



# section 7

## Miscellaneous

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### Helpful Hints

These are just some of the ideas that I have used with caring for and living with Kirstie.

As a parent your best tool in working with your son or daughter is knowledge. By going out and finding out about issues and learning along the way will be one of your greatest assets as there will be many times in your life when you will need to advocate (speak on behalf of) for your son or daughter. The more aware you are of services and issues the better equipped you will be to deal with them as they arise. Not easy as there is so much to learn and so many obstacles.

### Networking

Forming networks of friends and acquaintances is important. By establishing networks you provide a vital means of support for yourself and your family. The network can involve families who have similar needs and have a high level of understanding of your day to day life. It can also involve families who have very different needs to you, but the difference is stimulating for everyone involved. Your network would ideally involve both friends who have a son or a daughter with a disability as well as friends who do not.

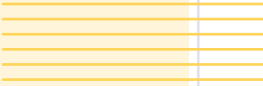
### Angelproof Bedroom

Keep it simple - bed, wardrobe & accessible storage for them to get to their toys.

A dutch or stable door. Keep the top half open so they can see and hear and so can you.

A privacy door handle (just like the toilet or bathroom) only with the lock on the outside. If the lock is activated/deactivated by pushing and turning the handle this may be a good deterrent for those Houdini's amongst our Angels! If this doesn't work try adding a 75mm x 19mm (3" x 1/2") ledge along the top of the bottom section with the door handle not far under that (don't forget to leave enough room for your hand).

A wardrobe with the drawer unit concealed behind a door. An idea that has worked for us was to tailor the robe door opening to just 10mm larger than the drawers - try opening the drawers any other way than straight and they only open as far as the door or the door jamb. With the drawer unit we have, the drawer doesn't even open far enough for an adult hand to go in. So far it has been Angelproof.



## **Bedding**

- One piece pyjama suits were successful during Kirstie's nappy (diaper) shredding phase. She never worked out how to undo them successfully.
- It is still common for her to kick off the blankets when asleep. She won't go to sleep without them right up to her chin though.
- For years she would only go to sleep if someone laid down with her. She has slept in her own bed without sides since 1995 without any problems. This has been in her own room next to the master bedroom.

## **Plastic, Paper, Cardboard — Simply put - training**

At school, Kirstie had never tried to go for these, I wondered why she didn't. At home, I would ask her to give the paper or plastic to me and she would offer them to me. If there was no other paper or plastic around her, she would either watch TV or go exploring.

Nowadays when she comes to me for a holiday she doesn't even go looking for them. Possibly it is just environmental behaviour, where she does what she considers is appropriate. Years ago I would have had no doubt that the behaviour was obsessive/compulsive. It may even be possible now that when I have her for a holiday that her time is so occupied that she doesn't feel the need to go looking for these.

At home she still mouths paper and plastic!

## **Personal Profile**

I have put together a personal profile that can be given to respite service providers or support staff who will work with Kirstie. It contains essential information about her, including her likes, dislikes, challenging behaviours and her level of independence in daily living skills. It is designed so that the first page contains important information in case of a medical emergency that can accompany her to hospital (heaven forbid that it would ever be needed for this!).

## **Corner Chair**

The corner chair is used to provide posture support when your child is learning to sit up. Due to the design it would also help increase the strength in the back muscles. The chair includes a table that slips down the side walls.

Plans of these are available from Technical Aid for the Disabled (TAD) in your state.

## **Wrap Around Table**

The next step in the developmental stage after the corner chair. The table is height adjustable and helps prevent a fall sideways which can still happen even after a child has learnt to sit up. There are small toddler sized plastic chairs that can be purchased from outlets such as Target, K Mart or Big W. Also you could try some of the larger children's toy stores for a chair.

Plans of the Wrap Around Table are available from TAD in your state. Go to the main resource page for your state and click on the Therapy & Equipment link for contact details.

## **Safety in the Home**

If you don't want your son or daughter to learn how to do something then make sure that they don't see it being done! Incidentally this applies to all young children.



### Angelproof Kitchen

The best answer here is to keep them out of the kitchen in the first place. If this is not possible due to an open plan kitchen then try to narrow the opening down as much as possible with items such as mobile trolleys (jam the wheels first) or if possible put in something more solid and put in one of those stretchable childproof gates.

One idea demonstrated at the 5th Angelman Syndrome Association Conference in Canberra was a magnetic door handle that acts as a lock. The handle is magnetised and the lock is inside the door. Put the handle over the area of the lock and it unlocks, take the handle away and it locks. Contact Kidsafe for further information on the lock. It was said that this system is rather expensive.

### Internal Doorways

An all purpose gate for standard internal doorways can be made from 50mm x 25mm (2" x 1") timber with a 'z' brace. Pre-drill all screw holes and use 40mm screws. A hasp and staple lock can be used together with a dog collar clip.

### Water

No options here! I just have to keep one to one with her as there is no other way that I can keep her away from the water! Thankfully she is petite, so this helps.

### Safety in the car

If your child can undo his seatbelt, you can purchase a plastic seat-belt buckle guard, which fits over the locking device and when in place, the child cannot undo the belt. It comes with a key to enable an adult to release the guard but it cannot be released by the child (without the key). You will need a medical certificate from your GP to order one. It is available from: Functional Adaptive Supportive Equipment Melbourne, Cost-approximately \$30. To order or for more information: phone toll-free 1300 303 536.

You can also obtain these from authorised (vehicle) child restraint fitting services in other states (e.g. Little's Car Restraints, Sydney (Burwood) phone (02) 9715 2121.

## GRIEF AND LOSS

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*(Notes taken from: An Unrecognised Grief: Loss and grief issues for carers. A worker's guide by Maggie O'Shea for the Carers Association, Vic. 1999)*

"Carers who are parents of a child with a physical, intellectual and/or psychiatric disability may experience:

- (A) loss of dreams about how their child's life might develop and what they might do and achieve in their lives;
- (B) loss of the expectation that their child will become independent from them when they reach adulthood;
- (C) loss of other hopes about future family life such as seeing their child form a relationship with a partner, parent their own children and perhaps even later care for their parent/s;
- (D) loss of financial security, identity and self-esteem if the carer cannot return to paid work or pursue other interests outside the caring role;
- (E) loss of time and energy to spend with other children or partner;

- (F) loss of own personal space, health and vitality due to the physical and emotional toll of caring;
- (G) loss of freedom to make life-style or family choices based on criteria outside of what is best/necessary for this one child;
- (H) loss of privacy when government benefits and support services require details about income and family situation;
- (I) loss of friendships and connections due to being too busy, too stressed, or because friends feel unable or unwilling to understand and be supportive....."(p.8,9)

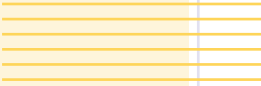
GRIEF is the common response to loss which all carers experience. Grief comes from loss. ..." The grief of carers is similar in many ways to the grief of someone who has lost a loved one through death...."(p. 13). However, the grief response may be different to or more complicated than, that experienced after a death.

*For example:*

- (A) There may be no definite starting point at which the grieving process can begin (it may be a long time before the extent of the problem can be established).
- (B) There is often no final loss or end-point for the carer to try to accept. The future is uncertain and the grieving process may continue on and on alongside the caring
- (C) The grief may keep coming back (e.g. the family may enjoy good times when there is stability, progress or improvement only to have their hopes totally dashed again by a major set-back).
- (D) The losses experienced by carers are ambiguous because the person with care needs is still alive (e.g. How much should I grieve? Which things should I hold out hope for? How do I know at which point to strive for acceptance rather than to try to improve the situation through special therapies?) Carers may feel overwhelmed, exhausted and confused by the lack of certainty.
- (E) The losses associated with disability and illness are often unacknowledged or misunderstood. Carers do not often experience the level of recognition, support and understanding that they need over the course of the long haul of caring. For example, there is a common perception that grief will diminish or disappear if the disability has been diagnosed for a long time but parents may experience a kind of chronic sorrow as they watch their child grow up unable to enjoy or achieve the various milestones of their peers.
- (F) Carers grieve not just for what has already happened but what is likely to happen or not happen in the future (anticipatory grief). (p. 13-16)

***Many carers are successful in learning to live with their grief and still enjoy many other aspects of their lives.***

Other people's negative responses to grief include fear (saying the wrong thing), censure (growing impatient as the months go on) and avoidance (may be literally avoiding the family or perhaps being there physically but not allowing the person the opportunity to share their feelings). These responses send a strong message that painful feelings are unacceptable. This leads to isolation for carers as does the fact that the losses are often unrecognised by family, friends and the community. There are no supportive and healing



rituals such as a funeral ceremony and sympathy cards. Carers may feel they are going mad without the recognition and knowledge that their strong and conflicting emotions are a normal part of a grieving process. (p.21)

Most theories of loss and grief suggest that the grieving process involves a number of stages:

1. **Shock** (including physical symptoms including lack of appetite, sleep disturbance, nausea)
2. **Denial**
3. **Bargaining** (if I can try this therapy, maybe everything will be OK)
4. **Anger And Other Intense Emotions** (Frustration, Sorrow, Anxiety, Stress)
5. **Depression**
6. **Acknowledgement/Hope/Acceptance**

These stages are likely to be phases with the person moving back and forth to re-visit different phases over and over again. This is considered healthy but it is less healthy when a person becomes totally 'stuck' in one or other phase and is unable to enjoy other aspects of their life.

It is difficult to apply this model to a long-term care situation as it may be impossible to assess if a person has become 'stuck'. The carer may seem very angry because they have every good and current reason to be not because they are 'stuck' in an anger stage. Similarly, carers can remain hopeful in the face of an unpromising diagnosis but they are not necessarily 'stuck' in an unhealthy denial stage. Hope and grief can co-exist. (p.23)

Despite these limitations, an understanding of the phases of grief can reassure carers that their intense feelings are a normal and healthy response to loss. Carers may feel reassured by the knowledge that in time they will be able to enjoy aspects of their life again even though the grief may still be present.

Each individual needs to be allowed and supported to grieve differently according to personality and other social, familial and cultural factors. Some carers try to deny, block out or avoid experiencing the loss and grief. They may feel they need to be strong for others. These strategies can be helpful in the short term but may ultimately create a lot of extra stress, resentment and guilt which can leave the person more vulnerable to develop serious physical and other health problems including depression.(p.17)

The psychologist, Elizabeth J. Bruce ( Ph.D MAPS. MNALAG.) has worked with many parents of children with a disability. She uses the term 'Elite Parenting' to recognize the enormous psychological challenge parents have "...to recover from their trauma and manage their chronic grief so that they are as able as possible to hone a skill base to parent their children...". She formed group skill workshops called "Block and Tackle" groups where it is acknowledged from the start that this experience is traumatic, that there is chronic grief and it is normal to feel like this. Bruce doesn't believe parents have to 'get over' their grief – instead they need to "...talk about what must be put into place if one is to 'adapt' to this life experience..." (Bruce, see references).

*References:*

*"Elite parenting: Mother father, siblings and children adapting to disability", Pep Talk magazine- Association for Children with Disability Tas., Vol 5 Issue 2, June 2002.*

*Bruce, E.J. and Schultz C.L.(1992) Complicated Loss: Considerations in counseling the parents of a child with an intellectual disability. The Australian Counselling Psychologist, 8, 8-20.*

*Bruce, E.J. and Schultz, C.L. (1998) Grieving nonfinite loss. Journal of Family Studies, 4, 215-220.*

## SIBLINGS

Having a child with a disability affects everyone in the family including the brothers and sisters (siblings).

### Factors affecting siblings adjustment

Age and position in family. Number of children in family	Personality of sibling	Family resources including extended family, child rearing practices.
Community Support Services.	Coping mechanisms in the family including communication and support parents give all the children. (How parents manage a child with a disability affects how brothers and sisters react.)	

### Positive effects on siblings

Empathy and opportunity to learn about life.	Pride in sibling's achievements.	Tolerance
Maturity- eg delegated to help dress, bath etc.	Protection and loyalty	Appreciation and knowledge eg greater appreciation of their own health.

### Issues siblings identify

Loneliness	Lack of attention	Anger and jealousy	Confusion, fear and anxiety
		family life and activities are affected	siblings may not understand they cannot catch it.
Guilt	Genetic issues	Worry about future	Embarrassment
eg may feel guilty if they complain because they are expected to be sympathetic		eg fear if parents die sibling will be responsible	eg when friends visit.

Community agencies such as Rehabilitation centres can help families by providing information; by focusing on the family as a whole; by referring on for specific help; by organising sibling support programs and activity days; by listening to families and by recognising signs of stress.

Research shows that one of the best supports for siblings is having contact with other siblings. Our local Carer Respite Centre runs regular sibling activity days and camps for groups of young siblings as well as teenage siblings.

### What can parents do?

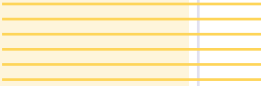
Recognise individuality, when you talk with friends' talk about achievements of all your children.	Open-ness and honesty, eg explain how the disability was caused.	Limit responsibilities such as care-giving.	Use respite and Support services.
Acceptance- try to understand and accept feelings of siblings.	Recognise stress eg. signs such as low self-esteem, extreme tiredness and behaviour changes.	Listen and help your child problem- solve eg help them think of things they can say to their peers. Keep some sense of fairness, don't make unfair allowances for child with disability.	Welcome friends. Let siblings know they do not always have to include child with disability just as they will not always want to include each other. Give siblings a safe place to keep special items.
Praise all siblings make group decisions so siblings feel part of decision-making.	Time with siblings, support them in helping them follow their own interests.		

### Sibling Support Programs:

Various programs operate in different states. One example is a SibSupport Program run by Irabina Childhood Autism Services in Victoria. This is a recreation-based program for siblings held once per term. In addition organisations such as The Association for Children with a Disability Inc in Victoria (contact details, see under Support Groups, Victoria) hold sessions for parents, "Supporting Siblings Information Sessions". These sessions consider the emotional responses of siblings from childhood to adolescence and those factors which research has shown influence their development and coping.

### Recent publication:

Miranda Smith, the Siblings Project Worker for the Association for Children with a Disability Inc, Vic. (see under Support Groups) has reviewed past research on the experience of young people who have a sibling with a disability or chronic illness. She was interested in the needs of siblings and what factors promote or erode sibling resilience and coping. A copy of Supporting Siblings may be obtained by contacting the Association's office on 03 9500 1232.



Siblings Australia Inc.: A new organisation that has grown from the Sibling Project in S.A. (see References). This organisation has created 4 new internet discussion groups for children, teen and adult siblings as well as a group for professionals. All can be accessed via the website: [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au). Other details:

Siblings Australia Inc.  
Women's and Children's Hospital  
72 King William Road  
NORTH ADELAIDE, S.A. 5006  
ph. (08) 8161 6737  
Email: [info@siblingsaustralia.org.au](mailto:info@siblingsaustralia.org.au)

*References:*

*Sibling Workshop, Nov. 6, 2001, presentation by Kerry Haddad, School-Age Team - Social Worker, Calvary Rehab., New Town, Tas.*

*Parent Easy Guide, Parenting SA #61 Disability - Brothers and Sisters  
(<http://www.parenting.sa.gov.au/pegs/display.p1/61>)*

*Sibling Presentation by Julie Hyman, M.S.W. at I.A.S.O. World Conference, July 4-8, 2000 (refer I.A.S.O. website: <http://www.international.angelmansyndrome.org>).*

*(A good reference is the website of the South Australian Siblings Project: [www.wch.sa.gov.au/siblings](http://www.wch.sa.gov.au/siblings)). Kate Strohm is the Manager of the Sibling Project. She herself is an experienced health professional and journalist and has a sister with C.P Her book, *Siblings*, is published by Wakefield Press and is available by phoning Wakefield Press on 08 8362 8800.*



## Behaviour Management

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### Rule No 1

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#### *Be consistent!*

There is no point having one person doing one thing or everyone doing different things when it comes to behaviour management. As with any child who has Mum doing one thing and Dad doing the opposite, an Angel just can't resist playing one parent off against the other. The other possibility is that you will have a confused and frustrated child who is going to take it out on somebody.

#### *What's the Problem?*

##### *Angel to Mum/Dad or Can I Have Your Attention!*

Quite a lot of the things that our son or daughter does are attempts to communicate. The next time you get a slap on the face or a bite on the hand, it may be that they are trying to get your attention. As your son or daughter is unable to communicate verbally they resort to pre-verbal communication. The more you talk to your son or daughter the more you will learn about them and HOW they communicate. You will become more intuitive in recognising their attempts to communicate and respond appropriately to them. Your son or daughter just loves attention. You will also learn to recognise the difference between them trying to communicate and unacceptable behaviour.

### Rule No 2

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#### *Is it a medical problem?*

Always ask yourself this before assuming that you are seeing a behaviour as there could be a medical reason for what you are seeing. E.g; If your son or daughter is banging their head they may be trying to overcome the pain of a toothache or earache.

#### *It's a behaviour - What can I do to stop it?*

Well actually you can't - you have to replace it with a more acceptable behaviour.

#### *How?*

By using "Positive Behaviour Strategies/Intervention/Modification/Management" (they all mean more or less the same thing).

### Rule No 3

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#### *Expect to see an increase in the behaviour before things start to change*

Simply put you have learnt that if you turn the kettle on it will eventually boil (provided you have enough water in it). If nothing happens what would you do? That's right you'd try again. You have just used a behaviour. There is no difference with someone who is using unacceptable behaviour - they'd just try again and again until they realised that it doesn't work anymore. Then they would try something different to try and get the same result - just like you would with the kettle.

#### *What is Positive Behaviour Management.....?*

Literally volumes have been written on this subject. Briefly it is when you teach the

behaviour you want to see and reinforce it by using rewards. Remember when you were a child and got something you wanted ..... after you cleaned your room? No clean room and no reward? That is Positive Behaviour Management.

*But how do I teach my Angel this positive behaviour?*

Just as you won't get rich overnight, your son or daughter may take a while to pick up the behaviour that your are teaching them. It can take a lot of patience and could even be frustrating. Some things take years for them to learn other things they pick up pretty quickly (show me an Angel who didn't learn the first time the effect of playing with the remote control for the TV or video!)

Please remember that you are "working" with someone who has a functioning age of around 2 years old. Well maybe I shouldn't have said that - but it should put things into perspective.

*So how come this doesn't happen at school?*

Remember your old school class timetable? It told you how many periods there were, what time from and what time to, as well as the recess and lunch breaks. This is a STRUCTURED ROUTINE. You knew what to expect and what was expected of you each class. You could only focus on the subject and only had access to equipment that was relevant to the subject.

No, you don't need to turn your home into a military establishment. What you can do is provide an informal structure and routine. The more you involve your son or daughter the less time they have for getting into mischief and the less time you need to spend on stopping them from getting into mischief. In turn they are getting the attention that they so enjoy.

*But I've tried everything and nothing works!*

Before you call in the local Program Support or Behaviour Intervention Support Team, please remember everything they know about your son or daughter will have more than likely been told or taught to them by you. So before you call them have you spoken to other parents with an Angel to see what they have tried? A very good source for this type of information is the Angelman Syndrome Listserve. How soon did you expect to see changes - are your expectations realistic or reasonable?

**If you still feel that nothing works, now is the time to get serious and learn your ABC.**

**Antecedent**      ...what happened immediately before the behaviour?

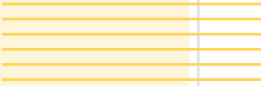
**Behaviour**      ...what it is you are observing that you want to change?

**Consequence**      ...what happened after the behaviour?

Why the need for the ABC? Because this is the sort of information that the professionals you will be dealing with, will ask for. e.g; You see your Angel mouthing some paper (Antecedent and a Behaviour) you take it off them (Antecedent) and they bite you (Behaviour) you throw the paper in the bin (Consequence).

Alternative response by you could be:- You ask your son or daughter to give it to you and hold your hand out (Antecedent) your son or daughter gives it to you (Behaviour) you say thank you and smile before taking the paper to the bin (Consequence). You then remove all paper that is within reach and put it in a place that is out of reach for your son or daughter (Consequence).

Each time that your son or daughter hands you the paper you give them the same response - a thank you and a smile. It would not be a good idea to give them a biscuit, for



example, as they may learn that they will get a biscuit each time that they mouth paper. You are then reinforcing negative behaviours.

By following the ABC you learn to identify the signs that tell you that a behaviour is about to occur, you learn what works in changing the behaviour and the consequences that work for you.

### **This is all too technical! - How about some ideas?**

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#### Diversion or re-direction

The most useful instant quick fix to behaviours. You get your son or daughter to focus onto something else that needs them to concentrate enough so that they stop using the behaviour. Not always successful as they can be very single minded when they want to be. Diversion or re-direction is not a long-term solution to change behaviour, as it may not be able to be used everywhere, as every situation is different.

#### Game Play

Try turning it into a game - this is a form of diversion or re-direction, however this is more positive as you've changed it into a game.

#### Ignoring

This can be used with behaviours that you know are attention seeking. It can be a big ask if you're being hit, as a means, to get your attention. But if you turn away and move yourself out of reach then it hasn't worked, bet your son or daughter will try something else!

#### Removal

Especially in regard to assaultive behaviours. The victim is removed from the scene and a lot of fuss is made of them.

#### Escape - (your angel not you)

This is hard, because they are in a situation that they are not comfortable with and want to get away from it. There are even angels who despise water and will do anything to be away from it. The problem here is that they have learnt through reinforcement to dislike what is happening. How do you change that? Try other methods that make it easier for them to adapt and learn to accept what is happening as positive rather than negative. E.g; an angel who hates having their hair brushed - try water with some conditioner mixed in a spray bottle, sprayed onto the hair before brushing or combing. Try not to test their attention span for too long - keep it short and simple.

It still doesn't work.

The next step will involve a psychologist and/or a behaviour intervention program team.

Contact your local office:

ACT	ACT Community Care
NSW	Department of Ageing, Disability and Home Care
NT	Aged & Disability Services
QLD	Disability Services Queensland
SA	Department of Human Services
TAS	Department of Health and Human Services
VIC	Department of Human Services
WA	Disability Services Commission



## Legal Issues, Wills, Guardianship Board

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### Your Angel Child

Being the parent of a disabled child means that you have taken on additional responsibilities that place a lot of pressure on you. Your child has exactly the same rights as any other child. Your rights in making decisions about your son or daughter are no different to the rights that you would have with any other child you may have.

### ***What legal issues are there that could affect my child?***

#### Major Medical Procedures

Some major medical procedures will require the approval of the Family Court of Australia or a court that has been approved to make decisions in this respect in your state, before they can proceed. Examples of this include hysterectomy or sterilisation.

#### Financial Issues

While your son or daughter is still a child things are simple. You have precisely the same level of responsibility with financial issues in that you perform the role of managing the money. However as it is improbable that your son or daughter will be able to learn money related skills beyond taking and giving money (and even that may be ambitious or in some cases even potentially dangerous).

When your son or daughter reaches adulthood, then a financial manager will need to be appointed to manage your son or daughter's money. If your son or daughter is at home with you there should be no problem - you just continue performing the role of financial manager. However, if your son or daughter accesses services that involve that service dealing with any unusual amount of money then it would be wise to apply for a guardianship order to identify who has the responsibility and control of your son or daughter's financial management.

### **Wills**

*Can I include my son or daughter in my will?*

Yes, you can. Due to their inability to handle their own financial matters it would be a good idea to also appoint a trustee for them in your will.

*Who can I appoint as a trustee for my son or daughter?*

Anyone who is over the age of 18 and whom you have confidence in to handle the financial affairs of your son or daughter.

*Does the person also have to be my son or daughter's guardian?*

No they don't have to be the guardian for your son or daughter.

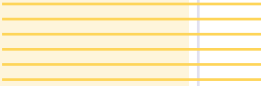
*Where can I learn more about wills and trustees?*

Either your solicitor or your nearest community legal centre can advise you.

### **Guardianship**

#### Your Angel Adult

Your adult has the same rights as any other adult. However, they are not able to make informed decisions about their accommodation needs, managing their finances, making



informed decisions about minor or major medical procedures or their day to day needs and care.

*How can I be sure that my adult son or daughter's best interests are being looked after?*

Your adult will need a guardian to look after their best interests in all respects. As their parent you can apply to be appointed as their guardian by making an application to the Guardianship Board or the equivalent body in your State . The main areas that are looked at with a view to appointing a guardian are accommodation, medical, financial and decision making.

What happens if I am not in a position to apply to be the guardian for my adult angel?

Somewhere along the way it will be identified by someone, you, a caseworker, a service provider, a medical practitioner, that your son or daughter needs someone to make a decision that they are not capable of making for themselves. If no one close to your adult son or daughter can be appointed then the Guardianship Tribunal will appoint a Public Guardian.

## Sexuality

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The changes of puberty (increased height and weight; developing ovaries and testes; secondary sexual characteristics - genitals, breasts, hair, menstruation, ability to ejaculate; changes in body composition - distribution of muscle and fat, increase in strength, increased sexual expression etc) will occur in individuals with A.S. but there may be a delay in the onset of puberty (1-3 years) as in other developmental delays.

When teaching children with A.S. it is important to realise that they may find it difficult to attend to an activity and a person at the same time so a 'hands-on' approach would be better than demonstration and imitation. We need to teach the social rules (such as 'private' and 'public' places and what is 'appropriate'/'not appropriate' such as being dressed in the lounge room) rather than rely on the child copying.

Meeting the Menstrual and Contraceptive Needs of the Young Girl with Intellectual Disability – Dr Sonia Grover Consultant Gynaecologist, Centre for Adolescent health Royal Children's Hospital, Melbourne.

### Issues the Centre deals with include:

- management of puberty;
- potential for pregnancy;
- the need for contraception, which relates to the
- level of social function;
- Behavioural issues such as masturbation,
- Social interaction--is effect on behaviour and
- thus the need for contraception, awareness of
- stranger, etc;
- medical issues such as osteoporosis. Vitamin D
- deficiency and epilepsy control



### **Onset of puberty**

Statistics show the onset of puberty for the majority of girls with intellectual disability is the same as their “normal” peers.

### **Risk of pregnancy and abuse**

Dr Grover tries to encourage parents (usually the mother) to see that the issues of menstrual management and risk of pregnancy are separate issues and to ascertain what is the real risk of pregnancy. As a general rule, the milder the level of intellectual disability, the greater the risk of pregnancy.

The risk of abuse is not the same as the risk of pregnancy, and it is important for parents to understand the difference between the two and to develop strategies to minimise the risk for both.

### **Medical issues**

Risk of osteoporosis -there is an increased risk of osteoporosis with reduced physical activity and with a lack of Vitamin D. 10 to 15 minutes of sunshine is needed per day on the forearms and face to avoid Vitamin D deficiency. Children “grow their bones strong” between the ages of 12 to 22, this is the window of opportunity to minimise the risk. Families should talk to their GP about supplements if you think your child may be at risk of becoming Vitamin D or calcium deficient.

Epilepsy Control – often it is found that when girls, who have epilepsy which has been difficult to control in childhood, reach puberty, their situations may worsen and they may develop cyclic epilepsy.

**Other Issues** which the Centre will take into account when deciding on treatment for a young woman, are:

- What self care skills has she attained?
- Is she still gaining skills?
- Are there any clues as to how she might or might not cope with menstruation?
- Who is involved with her care eg where “poos” and “wees” is involved, it may be fine to involve Dad or siblings with personal care, but once menstruation starts it is often just left to Mum.
- If a family feels that the daughter getting her period would be the “straw that breaks the camel’s back”, then they may be travelling “too close to the line” – the centre would look at the needs of the family such as getting more respite and involving DHHS, Family Planning and perhaps the school in more support and information for them.

### **Menstrual Management**

Problems associated with the onset of menstruation can include:

- Heaviness of blood loss;
- Frequency of the periods;
- Pain;
- Mood problems;
- Cyclic epilepsy;
- The need for contraception.

There are a number of options available for the management of menstruation, some of which act as contraceptives and some of which do not:



Nonsteroid anti-inflammatory medication e.g. Ponstan, Nurofen, Naprogesic;

- Reduce pain;
- May prevent nausea, vomiting and diarrhoea;
- May prevent fainting and dizziness;
- Reduce blood loss by up to 30%;
- Are non-contraceptive.

Nurofen is available as a liquid. Some anti-inflammatories are available as suppositories. Cyclic nausea, vomiting and diarrhoea can be related to hormones even before the onset of the first period, and these medications can help with the control of these symptoms.

Cyclic progestagen hormonal tablets e.g. Provera, Primulet:

- Regulate the cycle;
- Reduce menstrual loss;
- Are non-contraceptive;
- Can produce side-effects such as depression and a tendency toward aggressive behaviour;
- Can be used first to “test” sensitivity for Depoprovera - if the young woman is sensitive to Provera or Primulet, then injections of Depoprovera would not be recommended.

#### **Oral Contraceptive Pill**

- Regulates the cycle (therefore Ponstan can be taken the day before period is due, if pain is a problem);
- Is contraceptive;
- Reduces menstrual loss;
- Reduces pain;
- Provides the options of either “constant dose” or “changing dose” pills – “constant dose pills” have the same dose of hormone every day and thus provides the option of missing the sugar pills, which provides the many benefits set out below in “Continual Oral Contraceptive Pill”.

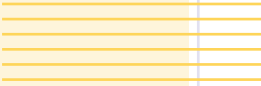
#### **Continual Oral Contraceptive Pill**

- Is contraceptive;
- Provides marked reduction in blood loss – no periods or only minor break-through bleeding;
- Reduces pain;
- Stabilises hormone levels which therefore helps to stabilise moods.

For those who are nervous about this for their daughters, Dr Grover answered my questions about the safety aspects of this option – she said that she would have no hesitation in recommending that a young woman with intellectual disability (like my daughter) stay on the continual pill for 10 years!! – in other words unless there is breakthrough bleeding she sees no reason why young women with intellectual disability who cannot manage their own menstruation, need to get periods at all.

Research indicates that since the introduction of the oral contraceptive pill in the 1960's;

- The rate of ovarian cancer has halved;
- The rate of cancer of the lining of the uterus has halved;
- There is no conclusive evidence that the rate of breast cancer has increased.



### **Tranexamic acid**

- Reduces menstrual loss by an average of 50%
- May reduce pain.

### **Depoprovera**

- As an injection which lasts three months;
- Reduces or stops periods (although there might be irregular bleeding for the first 6 months);
- Reduces pain;
- Is contraceptive;
- Stabilises hormones which helps the cyclic hormonal environment;
- Lowered oestrogen levels add to the risk of osteoporosis, therefore other factors such as exercise, calcium and Vitamin D levels need to be considered and the young woman on long-term use should have regular bone density tests.

For girls and young women with epilepsy and severe physical disability, who are in wheelchairs and who are unable to take the continual oral contraceptive pill, Depoprovera in combination with an oestrogen patch is a good solution – Depoprovera reduces/stops the periods and helps stabilise the hormones and therefore helps with the problem of cyclic epilepsy and the patch reduces the risk of osteoporosis.

### **Implanon**

- is an implant which is placed in the arm;
- last for three years;
- is a reliable contraceptive;
- should not be used by people using anti-convulsant medication;
- 10 to 15% of users have no periods;
- 15 to 20% of users may have irregular bleeding;
- in 70% of users there is no change to their periods.

### **Mirena**

- is placed in the uterus under a brief general anaesthetic;
- lasts for 5 years;
- is a reliable contraceptive;
- provides marked loss of bleeding – 95% less bleeding 6 months after implant, 98% less bleeding by one year;
- has been used in the UK and Scandinavia for 20 years and has been available in Australia for 5 years, although until recently it has been very expensive;
- may produce some minor side effects – e.g. Some people report an increase in aggressive behaviour;
- girls can be tested on the mini-pill first -they contain the same hormone in different amounts – if girls are sensitive to the mini-pill, Mirena is not recommended;
- it is not recommended for people with cyclic epilepsy.

Surgical Options (e.g. Tubal ligation, endometrial ablation and hysterectomy, see below):

- are irreversible;
- require Federal Family Court or Guardianship Board approval;

- do not stabilise hormones;
- do not protect against sexual abuse.

#### Tubal Ligation

- usually has no effect on periods;
- has 1 in 5 failure rate;
- is irreversible;
- is contraceptive;

#### Endometrial Ablation

- is a day procedure;
- is not contraceptive;
- burns the lining of the uterus;
- was very “fashionable” in the late 90's, is not performed much now;
- at 1 year after the procedure for 40 to 50% of the patients there is no bleeding, for 40 to 50% there is reduced bleeding, for 10% the procedure has no effect;
- at 3 years after the procedure, many require further surgery;
- it is not now considered to be a particularly good long-term solution.

#### Hysterectomy

- It is impossible to do this procedure vaginally for those who haven't had children, it has to be done abdominally;
- it is considered to be major surgery, patients are in hospital for 3 to 7 days;
- Complications resulting issues can include:
  - the necessity for blood transfusion (2 to 6% of cases require this.
  - Damage to the bowel, bladder or uterus (0.5 to 3% of cases);
  - the impact/trauma of admission for some patients;
  - coping with the dressing of the wound.

#### Dilemma

Things to consider when making the decision about what is the best menstrual management and/or contraceptive solution for your daughter:

- at what age does contraception become an issue?
- At what age does menstrual management become an issue?
- Is cyclic epilepsy an issue?
- The solution may vary at 13 years of age, 16 or later;
- for those with severe physical disability, who are underweight and at risk of Vitamin D deficiency and osteoporosis, HRT may be an option;
- supplements of Vitamin B1 and B6 may help with mood swings.

#### Pap Smears and Breast Examination

- A pap smear is unnecessary if the young woman has never been sexually active.
- Due to the very small numbers of breast cancers detected in women under the age of 30, breast examination is considered unnecessary before this age.

For More Information Talk To:

- Family Planning; • Your GP; • A paediatrician; • A gynaecologist; • The Public Guardian;
- or • ACD



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It may be worthwhile to practise menstruation before it happens, e.g. using sanitary pads and food colouring. This may reduce anxiety.

It is reasonable to expect that A.S. boys will go through the early stages of normal development e.g. masturbation. Try to teach "this is the right place" by imitating with a realistic doll or actually take the boy into the bedroom. Take hand away in public or distract with something else. If the person can learn toileting behaviour, he should be able to learn about the appropriate place. If you can teach appropriate ways to relate to others you will help your child to stay in the community as there is much hysteria in the community in relation to inappropriate sexual expression.

There are drugs to suppress sexual desire (libido) such as Androcur and Depo-Provera but use of these is very rare and to use these drugs there is similar legislation to sterilisation. Each state may have different legislation. In 1992 after a High Court case it was proclaimed that 'Parents/guardians could not lawfully authorise sterilisation'. You may need to make a submission to the Guardianship Board. Parents may need to outline issues such as physical and behavioural difficulties; details about previous approaches; possible and preferred alternatives and risks associated with each; outline how proposed treatment is in the best interests of the individual.

Family Planning Centres employ people who specialise in the field of sexuality and disability. They can provide information for parents, teaching videos, pictorial references etc.

#### References:

*Corinne Lusty, Psychologist, Intellectual Disability Crisis Care Unit - Presentation made at National Conference, Adelaide, 1995.*

*Gaye Avery, Parent, 'Adolescence - Puberty and Sexuality' - Presentation made at National Conference, Adelaide, 1995.*

*Annelise Beckmann, Family Planning Counsellor, Disability Co-ordinator - Presentation made at National Conference, Canberra, 2001.*



## Child Care

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The Special Needs Subsidy Scheme (SNSS) commenced in 1997. This Commonwealth Government scheme helps Commonwealth funded child care services care for children with ongoing high support needs. Children with disabilities such as Angelman Syndrome can be cared for while parents work or study. As well, children may attend after school programs or holiday programs at Out of School Hours Care (OSHC). The Scheme helps provide funding for the extra staffing required to care for a child with high support needs. In Hannah's case, she has attended a local Child Care Centre usually once a week during school holidays. As well as ensuring she has some variety and interaction with other children, it also gives the rest of the family a break. I can do things with the other children that we cannot do when we have Hannah with us. In our case the Lady Gowrie Support Team has liaised with the Child Care Centre and filled in the paperwork!

## Respite Options

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Respite is used to enable the primary caregivers (parents, foster carer, guardian or the person/s who have the main responsibility of providing care and support to a person with a disability) to have a break and vice versa. This may be for a short period so that they can go and do the family shopping or overnight, for a couple of days or for periods generally up to a week.

### Host Family Respite

The host family have the child stay with them in their home.

### In Home Respite

This service is provided in your home and is generally provided by your State Government through programs such as Home and Community Care (HACC) in NSW or Care Connect in Victoria. The service allows you to have a break to go shopping, for example, while your son or daughter is being cared for in a familiar environment.

### Centre or Community Based Respite

These are provided from premises operated by a service provider. The service provider can be either a Non Government Organisation (NGO) or a disability specific government agency. The service may provide respite for short periods similar to day care to overnight accommodation and care over several nights.

### Costs

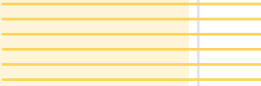
Organisations that are provided with funding will still ask for your son or daughter to be provided with enough money to cover costs of activities and any spending that they would normally do while out and about in the community.

Unfunded services will quote you a service fee for the period of respite. This will cover costs such as food, cleaning.

### Other Information

Some services have funding packages for allocation to individuals who access respite with their respite agency.

Some individuals are allocated funding packages direct from the state government funding agency.



Some organisations have been set up to look for respite opportunities with service providers in their area. They arrange the respite and advise the family of the dates, times, locations, etc. These organisations are called respite brokers.

Don't be frightened to ask accommodation services in your area if they are able to provide respite. Some organisations use this option to fill temporary vacancies in their service.

Some organisations use respite as a means of evaluating how a service user fits in with other residents in the home to see if they are compatible. This is ideal if you are looking at the long term with a view to your son or daughter moving into the home as the move will be with a minimum of stress for all concerned.

## Housing

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Housing for your son or daughter can be obtained from a service provider catering for supported accommodation, that involves living with people with similar needs. This may be in a unit, a flat attached to a group home, a duplex, a group home or a large residential service. With a child this may also include living with a (foster) family in their home, this is the preferred model of accommodation support for children.

Support staff are provided to support the residents in areas between their capability and full independence.

For people with a severe or profound intellectual disability or severe physical disability there is 24-hour support involving staff being on duty at all times. It may also include multiple staff members being on duty at various times.

*PLEASE NOTE:* Service Providers may not be able to provide support in all areas described above. Some only cater for mild or mild/moderate intellectual disabilities. Others only cater for specific disabilities or high support needs.

If your son or daughter has a recent history of epileptic seizures then it would be better if the home has staff on duty, including a night/awake shift. (This does not mean sleep over staff).

## Funding

There are different methods of funding supported accommodation not only between states, but even within any individual state.

Some services are provided funding by the state government agency to provide a certain amount of accommodation places. In this case you may not need to apply for funding for your son or daughter's accommodation placement. Check into the organisation and satisfy yourself that it receives enough funding to ensure the long-term viability of the service.

There may be funding packages available from the state government funding agency that are allocated to the specific individual. This may involve you in finding a service that is able to provide the necessary support for your son or daughter to move into a group home. It is important that the home is staffed 24 hours a day. It is also important that there are enough staff members on duty at times when the residents are home to adequately support everyone's individual support needs.

## Transition from School to Adulthood Programs

As there are different names for these programs in each state below is a list of programs and the state that they apply to...

ACe-Link	<b>ACT</b>
Adult Training Learning and Support (ATLAS)	<b>NSW</b>
Community Access Service (CAS)	<b>various states</b>
Futures for Young Adults (FFYA)	<b>VIC</b>
Independent Living Service (ILS, ILSS, ILT)	<b>various states</b>
Post School Options (PSO)	<b>NSW, QLD, TAS</b>

Whilst there are stories of adults with Angelman Syndrome being successfully supported in employment in the USA, the vast majority need access to meaningful activities and programs that can improve their life experiences, skills and quality of life.

This would involve your son or daughter going on to day programs that are available to school leavers who do not have the skills or abilities to go to work.

Often the source of information is the school that your son or daughter attends. They will be able to advise you when they sit down with you to do a transition plan. The transition plan will cover all the steps, who does them and the time they need to be completed by to ensure the smooth transition of your son or daughter from school into one of these day programs.

Sometimes this involves your son or daughter needing individual funding. Sometimes they will involve you doing the footwork to find out what services are out there.

The best place to start is your local council - ask if they have a disability worker or the equivalent. Ask them what services are in your area.

If this does not give you the information you need, try your local Commonwealth Carelink Centre. They have a database of all disability related services close to you and what services are provided by each service.

Talk to other parents whose sons or daughters are leaving or have left school and see if they can help you with information.

If you live in a large rural city or in one of the capital cities you may have a choice from a range of service providers. Find out as much as you can from a number of sources about each service. Ask questions of parents, staff, management, board members (non government organisations). Find out which service you feel is the right one for your son or daughter.

If your son or daughter does not receive individual funding the decision you make may involve them going to that particular service for the rest of their life. It would be comforting to know that they are happy and enjoying their time with that organisation every day. It also allows you the peace of mind to have a break each day too.



## Angelman Syndrome Support Groups

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### Angelman Syndrome Association

#### ACT

Kerry O'Kane and Keith Bradley  
Email: bradkane@bigpond.com

#### NSW and Australian Association

Angelman Syndrome Association  
PO Box 554  
Sutherland, NSW Australia 2232  
Ph: (02) 9520 5857  
Email: kevink@angelmansyndrome.org

#### QLD

John Beith  
43 Tradewinds Drive  
BANKSIA BEACH QLD 4507  
Ph: (07) 3410 7903  
e-mail: m.moore@student.qut.edu.au

#### SA and NT

#### Angelman Syndrome Association

**of South Australia**  
PO Box 3143, Rundle Mall,  
Adelaide, SA 5000  
Ph / Fax: (08) 8371 4255  
Email: simsclan@cobweb.com.au

#### TAS

#### Angelman Syndrome Association of

**Australia Inc Tasmania**  
PO Box 364  
Margate TAS 7054  
Ph: (03) 6267 2025

#### VIC

#### Angelman Syndrome Association Inc

c/- 18 Baker St  
Lilydale, VIC 3140  
Ph: (03) 9735 4877

#### WA

#### Angelman Syndrome Association Inc

16 Kirkcolm Way  
Warwick, WA 6024  
Ph: (08) 9447 8606  
Fax: (08) 9343 4431

### Other Support Organisations

#### National

**Australian Assoc for Families of**  
**Children with Disability** (auspiced by the  
Assoc. for Children with a Disability)  
8 Grubissa Court,  
Benalla, Vic 3672  
Ph: 1800 222 660

#### ACT

#### Carers Association Of The ACT Inc The

Minns Pl  
Weston, ACT 2611  
Ph: (02) 6288 9722

#### People First ACT

Rm 17 and 18  
Bldg 3  
Pearce Community Centre  
Collett Pl, Pearce, ACT 2607  
Ph: (02) 6286 9422

#### NSW

#### Carers NSW

Level 17,  
323 Castlereagh Street  
Sydney 2000  
Ph: (02) 92804744  
Freecall: 1800 242 636

#### NT

#### Support Group for Parents of Children

**With Disabilities**  
19 Bayfield Street  
Malak, NT 0812  
Ph: (08) 8948 4417

#### N.T. Carers Association

17 Winnegate Centre/  
Sadgrove Crs  
Winnellie, NT 820  
Freecall: 1800 242 636



## Angelman Syndrome Support Groups con't

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### QLD

#### **Carers Of Disabled Adults Assoc Inc**

Shop 3  
96 Gaynesford St  
Mt Gravatt, QLD 4122  
Ph: (07) 3849 8094

#### **Carers Of Disabled Adults Inc - South**

1/55 Clarence Street  
Coorparoo, QLD 4151  
Ph: (07) 3849 8094

#### **Queensland Council of Carers**

15 Abbott Street  
CAMP HILL, QLD 4152  
Ph: (07) 3843 1401

#### **Queensland Parents Of People With A Disability**

P.O.Box 470  
Paddington, QLD 4064  
Ph: (07) 3368 3055

### SA

#### **Carers Association of SA**

93 King William Road  
Unley, SA 5061  
(08) 8271 6288  
Toll Free: 1800 815 549

#### **Carers Association of SA Inc (CASA)**

4 Third Street  
Murray Bridge, SA 5253  
Toll Free: 1800 052 222

### TAS

#### **Assoc. for Children with a Disability (Tas.) Inc**

GPO Box 730  
Hobart, Tas 7001  
Freecall: 1800 244 742

#### **Tascare Society for Children**

231 Main Road,  
Derwent Park, Tas 7009  
Ph: (03) 62728265

#### **Tasmanian Association Of People With Disabilities & Their Advocates**

15 Mill La  
Glenorchy, TAS 7010  
Ph: (03) 6273 0916

#### **The Carers Association of Tasmania "Westella"**

181 Elizabeth Street  
Hobart, TAS 7000  
Ph: (03) 6231 5507  
Freecall: 1800 242 636

### VIC

#### **Association for Children with a Disability Inc (Vic.)**

590 Orrong Road,  
Armadale, VIC 3143  
Freecall: 1800 654 013  
website: [www.acd.org.au](http://www.acd.org.au)

#### **Carers Victoria**

5th Floor  
130 Little Collins Street  
Melbourne, VIC 3000  
Ph: (03) 9650 9966

## Angelman Syndrome Support Groups con't

WA

### **West Kimberley Family Support Association**

Lot 642 Cable Beach Rd  
Broome, WA 6725  
Ph: (08) 9193 7508

### **Goldfields Individual & Family Support Association**

42 Wilson St  
Kalgoorlie, WA 6430  
Ph: (08) 9091 4356

### **South West Family Support Association**

11 Victoria St  
Bunbury, WA 6230  
Ph: (08) 9721 9088

### **Carers Association Of Western Australia Selby Centre,**

2 Selby Street,  
Shenton Park, WA 6008  
Ph: (08) 9380-4900

### **Midwest Family Support Association**

180 Marine Tce  
Geraldton, WA 6530  
Ph: (08) 9964 8181

Carers' Phone Line  
Freecall: 1800 242 636

In addition to these organisations there are Carer Resource Centres located throughout Australia. The resource centres can provide information about support services or carer support groups that are located in your area as well as any information that is specific to your needs.

There are also many different advocacy organisations throughout Australia. While these organisations are not set up to be support groups they can quite often provide information and support that is useful to your family, especially in relation to problems being experienced with a service being used/not being used by your son or daughter.

For all of these check your local telephone directory or ask other parents with a son or daughter with a disability.

### **What is a Carer Support Group?**

Carer Support groups offer support, time out from the caring role, an opportunity to share information, and recognition of the role of carers and their contribution to the community. They provide important social and emotional support and can help reduce the feelings of isolation often experienced by carers.

### **How do I find where the closest Carer Support Group is?**

Contact your local Carer Resource Centre on Freecall 1800 242 636. Information about your local Carer Resource Centre is also available from your state's Carer's Association (In Queensland the title is Council of Carers).

### **Why would I need to contact someone from an organisation who may not even have heard of Angelman Syndrome?**

Many carers talk about the need to be supported in their role. Caring for someone can be rewarding but also demanding and exhausting. Sometimes carers may feel that others don't understand what they need. Often there is a similarity in the problems being experienced by carers, that is not unique to the specific disability of their son or daughter. Sometimes it helps take off the burden when discussing your problems with someone who has no direct link to you or your family.



## Glossary of Terms used by Professionals in the Disability Sector

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### **Accommodation Service**

A Service Provider that oversees the provision of services in either providing support for independent living or providing accommodation in a home with various levels of support for the residents.

Support staff are provided to support the residents in areas between their capability and full independence. This can range from 4 hours per day on weekdays for people with a mild to moderate intellectual disability.

The range goes on to full support for 7 days a week with sleepover staff (staff who sleep in a room/office attached to the residence overnight), with staff being on duty at times when residents are normally awake. This caters for people with a mild/moderate to moderate/severe intellectual disability.

For people with a severe or profound intellectual disability or severe physical disability there is 24-hour support involving staff being on duty at all times. It may also include multiple staff members being on duty at various times.

*PLEASE NOTE:* Service Providers may not be able to provide support in all areas described above. Some only cater for mild or mild/moderate intellectual disabilities. Others only cater for specific disabilities or high support needs.

### **Advocate/Advocacy**

An advocate is a person who may be a family member, support staff, service management, a friend or an independent member of the community who actively negotiates on behalf of a person with a disability. The advocate may be trying to obtain a service, a particular aspect of a service, supporting someone in ensuring that his or her individual or civil rights are being upheld.

Independent advocates should be trained so that they can achieve the best possible outcome/result for the person they are negotiating on behalf of. Organisations such as Citizens Advocacy can provide advice and information as well as help to find an advocate.

Advocacy is the process of negotiating until a resolution has been reached either in favour or against.

### **ATLAS (Adult Training, Learning and Support) – NSW**

Futures for Young Adults – Victoria

Various Names – All States

Generally refers to the Disability Support Program supplying the funding to support a young adult when they are leaving school and are unable to work due to their support needs.

A State Government program for support that assists the adult with a disability (generally from the age of 20 years) to acquire the necessary skills to be as independent as they can in living in the community and being a member of the community. Some of these adults will acquire enough skills to move on to employment either with or without long term support.



## **Glossary of Terms used by Professionals in the Disability Sector con't**

ATLAS Reform will remove the barriers that prevent people with disabilities from accessing the jobs, training and community access services they need. It will deliver greater flexibility to meet the needs of individuals, their families and carers.

*Source - Department of Ageing, Disability and Home Care (NSW) 2001*

### **Case Management – Case Manager/Case Worker/Key Worker**

With Angelman Syndrome there are two professionals who most typify the role of case manager - the family doctor who determines that certain specialists are needed then refers the patient on to them. They then provide the follow up support on an ongoing basis - typical of a case manager.

Another example is a paediatrician who performs a similar role in referring to and consulting with neurologists, occupational therapists, physiotherapists etc on a regular basis. Other terms for a Case Manager are Caseworker or Key Worker. When services are provided in the accommodation or day program sectors then each of these will appoint a Case Manager to oversee the IP (Individual Plan) as well as obtain support from medical and other professionals for the individual. The Case Manager maybe a support staff member or someone in service management, dependent on the Industrial Award in place.

### **Challenging Behaviour (Also Severe Challenging Behaviour)**

*Source - A Positive Approach to Challenging Behaviours (ADD 1997)*

...the behaviour of a person with a disability is of such intensity, frequency or duration that the physical safety of the person or those nearby is put at risk. The behaviour may also limit the person's ability to participate in daily life and enjoy the wider experiences.

Challenging behaviour is something that is seen, felt or heard that is not socially acceptable conduct.

Severe challenging behaviour involves physical or verbal abuse that can cause harm.

### **Consent**

Nothing too mysterious with this one. A person agrees to something being done for or by them.

Ironically a person with a challenging behaviour has to give consent for a Behaviour Intervention Plan and the associated documentation being done! (Compare that with someone being found guilty of a crime consenting to the magistrate or judge implementing a Behaviour Intervention Plan - by sending them to jail!!!!!!).

Where the consent involves issues of Duty of Care, Negligence and Dignity of Risk, then it needs to be Informed Consent.

In this case the person needs to be able to form an opinion based on their understanding the information, which is given to them in a way that is easiest for them to understand. If a person with a disability communicates with PECS or sign language then the information would be given to them in this format. This is called Informed Consent.



## **Glossary of Terms used by Professionals in the Disability Sector con't**

If an adult with a disability is unable to make a decision based on Informed Consent then someone such as his or her primary caregiver (a family member) may be appointed as guardian for this process. In the absence of a family member a Public Guardian may be appointed to perform this role.

You can find more information about the meaning of consent at the Villamanta Legal Service website:

[http://www.villamanta.org.au/legal/free\\_information/capacity\\_and\\_consent.htm](http://www.villamanta.org.au/legal/free_information/capacity_and_consent.htm)

There are areas involving medical procedures, which require that the matter be referred to a court or to a Guardianship Tribunal for consent. Contact the relevant body in your state for more information about this.

### **Day Programs**

There are a multitude of different programs covered by this term. The one common factor is that they operate during the weekdays in the daytime. Some of the programs are Independent Living Skills/Training (ILS/ILT), Community Access Service (CAS), Post School Options (PSO), Adult Training, Learning and Support (ATLAS).

Some are centre based where the person with a disability accesses different programs from the centre or at the centre itself.

Others are home based where the person stays at home for all programs and is taken out into the community for those programs that are based in the community.

Whether the service is centre based or home based depends on how the service provider operates their service and support structure.

Typically the programs involve different aspects of the persons life such as daily living skills, social skills, communication, self care, community access/use, functional academics (numeracy and literacy), leisure and vocation. The program does not cover supported employment, but can provide training which will provide the skills to go on to supported employment.

### **Dignity of Risk**

Dignity of risk is the right of informed individuals to take calculated risks. Everyone has a right to an assumption of competence. Informed decision making involves a general awareness of the consequences of the decision and the decision is made voluntarily and without coercion.

*Source: <http://www.mapl.com.au/support/DIMIA/Crisis1.htm>*

Dignity of risk is balanced by duty of care. Basically if the person can carry out the activity with reasonable precautions being in place to minimise or prevent the likelihood of injury then the person has a right to undertake that activity with those precautionary measures in place.

This is an area that most parents and carers would regard as one of needing to err on the side of caution.

## Glossary of Terms used by Professionals in the Disability Sector con't

### **Disability Services Act (DSA)** and the accompanying **Disability Service Standards (DSS)**

The Act in each state covering the provision of services to people with a disability by service providers. The Commonwealth also has a DSA covering the services, which are administered by the Department of Family, and Community Services (FACS).

The DSS (generally 10 standards) cover how a service will work with or provide support on a daily basis and may cover the following areas (NSW Standards are used in this example).

<b>Service Access</b>	<b>Individual Needs</b>
Decision Making and Choice	Privacy, Dignity and Confidentiality
Participation and Integration	Valued Status
Complaints and Disputes	Service Management
Family Relationships	
Protection of Human Rights and Freedom from Abuse	

The Commonwealth DSS are similar other than extra standards covering the supported employment/work environment.

### **Dual Diagnosis**

Specifically in the area of intellectual disability. I say this, as there are other areas in the Health sector using this term as well.

When a person with an intellectual disability is diagnosed with having a long term mental illness by a psychiatrist then they are classified as having a dual diagnosis of an intellectual disability and the mental illness.

This does not apply when the mental disorder is Autism, as the primary diagnosis will always be an intellectual disability.

### **Duty of Care**

For an excellent explanation of Duty of Care visit the Villamanta Legal Service website. Go to the specific page on their site.

[http://www.villamanta.org.au/legal/free\\_information/duty\\_of\\_care\\_and\\_negligence.htm](http://www.villamanta.org.au/legal/free_information/duty_of_care_and_negligence.htm)

### **Early Intervention**

Specifically in the area of intellectual or physical disability. Again, there are other areas in the Health sector using this term as well

Early Intervention involves providing medical services at an early age in areas such as physical therapy, occupational therapy and speech therapy. Often these services are provided in your home or are centre based, such as a community health centre.



## **Glossary of Terms used by Professionals in the Disability Sector con't**

### **Environment**

Generally an environment is either a physical structure or an emotional state or one which causes emotional stimulus. (So much for making jargon easier to understand!!)

### **Physical**

This can be a room such as a doctor's surgery, a living room, and a classroom. It may also be an open area such as a car park, a school playground or even a sports stadium.

### **Emotional**

This is more difficult to explain.

It can be the presence of a person or people that affects a person's emotional stimulus in either a positive or negative way. If a person is in the company of another person or a group that they do not want to be with, then they will want to get away, if they can't then this impacts on them in a negative way. Therefore the environment is negative.

It can be something that happens that affect's a person's emotional stimulus. For example hearing a specific song can be good or it can be bad, depending on the feelings that it generates in the person who is hearing it. They may have fond memories associated with the song, which makes them glad to hear it, so the environment is positive.

### **Group Home**

A home provided by a service provider that has between 1 and 7 residents. Each resident has their own room and generally shares other facilities such as laundry, bathroom, toilet, kitchen and common living areas. The Service provides staff support based on the individual needs of the residents. Support staff assist in skills training, support in areas that the individual residents need assistance, community access, individual financial management as well as assisting with the overall operation and maintenance of the home.

Group homes can be a unit, a home in a community residential setting, a granny flat attached to a group home, a duplex that caters for differing support needs and sharing of staffing resources between the two residences.

Any residential larger than 7 bedrooms would have to be classed as a large residential or an institution, in my opinion. How many 7 bedrooms houses other than multiple occupancy dwellings do you see in your real estate agents window??

### **Guardian/Guardianship**

A guardian is appointed when an adult with an intellectual disability is unable to manage their affairs in one or all of the areas of accommodation, medical or finance. The Guardian may be a family member, a long-term friend or a Public Guardian. The Guardian is appointed by a hearing of the Guardianship Tribunal following an application by "someone" who identifies that a Guardian is needed. This is not always a family member.

The appointment of a Guardian does not usually occur in the case of children unless their parents are not the primary caregiver. Guardianship is the process that a Guardian goes through in making their decisions.

For more information go to the guardianship page of the Villamanta Legal Service website



## Glossary of Terms used by Professionals in the Disability Sector con't

[http://www.villamanta.org.au/legal/free\\_information/Medical\\_Treatment\\_and\\_Guardianship.htm](http://www.villamanta.org.au/legal/free_information/Medical_Treatment_and_Guardianship.htm)

### **Individual Plans (various acronyms include IP, IEP, IPP, IRP, ISP, ITP, IVP)**

IP - Individual Plan used by service providers in accommodation, day program, supported employment and case management areas

IEP - Individual Education Plan used by schools

IPP - Individual Personal Plan used by service providers in accommodation, day program, case management areas

IRP - Individual Recreation Plan - used in areas of recreation support.

ISP - Individual Service Plan used by service providers in accommodation, day program, supported employment, case management areas.

ITP - Individual Training Plan used in training and areas of supported employment.

IVP - Individual Vocational Plan used in the supported employment area.

IP's are plans that are developed to outline the goals and achievements that are being aimed for within a specified time. In the case of education, accommodation, employment, day programs and training these will usually be for a 12-month period. In case management they will be for an agreed period for example 3 months, 1 month, usually no longer than 6 months.

The goals can include accessing specific medical or therapeutic resources, a holiday, a daily living skill, a recreational activity or a specific skill or job in the employment or education/training areas.

To meet their funding obligations, service providers put these plans together and provide the support for the person concerned to achieve the goals that have been agreed to in the plan.

### **Non Government Organisation (NGO)**

A community based organisation with it's own management structure.

The organisation may receive some or all of its operating funds through a government department known as the funder, however it is accountable or answerable to its stakeholders - the people who stand to benefit or lose by its actions. The funder is one of those stakeholders.

### **Programs**

Just like you TV program or the program at a sporting event, this can be a government program providing the funding for service delivery, how a service operates in its day to day business to how services are delivered each day. These are all called programs.

### **Respite**

Respite is used to enable the primary caregivers (parents, foster carer, guardian or the person/s who have the main responsibility of providing care and support to a person with a disability) to have a break and vice versa. This may be for a short period so that they can go and do the family shopping or overnight, for a couple of days or for periods generally up to a week.



## **Glossary of Terms used by Professionals in the Disability Sector con't**

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### **Service Provider**

A person or organisation that provides a service, covered by a funding agreement with the State or Commonwealth Government, in the area covered by the Disability Services Act (DSA). Each State and the Commonwealth have their own DSA's, however the main difference is in the wording used.

### **Supported Employment**

Commonly referred to as sheltered workshops in bygone days. In theory (I wouldn't say necessarily in practice) supported employment provides a workplace where a person with disabilities can receive the training and support to acquire the skills necessary to do their job. They are paid a productivity based wage that involves an independent assessment of their skills. The wage that they receive is a percentage form of the full award wage for the job that they are doing. It appears that a wage rate of about \$1 per hour is common in this area.

### **Transition (Plan or Time of)**

The time just before, during or the settling in period following change. For example packing, moving and setting up in your new home are all parts of the transition. In behaviour terms in can be the cause of an incident – the transition from one activity to another especially from home or going home at the end of the day.