also assists in reducing the potential for other problems, like dealing with waiting lists, and other criteria for entry to the educational setting. (In other words, don’t jump to the conclusion that difficulties getting a place in a particular educational setting are “disability” issues, there could well be any number of other reasons.)
- b. Collaborate across schools. The need for this to be a shared process, involving Educators, Administrators, Counsellors, and the child’s parents.
- c. Prepare the student early. The student may well have anxieties about the move to a new school. E.g. who will be my teacher/s? Will I get lost? What happens about lunch? These sorts of concerns can be addressed by advance planning. The more the child is prepared for the new school, the less difficulties there are likely to be.
- d. Encourage and Support Family Involvement. While there will be more teachers in a High School setting, an agreed method of contact should be made as early as possible. This could be via; a.) Communication books; b.) Planned and scheduled school visits; c.) Notes to family members; d.) Phone calls or email messages. For the TAFE or University setting, this may mean keeping in contact with the *Disability Support Officer* that the educational institution has, to ensure that the student is able to deal with the mobility and access issues, and any academic assistance they may need, while at the same time trying to balance the independence, and self-sufficiency normally associated with adolescence, and young adulthood.
- e. Encourage Ongoing Communication. Parents should try to maintain open communication with the child or adolescent to try to minimise and circumvent any difficulties the student may have with the transition. It is important to initiate conversations with the young person, about issues like bullying, social isolation, peer pressures and related types of issues, as they will probably be reluctant to raise them themselves. The authors note;

¹ Carter, E., Clark, N., Cushing, L., & Kennedy, C., (2005) Moving from Elementary to Middle School: Supporting a Smooth Transition for Students With Severe Disabilities. Teaching Exceptional Children, 37 (3) 8-14

“...adults should remain alert to external indicators that a child is struggling with the adjustment to middle school [or high school in Australia]. The development of physical problems, behavioural challenges, poor academic performance, indices of unhappiness, or limited social relationships can be signs that a child is struggling to adjust to a new school.” (p. 12)

- f. Address Organizational Issues. This means dealing with things like perhaps having two sets of textbooks, one set at home, and the other at school. Teaching the child to use an electronic calendar to record and track assignments.
- g. Develop Peer Support Programs. Educators need to create situations where the student with a disability will interact with their general education peers. This could involve sitting peer helpers next to the child. They should also be designed to go beyond the classroom, and cover unstructured situations like lunch and other meal or recreational breaks. In this research, they say how other researchers have noted that “...peer supporters typically take pride in their support role and new responsibilities and students with disabilities acquire beneficial support and develop friendships.”(p. 13) In some other research about *Creating Helper Children*² the authors note three primary areas of concern, where a school counsellor³ is involved in a *Creating Helper Children* program; a.) The availability of willing helpers; b.) The helpee’s (i.e. the child with a disability) ability to interact and relate to the helper; c.) The counsellor’s attitude towards students with disabilities, and their willingness to assume an advocacy role.
- h. Support School Involvement. Involvement in extracurricular activities has a number of benefits. This could be school/educational institution clubs, and associated organizations. These give the opportunity to develop new skills, friendships, and social networks, as well as explore interests, that may for the younger person, give some ideas for further study, and or employment after high school. The same researchers note that this also promotes a sense of belonging to the school/educational community.
- i. Foster Independence. There is the need to encourage independence, as a means of assisting in personal development, rather than excessive dependence (i.e. allowing and encouraging the young person to do things for themselves, as far as possible and practical.) This could involve using a rubric or checklist to evaluate their school performance, or using a communication book to initiate interactions with others. Also students should be taught how to advocate for themselves for accommodations, (or modifications of requirements) support for students with disabilities, and inclusion. As use of these advocacy skills will be invaluable in other settings.

² Pelsma, D., Hawes, D., Costelo, J, & Richard, M. (2004) Creating Helper Children as Natural Supports. Journal of Professional Counseling, Practice, Theory, & Research; 32, (2); 16-27

³ In the West Australian situation, this may be the School Psychologist, or other person in a *Pastoral, or Disability Support* role. .

Parents involved in the planning process of entry into the school system may also find of assistance, the following tips from the *Parent to Parent Handbook*⁴ which include;

- a. Strive for partnerships with professionals that are characterized by mutual respect, trust, and openness, with information being shared equally among all partners;
- b. Celebrate the expertise that all members of the educational planning team bring to the process;
- c. Ask for explanations for any terms that you don't understand;
- d. Consider taking notes during the meeting so that you will have a record of the discussions and decisions;
- e. Prepare for the meeting by writing down any questions or concerns that you would like the team to address during the meeting;
- f. Let the professionals know if you are concerned about their recommendations for your child;
- g. Consider how suggested home activities will fit into your family schedule;
- h. Think about what role you want to play as you partner with professionals around your child's educational needs (p.31.)

2. Classroom layout and teaching practice need to be considered to ensure as effective as possible an educational experience.

In the classroom setting various steps can be taken to assist with the physical and social integration into the classroom, and educational outcomes. This can involve thinking about the following ideas noted in Rocky Bay's L.I.N.C.K.S. 5 resource, in relation to children with a neuromuscular condition.

Getting around the classroom and school community. Give some thought to:

1. Where the child will go on entering the room at the beginning of the day and following breaks - look for direct routes that have minimal obstacles.
2. Where the child will spend most of their class time. That may be on floor mats, at a custom height table, at a computer station, or a desk.
3. Clustering frequently used spaces together will help the child with NMC (Neuro Muscular Condition) navigate the classroom with greatest safety and ease?

⁴ Santelli, B., Poyadue, F., & Young, J. (2001) *The Parent to Parent Handbook*. Baltimore, MA: Brookes Publishing.

⁵ Rocky Bay L.I.N.C.K.S. Education Package [Learning and Integration for Neuromuscular Conditions in Kids at School] available from *Rocky Bay Inc.*

4. If time is spent on the floor and at a table, place the table next to the floor space.
5. If the child uses the computer regularly, put their desk next to the computer desk.
6. If the class routine involves frequent visits to the board at the front of the class, place the student at the front of the class so they don't have to walk past many desks or children to get there.

Classroom Layout;

1. Marking the pathway and 'keep clear' areas by tape or chalk on the floor reminds the other class users not to leave obstacles in the path.
2. Keep school bags open on hooks. Ensure doors can open fully to allow the best access.
3. If the child uses their own laptop or a scribe, extra space alongside their desk will be required. (Planning this extra space prevents the class area becoming cluttered and helps the child access assistance with minimal disruption to the rest of the class.)
4. If the child is a part-time wheelchair user, or uses other equipment in the classroom, safe and convenient storage of the equipment should be planned.

Classroom Rules. These could include;

1. Navigation – power chairs give way to pedestrians;
2. Use of equipment – only an adult or the chair user touches the controls of the chair;
3. Pushing the chair – a nominated daily driver can push the chair with the consent of the child with a NMC;
4. Sitting in the chair – only the child with a NMC sits in the chair;
5. Rides – no rides on the chair;
6. When equipment can be used – for example, the manual wheelchair stays out side the class for use in recess only, computer can be used during class desktop activities, not recess or lunchtime;
7. Where equipment is used – where chairs are parked when not in use.
8. Sometimes signs can help the students remember the rules – **Stop and Look**, before going through a doorway, **Keep to the left**, when driving outside.

Using Alternate Positions: In early primary years students often spend a lot of time on the floor. The child with a NMC who has limited mobility may find it difficult to get up and down off the floor, and may find it difficult to sit independently on the floor. Keeping the child with a NMC in their chair while the rest of the group sits on the floor excludes the child from the group, however continually putting the child on the floor with their peers can be time consuming, fatiguing and disruptive to the rest of the class. With planning, alternatives to sitting on the floor can be used in the classroom. These include:

1. Do some activities that are normally done on the floor on a big table instead, e.g. construction activities, board games;
2. Use tables that the child with a NMC can sit at while their peers stand, so they are all at the same height;
3. During floor time, use a modified seat for the child with a NMC;
4. During floor time, have an outer circle of chairs so that some children can remain sitting, with the child with a NMC.

Managing Fatigue: Muscle weakness and fatigue resulting from a NMC can limit a child's participation in some classroom activities. Minimising fatigue will maximise participation. Remember that the muscles of a child with a NMC do not respond to exercise the same way normal muscles would. Overexertion can increase the weakness; however a child with a NMC is likely to have a specific exercise program provided by a physiotherapist. Some of that program may be carried out at school. Often the child themselves will let you know when they have reached the limits of their endurance.

Some useful strategies include:

1. Doing tasks that require a high degree of concentration or motor control early in the day. E.g. handwriting or drawing.
2. Use less physically demanding tasks such as listening to a story as breaks throughout the day;
3. Plan quiet time for the whole class.
4. Have rest areas in the classroom so that the child can still be involved in the classroom environment while they rest.
5. Use a scribe or computer.
6. Together with parents decide if regular mornings or afternoons off school will help manage fatigue.

7. Help the child save their energy for tasks that are most important, for example have someone else push their chair to the playground or oval, so they have enough energy left to participate once they get there.
8. Look for signs of fatigue – deteriorating behavior, reduced concentration, slumping, using the desk to prop their arms or head, falling over more frequently. Give the child a rest if they look fatigued.
9. Listen to the child – if they say they are too tired, they usually are, and will need a break.
10. Liaise with last years teachers to find out what worked best for them.

Managing Behaviour. This can involve the following;

1. Have the same behavioural expectations for the child with a NMC as everyone else;
 2. Use the same management techniques for the child with a NMC as everyone else;
 3. Consider if fatigue is contributing to the behavioural difficulties – managing fatigue may resolve behavioural problems;
 4. Involve parents if any behavioural problems arise;
 5. Use visiting teachers, they are there to help you;
 6. Use support services provided by the school, such as school Psychologists.
- 3. In the school setting, the issue of how degenerative conditions are dealt with, depends on the teacher, as much as anything, which may well be affected by the response of the primary carer;**

It is generally agreed that children should be given information appropriate to their age, and potential understanding.

However teachers and other support staff, should in the first instance discuss with the child and the parent/s what and how much information should be shared with the class, (some parents prefer others not know about the condition,) and the manner this is done. As well as how to deal with particular scenario's.

It may be appropriate to ask about;

1. Whether the child and parents feel it is acceptable to have a “general discussion” as part of a lesson?

2. How to respond when a question is asked in front of the whole class? (Either use it as an opportunity to discuss, or deflect the issue, while keeping in mind the teacher's discretion, depending on other factors.)
 3. What information is to be given to the class about the condition?
 4. How much information the child with a disability knows about the condition, and their understanding of the longer term implications?
- 4. Preparation for life after high school, i.e. education, training, paid work or other activities, is something to be considered;**

Transition Issues: The need to look at life beyond the high school years is something for all parents, not just those of a child with a disability. Christopher Yates, a West Australian researcher, who looked at the transition from school for rural families⁶ with a child with a disability noted:

In recent years there has been a significant growth in the range of post-school opportunities, transition planning processes and adult services available to young people with disabilities. Despite the significant increase in services and opportunities it is likely that parents of a child with a significant disability will undergo a period of uncertainty and perhaps despair as they wonder just what will be available for their child. (p.7)

He notes that:

The outcomes for transition for the families involved in this study paint a clear picture of successful families as those who have a clear vision and a determination to make the process work for the benefit of all concerned. It is almost as though having a clear vision is a guarantee of success in itself. (p.71)

He goes on to say:

Along with a positive vision, what marked out the families who declared the transition a success, was a drive and determination to see their vision through to its achievement. The tremendous commitment and energy of the families in this study would perhaps be daunting for some and inspirational for others. (p.71)

Employment: Some American research, (that could be applied to Australia,) looked at successful women with a disability⁷ noted the following as factors in their success (may also apply to males):

- a) Building social support (the need to look at developing social networks);

⁶ Yates, C., (2002) Transition from School: Outcomes for Rural Families of School Leavers with a Disability. Unpublished Masters thesis, University of Western Australia, Perth, Western Australia.

⁷ Noonan, B., Gallor, S., Hensler-McGinnis, N., Fassinger, R., Wang, S., & Goodman, J., (2004) Challenge and Success: A Qualitative Study of the Career Development of Highly Achieving Women With Physical and Sensory Disabilities. *Journal of Counseling Psychology*, 51 (1) 68-80.

- b) Developing strategies for coping with anti-disability prejudice (developing and use of advocacy skills);
- c) Understanding the interactions between disability and other aspects of one's salient identity, (e.g. class, and ethnicity);
- d) Overcoming internalized discouragement regarding gender and vocational success (developing a positive, realistic attitude);

Carer Issues and “types”: Part of the transition to life after school includes working with care assistants, i.e. a paid assistant or carer, or a family member. Some research⁸ on children’s and adolescent’s roles and relationships with assistants notes:

For adolescents with restricted mobility the constant presence of adults can be perceived as over-protectiveness and can hinder the adolescents’ possibilities to make decisions of their own. These adolescents often lack control over their lives and perceive it difficult to liberate themselves from their parents, as we found in one study. (p. 919)

The following information is provided to give some ideas about how the different categories of carer, can impact on the child with a physical disability, and how they may feel about that “type” of carer;

a. The replaceable assistant

“The relationship that the children had towards their assistant was not perceived as mutual.”

“Intimate situations were perceived by all the children and adolescents as a difficult situation to obtain help.”

“It was also perceived as more difficult to obtain help in intimate situations if the assistant was of another sex than the child or adolescents, which was the case for five of the boys, who had female assistants.”

“Few of the children/adolescents perceived that the assistant really listened to their views.” (p. 922-923);

b. The assistant as mother/father

“The assistant in the role of ‘mother/father’ gives a description of the children and adolescents’ experiences of an assistant perceived to have the role of ‘mother/father’, both in relation to the children and adolescents, and in relation to their peers.”

“The assistant in the role of ‘mother/father’ was a woman/man aged over 35 who was a personal or school assistant.”

“When the assistant had the role of ‘mother/father’, the children and adolescents perceived that they were treated like ‘children’. However, the younger children perceived it as natural for an adult to decide over them in different situations even if they were not always pleased at this decision-making, while the adolescents (those aged over 13 years) felt wronged when they were treated like children.”

⁸ Skär, L., & Tamm, M., (2001) My Assistant and I: disabled children’s and adolescents’ roles and relationships to their assistants. *Disability & Society*, 16 (7) 917-931.

The adolescents thought also that the assistant in the role of 'mother/father' was an obstacle to their self-determination and they perceived that they had limited opportunities for autonomy. (p.923)

c. The professional assistant

[In this category] "...there were only three adolescents aged between 12 and 14 years who perceived their school assistant as a professional assistant. These three adolescents said that they appreciated this type of assistant, who was a woman aged under 30 years. She was perceived as a support in practical situations and showed the adolescents respect and showed sensitivity to their wishes and views."

"The adolescents perceived that the professional assistant saw and treated them as the persons they are rather than as the disability they have."

"This was appreciated by the adolescents, who thereby felt more similar to their friends. The assistant gave the adolescents scope to be adolescents with requirements for independence and autonomy."

"To the adolescents, it was important that the assistant should not participate when they were together with their friends, but that the adolescents with restricted mobility and their friends might be left alone. The school assistant in the role of a professional helped the adolescents practically to get to the peer group, but did not actively participate in the activities, withdrawing on the adolescents' initiative."

"For the adolescents it was important to be able to be in peace with their peers, since the assistant could be seen as something that labeled them as different. Therefore, the adolescents appreciated the fact that the assistant was sensitive to this and discreetly withdrew." (p. 924)

d. The assistant as a friend

"In this category, the assistant is described as a friend. This was not a frequently occurring role, and was seen only by one child of 11 years and some of the adolescents aged between 16 and 19 years, all boys. The assistant in the friend role in the cases in question was a male school assistant aged under 25, who according to the child/adolescents shared the same interests, activities and tastes as themselves. The assistant as a friend was much appreciated since he often actively participated in games and activities. They felt that in school the assistant saw them as friends when they played together or participated in activities. However, they felt that during spare time activities when the school assistant acted as escort, for example, when visiting café's or shopping, the assistant no longer saw them as friends, but instead as children or adolescents with restricted mobility. The adolescents' interpretation of this was that in his capacity as escort, the assistant did not wish to be seen together with them in public."

“This caused disappointment, especially among the adolescents who felt let down in their friend relationships with the assistant and this brought limitations in their participation in different social events in the community.”

It was the experience of the child and the adolescents that an assistant who was a friend was in demand among other children as a participant in games and activities, and thereby the other children felt that they had lost their assistant to others. The child and adolescents said that they sometimes even refrained from being with peers if there was a risk that their school assistant might take their place in the peer group” (p. 925).

e. My ideal assistant

“In this category, an ideal assistant is described, something all the children and adolescents include in their accounts. The ideal assistant was not a specific type of assistant (personal/school/escort assistant), but was described more as a person with certain desirable properties or behaviour. It was important that the ideal assistant should be younger than 25 years, since the children and adolescents perceived that it was easier to play or carry out different activities with a younger assistant.”

“In addition, a younger assistant would not decide over the children or adolescents, in the opinion of the interviewees, but would give them greater opportunities to develop independence and autonomy. The ideal assistant would also be of the same sex as the children/adolescents, in order to be able to help in practical intimate situations, where none of the children or adolescents could consider accepting help from a person of the opposite sex. The children and adolescents considered that it was important that they themselves should be able to choose their ideal assistant based on their own criteria for a good assistant. One of these criteria was that the assistant should give confidence and security.” (p. 925-926)

Resources

ACTIV Foundation Library http://www.activ.asn.au/2/2080/8/activ_library.pm

Centre for Inclusive Schooling www.cis.perthwa.net
Hale House, Parliament Place, WEST PERTH WA 6005
Ph: (08) 9426 7168

Rocky Bay L.I.N.C.K.S. Education Package [Learning and Integration for Neuromuscular Conditions in Kids at School] available from Rocky Bay Inc

Thomas, G., & Vaughan, M., Eds., (2004) Inclusive education: Readings and reflections
Maidenhead (UK): Open University Press.