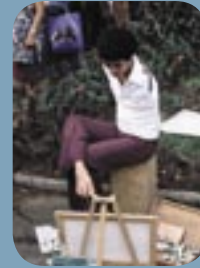


NETWORKER

nothing about us without us

An important annual event for Travis Brown, is the ANZAC Day Parade.



Welcome to the May 2006 NETWORKER. All of us want the very best for our children regardless of their abilities. When there is a person with a disability in the family, often parents are so busy sorting out the day to day issues that the long term ones are continually put aside.

This issue of NETWORKER serves as a bit of a jolt to those of us with older people with disabilities in our families and as a timely reminder to parents of younger children to think about the very serious issue of welfare guardianship. I'm sure we know the stories of people with disabilities in particular residences or places of work which on examination were not where the person concerned wanted to be. We also know that often the parents who placed their dependents there did so for the very best of reasons at that time.

It can be a challenging time for all of us as parents to face sitting down with a group of people including the person with a disability to sort through the next steps in their lives. But the most important thing is that it is their lives. We have to learn to listen and become part of a wider circle of people influencing our children's lives, just like all our other dependents, and being part of the decision-making process. One of the key things I feel is important is that parents themselves are supported in a positive manner to make these steps earlier on so that when their dependent is 18 they are prepared, rather than be confronted by the harsher reality of the law.

The Parent and Family Resource Centre welcomes your views on this or any other matter.

Colleen Brown
Chair Parent and Family Resource Centre

Towards SELF-DETERMINATION

How does the PPPR Act and welfare guardianship support people with disabilities?

We have all made poor decisions. We have all watched others make poor decisions. But socially and legally we want to protect adults with a disability from making poor decisions.

SUCH PROTECTION, while well intentioned, is inevitably putting pressure on the right to personal autonomy. The purpose of the Protection of Personal and Property Rights Act (1988) is to assist adults who are unable to make or communicate their decisions, essentially by permitting others to make these decisions. But taking a step back, what

is being done to help adults be able to make and communicate their decisions?

Encouraging decision-making early

"Parents need to encourage decision making at an early age so the young person is not suddenly faced with making decisions with no experience," says Cindy Johns (Advocate for IHC Advocacy Service). Experience with decision making at an early age can include involvement in IEPs and PATH planning, as well as taking the time to ensure understanding. The aim is to give children a sense of ownership of the decisions and planning that are made in their lives.



Decision making needs to be practised

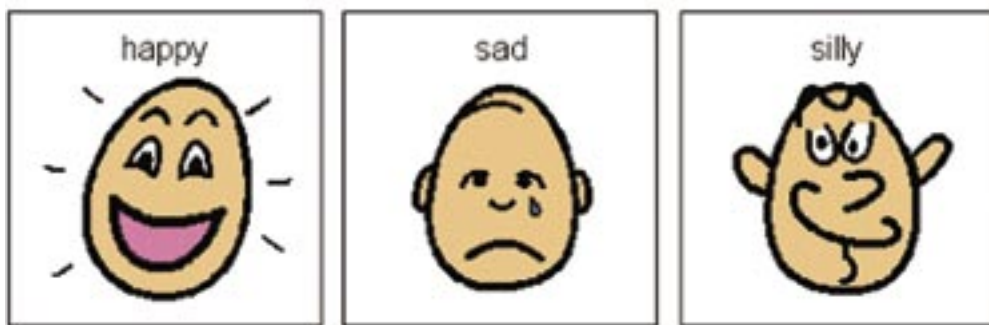
Involvement in decision making leads to self-advocacy and self-determination, asserts Cindy Johns:

“Just as with other children, it is much easier to decide things for them than engage in a process of choosing. If parents start early and engage their children in decisions that affect them, starting small by offering choices, then this leads into meaningful participation in the future and not a major change just because the child turns 18.”

Every parent evolves from a protective parenting style to a person-centered parenting style, observing as their child moves towards becoming an autonomous individual. Critical to reaching this outcome is the parent believing that their child can be a participant in making choices. Disability aside, decision making ability is an evolving process that has to be worked at, both by the individual and their support network.

“Under law, everyone, including people with intellectual disabilities, is presumed to be able to make their own decisions unless it is proven otherwise,” states IHC. “The existence of a disability does not mean individuals are not able to learn about their rights and responsibilities and make their own choices”

Speech language therapists can assist with communication



BOARD MAKER software was used to create these tiles which communicate a range of emotions

Assisting Communication

“Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have” (New Zealand Disability Strategy 2001). So what is being done to break down barriers to the communication impairments some people have?

Action 8.3 of the New Zealand Disability Strategy states: “Support the development of independent communication for disabled people.” This has been happening with the advent of new technology such as computer programmes (including Board Maker), clip art and digital cameras, comments Cindy Johns. “Within the disability sector things are improving in this area with parents and professionals becoming more aware about creating different ways of communication.”

IHC believes people with an intellectual disability “if necessary must be helped to communicate their decisions.” In the same way, “parents and professionals need to work hard to create ways and means of communicating for children and young people and not leave this until adulthood,” reiterates Cindy Johns.

It can be hard to keep up with changing technology. For this reason “IDEA Services has a new innovative service called Total Communication which employs speech language therapists to advise on environmental change to assist people’s communication and up-skill staff to enable them to be supportive communication partners” reports Cindy Johns.

Influencing decisions

Asserting that you can make, and have the right to make, your own decisions doesn’t mean you can’t have support. Every decision we make is affected by the opinions of somebody else. Often the best decisions are those made with the most input from others.

Unfortunately the scope of social connections is often more limited for people with a disability. This in turn impacts on the ability to make an informed decision, making a

wide and varied circle of support particularly needed for young people with a disability.

Parents hoping that welfare guardianship will prevent others from influencing their child to make decisions in contrast to theirs, may be surprised to find they could still end up back in Court. This is because the PPPR Act says the welfare guardian cannot have a conflict of interests with the “person who lacks capacities”.

There have been cases where the person who is the subject of the welfare guardianship order has other people in their lives who disagree with the parents interpretation of what is in that person’s best interests. If the person who is the subject of the order disagrees with the decisions the welfare guardian makes, the Court can once again become involved, appointing a lawyer for the subject person, listening to both sides, and making a decision.

Is it necessary to bring the legal system into decision making?

Cindy Johns believes that, “while the PPPR Act provides a legislative framework for substitute representation in New Zealand, it is a misconception that all adults with intellectual impairments require this level of intervention in their lives. This Act should be viewed as a last resort and only used when absolutely necessary to protect the person from abuse, not as a form of control.”

An informal, supported system is similarly advocated by Inclusion International: “What is needed is legal recognition of the legitimacy of supported decision making. That is, legal recognition that all people require supports in order to make choices and decisions.”

While the Court definitely has a role to play if things break down, there is value in continuing to search for alternative processes that can bridge an idealized situation and the less ideal situation that many parents experience. As Cindy Johns says; “We need to advocate for other ways of supporting decision making that do not require the Court to be in the lives of people with an intellectual disability.”

The contention over welfare guardianship

Although parents can find the time and cost of applying for and renewing welfare guardianship annoying, Cindy Johns points out that parents should be pleased this protection exists for their child. "The legislation is designed to protect the vulnerable person, not make life easy for the appointed guardian. Short term orders offer more protection than a blanket welfare guardian being appointed".

Disagreement can arise between service providers, advocates and family etc over:

- 1 whether there should be an application for a personal order or welfare guardianship,
- 2 whether the person applying is the right person, and
- 3 in whose interest are they doing so.

Many argue that welfare guardianship may be becoming too embedded as a routine "next step" in the care for a child with a disability.

Inclusion International reports its position as:

"It is the view of our community that traditional guardianship laws are used to control people's lives and to deny people the right to make decisions on their own behalf. This runs counter to the principle of self-determination. Inclusion International's position is that if people have access to legal assistance when this support is required then the old guardianship laws will not be needed".

Supported Decision Making Model

The search for alternatives to welfare guardianship laws has been boosted by the recent development of a United Nations convention on the rights of disabled people.

The Office for Disability Issues (ODI) is working with the Ministry of Foreign Affairs and Trade and with disabled people and disability sector organisations on New Zealand's contribution to this convention. An ad hoc committee was formed in 2001. If ratified, the convention becomes a legally binding treaty. The ODI reports that in the last 20 years the UN has "moved from a welfare perspective to a development and human rights perspective".

Chris Hansen was part of the NZ delegation to the UN in 2004 and 2005 for meetings for the disability convention and reports:

"Guardianship removes a person's right to make decisions about their own treatment, finances etc. The convention could require supported decision-making, where the person is supported to make

WELFARE GUARDIANSHIP

one family share their experience

Paul and Marie have just been appointed joint welfare guardians for their daughter Jessica (19). While their minds are buzzing with details of the nine month process, they think Jessica is unlikely to have any real understanding of the process, or the implications of the Court order.



Jessica and canine companion

MARIE, TOO, is still learning what her new role involves. "This is a whole new area for us." The mum of six can't recall ever being given information on what her role as welfare guardian entails. Nor does she recall alternatives to welfare guardianship being discussed with her.

Jessica is the couple's fourth child, and while she has good social skills, she is cognitively at the level of a five or six year-old. Of Jessica's decision making ability, Marie says, "She can say what she does and doesn't like, but can't go into detail."

Welfare guardianship has always been in the back of the couple's minds. But the process was kick-started when the age of legal adulthood was lowered to 18. Although Marie explains, "we didn't want to be shut out," their main reasons for applying as welfare guardians were medical and financial.

Jessica has required hospital treatment since birth and will need treatment for the rest of her life. One day unfamiliar hospital staff questioned Marie's legality to make decisions for Jessica, an incident that made Marie understandably fearful for the future. "Jessica would say no to medical treatment she doesn't like. Even if they took time to explain it to her, there is the chance that she could still say no."

Similarly Marie has once been questioned by bank staff when withdrawing money from Jessica's account. While Jessica uses the money from her Invalid's Benefit

to pay for prescriptions, Marie says she has let Jessica waste money on her favourite Holden clothing and DVDs. From her experience with her older children Marie is well aware of the financial mistakes young people make. "With eighteen year-olds you have to let them go and find out for themselves. But there will be some that will never learn."

The lengthy process through the Family Court also came with a \$1,500 lawyer's fee. Of the free assistance available, the couple felt that the Public Trust didn't have the answers they needed and likewise the Family Court weren't very helpful. However Jessica's Court-appointed lawyer was fantastic. Although Marie and John applied for five years, they were given three years before they would need to apply for a renewal of their guardianship. The Court experience, "became another thing we had to go through," recalls Marie.

Upon being asked whether she could imagine a better system, Marie reiterates, "We just don't know. This is a whole new area for us." However they would have liked more support and advice on what their role could be when Jessica turned 18. Also free legal help and a five year term for welfare guardianship.

Can personal autonomy be paramount for every situation? Marie doesn't think so, and says she often gets brassed-off by idealists. She is adamant that, "we would love it to be like that, like our older girls. But every child is different".

decisions by someone they trust in a non-coercive way. Most guardianship laws allow only for substituted decision-making, where someone is appointed to make decisions on the disabled person's behalf"

Supported decision making is also the process advocated by IHC. "While the PPPR Act has good principles and its intentions are for all decisions to be in the best interest of the person, the reality in New Zealand has not always been this," says Cindy Johns. "If the supported decision making model was to be formally adopted in New Zealand, legislation would require reviewing to revoke guardianship decision making and therefore allow personal autonomy to be paramount."

Under the PPPR Act, the welfare guardian must "promote and protect the welfare and best interests of the person for whom they are acting", but also "encourage the person for whom you are acting to develop and exercise any capacity they have" and "encourage the person for whom you are acting to act in their own interest wherever possible". This hybrid of protection and encouragement is the cause of the contention – the Act does not have personal autonomy as its first priority.

"A successful model could create supportive decision making environments using friends, family and community members" says Cindy Johns. The success of the model will be measured not only by the decisions made, but by the process – it will enable adults to engage and take ownership of their decisions, and receive the support they need.

The H&D Code of rights Right 7 (4) outlines health services that can be provided on behalf of patients who are not competent to make an informed choice and there is no other person entitled to consent on their behalf. It describes a consultative approach with next of kin, whanau, GP, care givers etc . Every DHB has policies related to informed consent and in response to the code. Regular health intervention is permitted and intervention beyond reasonable treatment requires court intervention.

** The ad hoc committee meets again at the end of April. The Parent and Family Resource Centre will report on the outcome of the UN convention in the next Networker.*

The PPPR Act: Basic facts

The Protection of Personal and Property Rights Act (1988) was brought in to assist adults who are unable to make or communicate decisions or manage their own affairs.

The age for defining "adult", once 20, has changed with the amendment of the Care of Children Act (2004) in 2005. Now after a child turns 18 a parent must get their authorization to make decisions for them. For many parents with a child with a disability, this leaves them wondering how they can legally ensure that their child's best interests are met.

According to the Family Court:

"If a person lacks the capacity to manage their own affairs, an application can be made to the Family Court to make personal or property orders for their benefit. Alternatively, an application can be made to appoint a welfare guardian or a property manager."

Applications for personal orders and welfare guardianship are made through the Family Court. This Court describes its role under the PPPR Act as "to protect and promote the personal and property rights of people needing protection", with the "person encouraged to use and develop their capacity to the greatest extent possible".

	PERSONAL ORDER	WELFARE GUARDIANSHIP
What is it?	"A personal order is an instruction given by a Judge requiring an action to be taken to look after a specific part of an incapacitated person's care and welfare" This can include an order for medical advice or treatment, educational, rehabilitative or other services, appointing a welfare guardian.	"A welfare guardian is someone appointed by the Family Court to make and implement decisions on behalf of a person in relation to all aspects of their personal care"
Who can apply?	Almost anyone, including a relative, attorney, social worker, representative of a non-profit service provider – even the person who is the subject of the personal order.	Applicant must: <ul style="list-style-type: none"> • "be capable of carrying out the duties of a welfare guardian in a satisfactory manner." • "act in the best interests of a person who lacks capacities."
Where to apply:	Family Court.	
How much does it cost?	Usually no cost unless a private lawyer is used.	
What assistance can I get?	Forms are available from a Court or the family Court website www.justice.govt.nz/family The Court can help with the application and appoint a lawyer to represent the person who is the subject of the application. The lawyer will help the person understand the application as much as is practicable.	
What happens in Court?	Evidence is heard. The Court can request medical, psychiatric or psychological reports on the person concerned, and call witnesses. The person concerned is entitled to be heard and call witnesses.	
How long until a decision is made?	The Court will usually make an order or a recommendation immediately.	
How long will the order last?	The order will expire at the date set by the Court. Anyone at any time can ask the Court to review the order. A welfare guardianship order will generally last 3 years. If desired, the guardian must apply for a review before it expires – no reminder will be sent from the Court.	
More information:	<ul style="list-style-type: none"> • Power to care: A video explaining The Protection of Personal and Property Rights Act 1988, produced by Educational Resources, PO Box 19050, Wellington (may be able to borrow this video from your local Court or Community Law centre) • Copies of the PPPR Act are available in libraries • Guide to PPPR Act www.courts.govt.nz/family/pamphlets-html/courts044.html 	

Diary Note

PFRC Inc. AGM

31st May 2006 7.30pm
at PFRC cnr of Princes
& Spring Sts, Onehunga