PART THREE

Learnings from the Project

Memory is a responsibility because it becomes witness and reaches beyond the individual to the consciousness of the community.

Arthur Frank, *The Wounded Storyteller*

LEARNINGS FROM THE PROJECT

As CRU reflects on the work with the families there is a strong sense that the family support project was a very important piece of work to have undertaken. At its commencement CRU had little idea that there would be such rich learning. In this final section some of the significant insights that were gained through the work with families are identified. CRU believes that these insights have the potential to assist policy makers, health professionals, service practitioners, and families to advance a mutual understanding of the potent relationship that might exist between service systems and families.

The learnings and insights that arose out of the *Focus on Families* project occurred at different stages: some illuminations occurred in the midst of working with families; some occurred during periods of reflection and analysis following the completion of the project; and others occurred during the preparation of this book. During these various stages many themes and insights emerged, the major ones being:

✳ The centrality of love to human wellbeing;

✳ The centrality of families to human wellbeing;

✳ The unresolved anguish caused by loving without hope;

✳ The pain of giving up a loved family member to a formal service system and the abandonment of families to that pain;

✳ The power of the story-teller to teach;

✳ The need for the right kind of relationship to exist between professional practitioners and families;

✳ The characteristics of a helpful professional practitioner;

✳ The importance of strengthening and supporting families to be more resilient;

✳ The shortcomings of notions of 'empowerment'.

The centrality of love and family life to human wellbeing

When professional practitioners, in a role of helper, enter into the lives of families they show great wisdom if they respectfully acknowledge the fundamental love-relationships in families. The solutions that might be offered by professionals who do not make this acknowledgment can, at best, be only partially effective. The importance of working in ways that strengthen love-relationships, between parents and children, and between siblings, cannot be overstated.

The narratives in this book suggest that there may be a widely held assumption that parenthood, in respect of a child with a disability, is qualitatively different from the experience of parenthood of non-disabled children. Some parents who are associated with CRU, but who were not directly involved in the project, have commented that many people in the general community find it difficult to understand that feelings for their child with a disability are the same as their feelings for the other children in their family. Many parents speak of constantly needing to explain this to people.

Unrequited love

Throughout the project, when coming to understand what happens to the love that is held for a child during prolonged separation, it became clear to us that we were observing the effects of unrequited love, or love that had somehow been banned by other members of society. The infinite sadness and unresolved anguish that are the by-products of one member of a family being removed to an institution were seen. Love continues, but without hope of being reciprocated or shared. In her book, *Fugitive Pieces*,

Anne Michaels names this experience of love-without-hope very accurately; she calls the person's narrative a "biography of longing" in which "the shadow past is shaped by everything that never happened".

By 'unrequited love' we mean that although there is love held by one person for another, the natural opportunities for that love to be nurtured, expressed, and reciprocated do not exist. In the case of families, the removal of a child removes the natural context in which the development of shared, reciprocal love can occur. The undeveloped love remains a longing: a longing by the parent for the child; a longing by the child for the parent; or the longing of a sibling for a brother or sister in the absence of opportunities for that love to be nurtured and reciprocated. At the commencement of the project when we began to hear families telling their stories, we realised that we were listening to powerful love stories.

Love that is banned by others

One way of looking at what has happened to many parents of children with disabilities, especially parents of children who have been institutionalised, is to recognise that they have had their love for their child banned. The child that the parents have created has been judged by others to be imperfect. A valuing of the 'imperfect' is not readily sanctioned in our society and there are negative social attitudes that serve to censure parental acceptance of a child who has a significant impairment. This kind of disapproval can be felt even within the first days of a child's birth. Carolyn Friend has described this kind of experience in her chapter of the book, *Gathering the Wisdom*.

Many parents, even today, report feeling confused and troubled by the behaviour of hospital staff, relatives and friends once it is known that their infant child has a disability. And many older parents retain vivid memories of insensitive comments by doctors and nurses who expressed disapproval, bordering on condemnation, when they decided to take their child home to be one of the family rather than surrendering their child to life in an institution.

Permanent institutionalisation was frequently recommended to parents, and where the child's disability was severe, parents felt enormous pressure to comply with the medical opinion of the day.

In the general community, almost all parents experience a torrent of emotion at the time of a child's birth. But for the parents of a child who is born with a disability, it is not unusual for joy to be mixed with disappointment and anxiety about what the future might hold. Historically, the interventions of professional practitioners and service systems have tended to focus on the parents' perceived disappointment, often described as 'grief', as well as focusing on the 'imperfection' of the child. Strong, covert messages are conveyed to parents about the inappropriateness of loving such a child and often the practice has been to remove the child from the family, rather than to support the family to love and cherish their child.

By their very nature, social attitudes and beliefs are pervasive. Negative messages, if received over long periods, influence the judgements that each of us makes about events and experiences. Parents and families are not always protected from the intrusion of negative social attitudes about disability into their own belief systems and this may result in a form of 'love banning' within the child's own family. There are many examples of one family member saying to another family member such things as: "It's him or me"; "If you can't manage, then put her in a home for kids like her"; or when a child has been banished to an institution, saying: "You are never to see him again". The child's family, or at least particular persons within that family, may accept, as being legitimate, the harsh attitudes of the wider society.

The power of the storyteller

In his book, *The Wounded Storyteller*, Arthur Frank says: "In stories, the teller not only recovers her voice; she becomes a witness to the conditions that rob others of their voices". Through their narratives, the families who were involved in the CRU project have recovered their voices and provided readers with a greater consciousness about what is needed by families in times of stress or

heightened vulnerability. Their narratives have the power to inform those who are in public office, in the helping professions, and in the general community.

The need for these authentic accounts to be understood by the service sector and the wider community became very apparent during the project because the narratives contain indicators of how things might be different. Further, a thorough analysis of the narratives has the potential to inform both public policies and service practices well into the future. Nothing will change, however, without a reassessment of some of the entrenched views that are held about families. What was starkly revealed during the project was the almost cold dismissal, by those in service systems and the helping professions, of parental roles and the natural authority that one would normally associate with being a parent. In the light of these stark revelations, questions and concerns tumbled out.

In raising these concerns the intention has not been to condemn professional practitioners, but rather to move to a more enlightened position in which the valuable contributions of all relevant parties can be acknowledged and integrated into an adaptive approach that will strengthen families.

The parent-professional relationship

By highlighting the importance of families and love-relationships it may seem that the role of professional practitioners is being diminished or understated, but this is not so; good professional practitioners are always appreciated by families in times of need or heightened vulnerability. Although CRU often hears families of people with disabilities talk about how hard it is to find a good doctor, therapist, social worker or teacher, we also find that families are always keen to talk about how pleased they are when they do discover them. In his article, *Communality & Vulnerability*, Joe Osburn sees professional groups as being part of general social arrangements (or social structures) that are often looked to with great hope when seeking solutions to social problems. He says

that the problem is that social structures demand the allegiance of professionals and that these structures sanction their professional roles, even when that ultimately brings harm to vulnerable people. In other words, he says, the very kinds of social arrangements that have great hope vested in them, often have a long record of poorly addressing the needs of those who are vulnerable, or even inflicting great harm on them.

This is not to say that professional practitioners are unfeeling. But no matter how good individual professional practitioners may be, with good technical skills and a high commitment, they rarely have an emotional commitment to a person that is of the same magnitude as that of a parent or family member; a strong professional commitment to the goals of a particular person or project is an emotional involvement of a different order.

Many social policies and professional practices seem to be premised on the belief that parents of a child with a disability are incapable of making the informed decisions that they might otherwise be capable of making if they were parents of a non-disabled child. It is as if parenting a child who has a disability is seen as having a debilitating impact on otherwise competent, intelligent adults. Perceptions and assumptions about families that prove unhelpful today may have come about, in part, as a consequence of the way in which professional practitioners have been taught in the past. For example, writings before the 1980s were generally based on the assumption that family dysfunction and pathological reactions were an inevitable result of having a child with a disability, particularly a child with an intellectual disability. For example, in the 1960s (the pinnacle of the institutionalisation era in Queensland), Social Work students were taught that chronic sorrow was an expected natural parental response to having a child with a disability.

During the decades in which this type of professional instruction prevailed, parents who reacted to their son or daughter with a disability in positive ways were seen to be denying reality. Such

judgemental views of parents proved to be fertile ground for the creation of a dominant class of professionals.

Professionalisation and human service systems

Since the advent of modern human service systems, family matters that were once viewed as personal or private have been redefined as requiring the services of professional people. Public policies outlining what are thought to be the best responses to the needs of people with disabilities and their families have largely been determined by the views of a detached professional class.

By their very nature, professionalised human services tend to denigrate the contributions of ordinary people and therefore social problems, whether at an individual or collective level, tend to become the sole territory of so-called professional experts. Assumptions about the need for professional interventions have downgraded the knowledge of ordinary people and ordinary families, even of those who may have worthwhile knowledge; their contributions and insights have been regarded as inferior, unhelpful, and generally antagonistic to professional judgements and interventions. In order to justify the dominance of professional practitioners such as psychologists, therapists and medical personnel, 'disability' has had to be pathologised and mystified. As a consequence of this, our society appears to have favoured solutions that are generated by a professional elite.

The narratives in this book illustrate how detached professional practitioners frequently made major decisions affecting people with disabilities and their families without any participation by the families themselves. It is extraordinary to think that those who would be most directly affected by the decisions, played no part in the decision-making process. Such a fundamental disregard for the thoughts, feelings, wishes and concerns of parents is shocking, and this treatment came on top of families trying to deal with the particular circumstances that had precipitated their involvement in the service system in the first place. The narratives show that the combined impact of this was extremely stressful, and in most cases, traumatic.

The personal price that has been paid by families who were excluded from important decision-making processes has been very high indeed. The narratives make it clear that the solutions, which were offered by social planners, bureaucrats and practitioners, were no solutions at all. They may have provided a short-term amelioration of a stressful situation but what has been revealed many years later, is that these solutions hurt more than they helped. Decades later, in some cases thirty or forty years, we have discovered individual family members with deep emotional wounds. In almost every instance intractable anxiety, family breakdown, enduring sadness, a deep sense of loss and debilitating feelings of guilt were revealed.

The work of Community Resource Unit frequently puts us in touch with many families other than those who were part of the *Focus on Families* project. Their circumstances are different from those whose narratives appear in this book in that their children, who have disabilities, have not been institutionalised. However, these families speak of the many problems with the service system that they also encounter. The problems they describe include: a lack of communication; withholding of information; frequent turnover of staff in service organisations; parents made to feel inferior; parents' concerns not being taken seriously; and families being fobbed off from one agency to another.

Until recently this might have been attributed solely to the dominance of professionals over families, however, the rise of managerialism and market place ideologies, associated with economic rationalism, seem to be curbing even the power of professionals. This is not as welcome as it might seem, because it is well known that a good professional practitioner can make a positive difference for families. When economic decisions alone determine who will get assistance or what type of assistance will be offered, sound professional wisdom can be overlooked or dismissed in favour of financial considerations.

A transformed relationship between parents and professionals

It is clear that a fundamental transformation is called for in parent-professional relationships. The nature and effectiveness of such relationships will be critical if present and future service responses are to be relevant to the real needs of families. In much of the literature on family support, as well as in policy statements, frequent reference is made to the notion of 'empowerment', with the assumption being that this will be the apparatus by which a better relationship between families and professional practitioners will be achieved. But the rhetoric of empowerment does not get to the heart of what will really make a difference in the lives of people with disabilities and their families.

Shortcomings of the notion of 'empowerment'

The term 'empowerment' is often used in conjunction with efforts to address a variety of social problems, especially those relating to people who are marginalised in society. The term is frequently used in the disability sector in reference to people with disabilities themselves and their families. Unfortunately the term 'empowerment' is so widely used that it has ceased to be a useful concept, even as a rallying cry. It appears to be offered as an antidote to professional domination, the suggestion being that a good life is guaranteed through empowerment. In addition, its rhetoric has become a means of abandoning people to their own resources.

Generally speaking, 'empowerment' is a poorly defined concept, with little consensus about what it actually means. The term is problematic not just because of its lack of conceptual clarity, but because its uncritical acceptance can damage what might otherwise be a potentially fertile relationship between parents and professional practitioners. To view 'empowerment' as some kind of answer to the deeply wounding experiences of families seems to be a counterfeit response from policy makers and professional practitioners. Instead, a genuine response is called for; one that is more than a

re-distribution of power, taken from professionals and reassigned to families. In the past, most attempts at formal mechanisms of consultation and collaboration have proved inadequate for redressing the overwhelming shortcomings of human service systems.

Through the work of the project it has become clear that for any enduring change to take place in parent-professional relationships, professional practitioners need to acknowledge the fundamental strengths of families and their desire to maintain a life that is as ordinary and typical as possible. These acknowledgements will come more easily to those professional practitioners whose starting point, when working with families, is to:

❊ Highly value parental roles and recognise them as a critical factor in any intervention;
❊ Be attuned to the love and the hope that parents have for each of their children;
❊ Attribute to families the natural authority that they have in society (see Appendix 1).

Approaching families in this way is very different from an approach in which professional practitioners 'share' their professional authority with parents, based on notions of empowerment.

A partnership of concord

Good professional practitioners and families need to work as allies, in real partnership with each other. The term 'partnership' comes closest to capturing the essence of a new era in relationships between professional practitioners and parents. However, a partnership *per se* cannot guarantee that the problems, which have been described, will be overcome. A new concept has been proposed by Wills, Carmen and Robinson, which they call a 'partnership of concord'. The word 'concord' is derived from 'con' meaning 'together', and 'cor' meaning 'heart', and the term is defined as 'an affair of the heart'. The writers say: "It is rightful that parents are acknowledged as the senior partners in a partnership based on the heart, for we are the ones who first love and care for our child.

It is we who share the wounds and joys in the everyday lives of our children".

This concept seems to most clearly articulate what the *Focus on Families* project illuminated: that whenever others usurp responsibility for family decision-making, feelings of helplessness and dependency are likely to be fostered. In contrast, a true partnership of concord will be characterised by decision-making in which there is a complete absence of intimidation and manipulation.

The characteristics of helpful professional practitioners

The work of the project helped identify the characteristics of professional practitioners who are truly helpful to families. They are people who demonstrate the following attributes and attitudes:

* ✳ Show deep respect for people;
* ✳ Believe that most families can work out things for themselves given opportunity, information and practical support;
* ✳ Demonstrate personal qualities of genuineness and openness, and are prepared to show their own vulnerability;
* ✳ Understand that it takes time for families to work through major life issues, and do not expect families to make momentous decisions based on the timeframes of others;
* ✳ Recognise that decisions made during a time of crisis may not provide appropriate solutions beyond the crisis period, and will not pressure parents to make important long-term decisions while experiencing a highly stressful event;
* ✳ Believe that families should exercise as much control as possible over service provision;
* ✳ Accept that families may change their minds about some things;
* ✳ Support families in reviewing previous decisions while not making families feel that they have burnt their bridges;
* ✳ Are prepared to work at individualising and personalising policy decisions;
* ✳ Do not hide behind a professional 'mask' but relate as one person to another;

✳ Recognise that certain types of provision can weaken families rather than strengthen them and promote resilience;

✳ Recognise that the capacity of families to make important decisions will vary at different times and in different contexts;

✳ Recognise the strengths and the limits of their own professional expertise;

✳ Recognise what formal services can offer, and what they can't offer;

✳ Surrender all delusions of being the 'super person' who always happens to know what is best;

✳ Shield the family from the demands and pressures associated with service systems. This is especially needed where there are complex, rigid bureaucratic regulations about funding and reporting.

It is critical that professional practitioners show a willingness to be in the right kind of relationship with those families that they seek to support. The fact that CRU was neither in a policy-setting role nor part of the regime involved in the closure of Challinor, meant that we were genuinely able to position ourselves alongside families. In other words, a 'right' relationship with families, is not one in which two or more competing interests are served.

The spirit and intention of good assistance to families could not be expressed more eloquently than it has been by Marie, who says that good professional support is likely to be forthcoming from those who are ready to:

> .....deal with complexities and are willing to stick with a family in difficult times. They need to have a strong sense of vision. They also need to be flexible. They need to know when to compromise, when to use rules and when not to use them. They need to ignore the quick fix and go the long route to identify the causes of problems and anxieties.

The parent-professional concord: how might it work?

In contrast to what they describe as the intimidation of parents by experts, Wills, Carmen and Robinson go on to suggest some actions that are likely to be seen as doing the right thing, by genuinely involving parents. The writers suggest that the following actions work best for families:

◆ Small, informal discussions with relevant people, where people are respectful of each other;
◆ Looking at problems and working out solutions together;
◆ Parents being treated as the senior partner;
◆ Parents listening, and being listened to;
◆ Others with relevant expertise joining in on the invitation of professionals and parents, being people they both trust, and not just people assigned to the task;
◆ All parties making final decisions together, without coercion.

Obligations to families

Because better things are happening these days for families who have young children, there is a danger that older parents, wounded by earlier, less humane practices, will not benefit from a possible transformation of service approaches. There are scores of older people, well beyond the numbers who share their experiences in this book, who have suffered in similar ways to those whose narratives are told. In addition, there are countless others who have been able to keep their sons and daughters within the family but who have not received appropriate support. Stories are told of parents who are too frightened to allow service practitioners into their lives today, such is the power of the horror-stories they have heard in the past.

In thinking about future policies and practice, special attention needs to be given to the best ways of working with older parents who, broadly speaking, fall into two groups: those who have had the experience of a family member being institutionalised; and those who have retained their family member at home. For the former group of parents, the personal anguish arises out

of the sadness for the child who was lost to them in the past through institutionalisation. For the latter group, as they age and contemplate their own mortality, the personal anguish is likely to be about what the future might hold for their son or daughter.

Concluding remarks

Although we were apprehensive about asking families to share their deeply personal and painful memories in this book, their stories were shared with great generosity of spirit. Some of the family members who agreed to be interviewed for the book revealed that being able to talk about their experiences had actually helped them in many ways. The idea of publishing the narratives was not motivated by a desire to locate blame, but rather to foster a true understanding of the consequences of social policies as they relate to people with disabilities and their families.

For those whose experiences of institutionalisation appear in this book, and for many thousands of others, there has been a failure by service systems to recognise and respect what family life could mean for each of those people. A great injustice has been enacted against them and their families. Their wounds are deep.

The heartfelt experiences of family members that have been told in this book merit thoughtful and humble examination. The anguish and distress of the families needs to be acknowledged by all, and especially by those who are in positions of influence and responsibility within governments and service systems.

For those who work closely with families, however, an acknowledgment alone is insufficient; families need practitioners who can identify with them, engaging both 'head and heart' as they work with families who experience pain, joy and hope.

It is hoped that through the publication of these previously untold stories there might be a better understanding of family relationships by those in public office, professional practice, and in the general community. It is always timely that we are reminded about the centrality of love and family relationships in the lives of all people, and that this is never more true than it is for those

who are highly vulnerable to social rejection and exclusion. It is essential for policy makers, professionals and service practitioners to appreciate the importance of this centrality if they sincerely seek to be effective and helpful to families in times of need. This appreciation, as a starting point, is less likely to lead to the perpetration of further harm to families.

Despite the rupturing of family life that occurred with institutionalisation, most families have sustained their love; they are still around, still loving, still worrying, and still hoping. They continue to be involved in the life of the person who was for so long removed from their presence. We are aware that many of the people who were institutionalised also retained memories of their earlier lives, when they had been a part of their families. This was evident even in some situations where there had been very little contact (or none at all) between the person in the institution and other members of that person's family for periods of up to forty years.

The painful experiences described in this book are ones that have been experienced by many other people with disabilities and their families. There are vast numbers of stories that remain untold.

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