

## LEAD ARTICLE

### *When Parents are in Denial*

By Shirley Young



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playwright, musician and composer. Shirley began working in the field of childhood disability 16 years ago, co-ordinating eleven specialist play schemes. For the past 14 years she has been running SNIP, a parent led voluntary agency based in the Royal Hospital for Sick Children in Edinburgh. Shirley also chairs the Family Fund and the Scotland group of Care Co-ordination Network UK (CCNUK). She recently retired as a Guide Leader after 30 years service and has replaced this with trying to get fit by walking and ice skating before she hits 50!

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#### **Introduction**

For the past 19 years, as the mother of two disabled sons and director of a voluntary agency supporting parents of disabled babies and young children, I have experienced denial, my own and other people's, in all its various guises. I feel that denial can be an extremely useful and effective coping mechanism when used appropriately, both for parents and for the professionals who work with them, but seriously damaging when used beyond usefulness and left unchallenged. In my experience, denial and its impact are not always acknowledged or understood and, because of this, parents' personal relationships and potentially effective helping partnerships can break down. I hope therefore that this essay will encourage readers to reflect on their own use of denial and their attitudes to it. In the essay I aim to explore the following:

- The wide variety of coping mechanisms employed by parents of disabled babies and young children
- What denial is and why all human beings use it
- When denial can be necessary, welcome and helpful
- When denial may be damaging
- How denial can be used or let go of, supported or challenged within a helpful partnership in the best interests of the baby or child and their family

I will illustrate the essay with anecdotes from my own personal experience and from the families I have worked with. This is not to suggest that these are universal to all families of disabled children or to all professionals, since we are all unique, but I hope they will prove helpful in 'making live' my observations and references.

### **What are coping mechanisms?**

The terms 'coping mechanisms' and 'coping strategies' are used to describe how people deal with the circumstances of their lives. As human beings we all use a variety of different coping mechanisms to deal with what life may throw at us. The coping mechanisms most often used by people in relation to children who are sick or disabled are:

- over-optimism
- over-pessimism
- martyrdom
- self-harm
- grief state \* see note below
- anger

This list and the Table below are adapted from training material written by SNIP (Edwards, C. & Young, S. 2003). The Table shows the use, purpose and value that each coping mechanism holds for parents. These mechanisms are also used by siblings, extended family, friends and professionals working with families. The coping mechanism of denial is not included in this section, as it is covered in detail later. If you are a professional, please consider the following questions:

1. Which coping mechanisms are being used by parents you are currently working with?
2. Which, if any, of these mechanisms have you used and how have they benefited you?
3. When do you feel these mechanisms might become less than helpful to you and impact adversely on the relationship you have with families?
4. In what way can these mechanisms have some value for the extended family or friends of parents you work with?
5. Have you ever unwittingly supported parents in a coping mechanism that is damaging to themselves and/or to the

disabled child and any siblings?

[\* **Note:** Care must be taken in the application of 'grief theory' to parents in this situation as the process is not one of reaching an 'acceptance' as, for instance, when an adult dies. The process is better described as one in which the parent repeatedly revisits the stages of grief, usually around transition or change. Moreover, grief theory can probably only be applied to the actual death of a child (any child) with great caution, as the death of a child runs counter to societal notions of nature. It is a societal norm that people age and then die, each generation in turn. It is counter to this for children to die before their parents and is therefore never 'acceptable' (apart perhaps for parents who have a faith which enables them to believe it was the will of a higher being and the child has gone to a better place).]

These coping mechanisms and others enable families to survive the challenges of adapting and adjusting to their child being disabled. They may be used to varying degrees in any combination by any parent at any time. It is not unusual for parents to swing between them in the course of a day. It can be seen that some of the coping mechanisms, in particular self-harm, need to be challenged very quickly while others can be supported for longer, unless they are counterproductive to the parents or detrimental to the child. It is vital that professionals are able to recognise which coping mechanisms each member of a family is using and able to assess the impact they are having. Professionals can then challenge appropriately and move people to less harmful and healthier ways of coping. These include distraction, physical activity, informal peer support from other parents, and such therapeutic interventions as facilitated support groups, anger management, art therapy, counselling, massage, and/or, in my view, conscious denial.

### **What is denial and why do all human beings use it?**

In Frank Parkinson's book '*Critical Incident Debriefing*' (Parkinson 1997) he states:

*The normal reaction to a traumatic incident is the powerful defence of denial.*

following:

He elaborates:

*Denial is switched on as a protection against the unacceptable, both during and after an incident.*

He later goes on to talk about the cumulative effect of trauma and describes parents of disabled children as having an 'ongoing traumatic experience'.

No wonder then that parents are often 'in denial', either unconsciously when their mind just cannot take any more, or consciously as a way of facing each day.

### **How do parents present when they are using conscious denial?**

Such parents will appear to be going about ordinary life, getting up, getting dressed, while seeming not to see, or to be ignoring, the situation and not discussing or referring to it. Nevertheless, they will attend appointments, accept advice and seek appropriate interventions for their child. They will usually deal with current issues, but will be reluctant to talk about the future, recognizing that by taking one day at a time they can reduce their anxiety. This does not mean they do not understand what the future holds, but are simply coping with the situation in a way that is effective for them. This is unlike the parent who is so traumatised into *unconscious* denial that they simply cannot address any issue relating to their child and will constantly claim that interventions are unnecessary, that there has been a mistake, that they cannot understand what all the fuss is about, and so on.

### **The value of denial and the limits to it**

**(i) Denial in Hospital.** Unconscious and conscious denial may be used very early on by parents who have a baby in the Special Care Baby Unit (SCBU), and this can be supported by medical and nursing staff to enable bonding to take place. Both can also be used by staff themselves to enable them to work in this very emotionally and professionally challenging environment. In my experience only a small proportion of families opt to put up their child for fostering or adoption at this stage. The remainder of parents will do one or other of the

- a. Deny that the medical staff are correct in their assessment of their child's degree of impairment: *'The doctor told us she would never walk and talk but we know she will.'*
- b. Deny the effect that parenting a child with the impairment will have on their lives: *'It doesn't matter to us what we have to do, we are her parents and we will manage, no matter what it takes.'*

These two very different approaches have the same desired outcome: the family take the child home.

Difficulties can arise at this early stage when professionals are not sure, or do not check, which method the parents are using. There can then be conflicting 'supporting of denial'. When my son was in the SCBU, the doctors told us they could not tell us exactly the degree of impairment he would have, but that he *would* be impaired. They had correctly inferred from discussion that we were taking approach 'b' above. The nursing staff, on the other hand, kept falsely reassuring us that they had seen *'far floppier babies than this who went on to be fine'*. They were either assuming we were adopting approach 'a' or, for their own personal wellbeing or some other reason, were denying to themselves that this baby was going to have serious impairment.

These different responses left us feeling very confused, not knowing how our son would be. We eventually decided that the nursing staff's approach was the 'right' one. We were therefore moved away from a realistic assessment of our child, by which we could have received early support in considering what impact his impairment would have on our lives. Instead we colluded with the nursing staff's denial. Perhaps this denial was their way of ensuring we did not reject our son, but whatever the real reasons were behind their behaviour, it did prevent us from accessing support which could have helped us better to recover from the trauma of his birth.

***The essay continues after the Table***

**Table: Coping Mechanisms**

<b>Over-optimism</b>		
<b>Characteristics / How parent presents</b>	<b>Value to Parent</b>	<b>Potential Drawbacks</b>
<p>Belief that <i>'everything will be alright in the end'</i> – either because child will improve anyway or a cure will be found.</p> <p>Links to denial.</p>	<p>Allows parent not to look ahead to realistic future – reduces anxiety.</p> <p>Reduces anguish of facing up to immediate reality.</p> <p>Gives hope of 'cure'.</p> <p>Can enable parent to seek interventions which improve child's functioning.</p>	<p>Can become 'Martyrdom' if crusade for cure / interventions overtakes family functioning.</p> <p>Can also be a barrier to a parent accessing interventions for child as <i>'he won't need learning support because he'll soon catch up'</i></p> <p><b>or</b></p> <p>Can lead parent to seek support that will not make a difference – unable to believe that child will not make progress.</p> <p>Disappointment / depression if 'cure' fails to materialise.</p>

<b>Over-pessimism</b>		
<b>Characteristics / How parent presents</b>	<b>Value to Parent</b>	<b>Potential Drawbacks</b>
<p>Parent apparently unable / unwilling to see anything positive about child's progress.</p>	<p>Can be parent's attempt to get people to understand that, no matter what progress the child makes, they are mourning the child they 'should' have had – and are always comparing him or her to typically developing child of same age.</p> <p>Often a response to professionals' over-optimism – parent feels they are the only person who is realistic about child's real abilities.</p> <p>Misguidedly, parents feel that if they think the worst anything else will be a bonus.</p>	<p>Constant anxiety about the child's progress.</p> <p>Depression when they are 'right' and things do not turn out well – underneath they have always hoped they are wrong.</p>

<b>Martyrdom</b>		
<b>Characteristics / How parent presents</b>	<b>Value to parent</b>	<b>Potential drawbacks</b>
<p>Parent believes they have been 'chosen' to parent a 'special' child or may feel guilty that they have let the child down, especially if there is a genetic cause – and therefore they must do everything they can to 'make it up' to the child.</p> <p>Parent may believe there is virtue in 'coping'.</p> <p>Focuses on disabled child to the exclusion of self and other family members.</p>	<p>This role is supported by society in general and reinforced by media coverage about '<i>wonderful, amazing</i>' parents – parents are praised for it.</p> <p>Gives parent real sense of worth and purpose, may 'fit' with their faith and so feels very rewarding.</p> <p>Can assuage feelings of guilt the parent might have about the child and their real feelings towards them – which might be ambivalent or they might not value the child at all.</p>	<p>The parent cannot believe that anyone else can care for their child as well as they can – leading to them refusing support services.</p> <p>The child may suffer because the parent becomes too exhausted to maintain standards of care.</p> <p>The parent 'burns out' / reaches crisis point and the child may have to go into residential care in the long term.</p> <p>The family becomes dysfunctional as partner and siblings are not given attention – relationship breaks down.</p> <p>Lack of care for self results in poor health – physical and emotional.</p>

<b>Self-harm</b>		
<b>Characteristics / How parent presents</b>	<b>Value to Parent</b>	<b>Potential Drawbacks</b>
<p>Eating disorders.</p> <p>Cutting / hitting / burning self.</p> <p>Alcohol abuse.</p> <p>Drug abuse.</p> <p>Self-neglect.</p>	<p>Eating as a replacement for having emotional needs met – comfort.</p> <p>Not eating, dieting, as a way of regaining some control over life that feels out of control.</p> <p>Inflicting physical pain on self as a way to express anger at a situation when there is no-one to blame, or to feel some relief from build-up of tension by cutting self.</p> <p>Drugs and alcohol, etc. provide temporary escape from reality, they numb pain.</p>	<p>Damaging to parent's self-image, vicious spiral of weight gain, self-loathing and eating for comfort.</p> <p>Development of anorexia / bulimia with associated health risks.</p> <p>Physical injury, impact on family seeing this behaviour.</p> <p>Accidental suicide (rare).</p> <p>Overdependence, misuse and associated health risks. Damaging to self and family.</p>

<b>Grief State</b>		
<b>Characteristics / How parent presents</b>	<b>Value to parent</b>	<b>Potential drawbacks</b>
<p>'Chronic sorrow' characterizes the emotional life of many parents of children &amp; young people with special needs. Some families struggle to move through the intense feelings of sadness and grief, and these feelings appear to take over their life. The apparent permanence of their 'grief state' may be linked to a lack of acknowledgement from others at crucial times (birth, diagnosis, etc.) of the trauma, shock, despair, fear, etc. that the parent feels. Some children &amp; young people have numerous hospital admissions, investigations and procedures throughout their early years. The cumulative effect of this can be to increase disruption and trauma for the family.</p>	<p>Avoiding planning for the future, avoiding decision-making, parent may access some support with practical aspects, can avoid other aspects of life that need some attention, making sense of what has happened – <i>'my whole life is dreadful because...'</i></p>	<p>Parent may struggle to adjust and adapt to the reality of their life – may be unable to support child or other family members effectively – cannot get past own feelings.</p> <p>May develop depression.</p>

<b>Anger</b>		
<b>Characteristics / How parent presents</b>	<b>Value to Parent</b>	<b>Potential Drawbacks</b>
<p>Fury at everyone and everything. Depending on a helper's own feelings about the expression of anger, this can be difficult to work with – particularly if the anger is taken personally.</p>	<p>Expressing anger can be energising and active, helps the parent feel 'in control'.</p> <p>Can channel anger into lobbying for improvements in services, setting up support groups, etc.</p>	<p>Parent can gain control and manipulate situations which may not be in the best interests of them or their child.</p> <p>Parent can alienate supporters by constantly presenting as furious.</p> <p>May use anger inappropriately – against family members and/or disabled child.</p> <p>May turn anger inward – leading to depression.</p>

Difficulties will continue to arise, and can be compounded if professionals fail to check what parents are thinking and feeling at each meeting or appointment. An example of this failure was reported to me by a professional who said she was most upset about a parent of a baby with Down's Syndrome who had complained about her. The mother's complaint was that, even though she was not coping at all well, the professional had not asked how she was during that morning's visit. The professional was genuinely bewildered because in a conversation three weeks previously the mother had told her she was 'fine'. My own levels of coping are very fluid and, often, my only consistency is my inconsistency! How I am feeling and coping at any given moment can be literally that; an hour of feeling genuinely OK, or in conscious denial but presenting as well-adjusted to my situation, followed later in the day by feelings of sadness, grief, guilt or whatever other emotion has surfaced into my consciousness. It is therefore vital for the helping relationship that assumptions are not made based on previous encounters with a parent.

**(ii) Denial once the baby goes home.** Once home with their baby, some parents will continue to be in unconscious denial, whilst others will begin the process of adapting to and acknowledging their child's impairment, and will start to seek support and information. Those parents continuing to use denial may still be traumatised by the birth and the diagnosis or by the fact of their child's difference to the child they were expecting. Denial gives them space to concentrate on the positive aspects of the baby and to get used to being parents. (Second or subsequent babies may challenge this coping mechanism more than first-borns, as the parents are faced with comparisons to their previous experiences. Professionals may try to support these experienced parents by reassuring them that all babies are different and suggesting they should not make comparisons between siblings – a strategy which may not be successful).

Difficulties can arise now if each parent (if there are two), extended family, friends and professionals use conflicting coping mechanisms. For instance, a mother who is starting to adapt and acknowledge can feel extremely isolated in trying to access interventions for her baby, if her partner, parents

and friends are seeking to maintain their own, equally necessary, coping mechanism of behaving as though the baby has no problems and, therefore, resisting or questioning any interventions being sought. One mother told me how distressing it was when her own mother kept insisting that her 9-month-old son should be sitting up. The baby had Down's Syndrome but the grandmother kept telling the mother not to say 'those words': *'There is nothing wrong with him, other than you not being a good enough mother.'*

My own husband tells me that his steadfastness throughout many years of unconscious denial, no matter what evidence was put before him, was due to a deluded but absolutely genuine belief that he was going to wake up one day and our son would be eighteen and cured – not just a bit better, but actually completely without impairment. He and I now recognise that those working with us should have challenged him, but as we had no key worker, there was no one to get close enough to him to know what was going on.

As I took on the role of 'doing it all' in response to his lack of engagement, I spared him the need to get more involved in interventions and appointments which may have challenged his views. Thus, unwittingly, I was supporting what was for the rest of the family a very damaging coping mechanism in which he refused to carry out such tasks as feeding our son because he found it too upsetting. He could not set his own needs aside to do what myself and our sons needed from him.

Another example of what this meant in practical terms is that he carried our son for many years, even though he was using a wheelchair. My husband could not acknowledge he needed it. He believed that to carry our son was preferable and made him look more 'normal'. Being left to continue this coping mechanism has, of course, had a detrimental effect on my husband too. He did not get the support he needed around his grief and loss because he was allowed not to engage in any depth with professionals. This support would have enabled him to be more supportive to me and our sons. We are still working through all of this as a family and it is extremely painful for us, but at last my husband can see what effect his coping mechanism has had on us and has changed his behaviour. However, it would have been far better if he had

been supported in making these shifts sooner.

The professional who, for whatever reason, is using denial but is not aware of it can also be very damaging to parents. Once I had to remind a professional how distressing it is for a parent to have a baby who needs to be fed by a nasogastric tube. The professional told me angrily that she could not understand why that particular mother was so upset since *'loads of babies leave here tube-fed!*. That attitude seriously added to the parent's distress. The professional in this anecdote appeared, in order to maintain her own ability to work in a particularly stressful setting, to be denying how abnormal it is for a parent not to be able to orally feed their beloved baby. Rather than acknowledging that it was no longer an emotionally healthy place for her to work, or recognising that she was using denial, she took her own feelings of helplessness and sadness out on the parents and on me. This example illustrates why self-awareness and the effective provision and use of supervision are both absolutely vital for staff working in these stressful situations.

**(iii) Babies who are terminally ill.** Where a baby is not expected to live beyond infancy, parents are even more likely to maintain denial to give themselves the space they need to acknowledge, adapt and adjust as best they can to the horror of the situation. An example: When my own son was first born we were told he would die within the first two to four days. Later that day, when my husband had gone home to tell our families, I persuaded myself that I had not actually given birth and, when alone, talked 'in my head' about having to go to hospital soon to be induced. This extreme form of denial, which is known as disassociation, gave me a break from sobbing (which I had been doing for about twelve hours since we were told) and calmed me down so that I could then switch back to the awful reality. I was so grateful to have that delusional break which, although it is disturbing to recall, I can now appreciate as the human spirit's ability to cope with a horrendous situation. My son did in fact survive, but those days when we thought he would not, when we planned his funeral and made plans for life without him, are etched in our memories to this day, nineteen years on.

Families of terminally ill babies and young

children need times when they can escape from their reality. Denial can be an effective and appropriate response which, as long as it is not detrimental to the baby's care, can be supported by those around. What must be clear is that everyone in the team around that family, and indeed around any family of a disabled child, must have a shared understanding of the coping mechanisms being used, and of what the benefits are to the family at that time. It is also essential for everyone working with them to examine how they themselves are coping as they support the family.

### **How can helpers support the appropriate use of conscious denial by parents?**

When a parent is using conscious denial as a way of coping, for example, by choosing not to think about or be overwhelmed by their situation, by setting it aside in order to enjoy some distracting leisure activity, or by accessing education or employment, and is keeping well, then I believe this should be supported, as long as they are accessing the support their child needs. This can be a really healthy way of coping as long as they are not suppressing or repressing emotions, use opportunities to express their feelings in an appropriate way and allow themselves to feel sad, angry, etc. when they need to. After all, what can a family gain, other than acute anxiety, by constantly thinking, planning and agonising over the current issues or possible future outcomes for their child?

When a helper identifies that a parent is using conscious denial they can support them by using such phrases as: *'Last time I was here we talked about her transfer to school. Are you able to / would you like to / shall we continue that conversation today, or do you want to leave it until another day?'* This reminds the parent that they have been able to talk about a particular topic before, but does not make any judgement about the fact that today they may or may not be able to continue that conversation. This approach recognises the inconsistency of a parent's feelings about their situation. It allows the parent to stop and consider how they are feeling about the topic and it expresses permission for them not to discuss it – permission to use conscious denial.

When parents at a particular time are unable to access conscious denial for themselves and may be feeling pain, bitterness, anger, helplessness or some other difficult emotion, they may be



unable to be enthusiastic about something they have previously been very keen to access. To an inexperienced helper, or indeed to other members of the family or friends, this can be bewildering. For instance, a parent who has previously completed Disability Living Allowance forms, apparently having adapted and adjusted to their child's difficulties, may be distraught on the day they get the award. Another parent may feel on one day genuinely thrilled that their child's mobility has been enhanced by them getting an electric wheelchair, while on another day, just the sight of their child in the chair is enough to have them weeping on the floor.

These seesawing emotions add to the huge amounts of stress that parents suffer, and are a reminder that helpers should be cautious in their enthusiasm about some newly-acquired service or equipment for a child in front of parents. On a difficult day, the arrival of some 'good' news can be the most painful reminder for the parent of what the child cannot do. The approach in these situations is to take the lead from the parent, asking them how they feel about the arrival of the service or equipment. This allows the helper to join in the celebration, if that is how the parent is reacting, or to commiserate if the parent is obviously saddened or upset by the event. Helpers need to be aware that, in front of the child, the parent might show a different response to how they really feel and that, if there are two parents and siblings, each will have their own emotions and feelings, perhaps leading to conflicting responses that need to be managed.

### **What about when conscious or unconscious denial needs to be challenged?**

Sometimes it happens that a parent is using conscious denial in a very healthy and positive way, but helpers feel that, in the best interests of the child and/or the other children in the family, a particular issue that the parent does not feel ready to tackle, must be addressed. This requires the helper to explain to the parent that they understand why the parent has a need to live from day to day, and then to describe why, on this occasion, they need to look at something which may be painful to them. The helper must now work with the parent to identify what support they might need to enable them to tackle the issue. Whatever the issue is, for

example, surgery the child needs or a new intervention, such as a communication programme, that the parent is being asked to implement, it might be helpful for the parent to talk to another parent who has been through a similar situation. Or it might be that counselling or art therapy can help the parent to deal with their feelings.

When professionals identify continuing unconscious denial in a parent who persists in genuinely feeling that their view is real regardless of every piece of evidence to the contrary, they must challenge them in an extremely sensitive and supportive way. The helpers involved need to come to a shared view about why the challenge should be made, asking themselves how the parent benefits by the denial, what benefits the challenge will bring, if the denial is detrimental to the child's wellbeing, and whether the denial is damaging to the parent or an understandable reaction to an unacceptable situation that is too awful to deal with in any other way. If everyone is clear that the challenge is necessary, there must be consideration of how best to support the parent to 'let go' of the denial without them adopting something that could be equally as damaging, such as self-harm. A parent might need medication and/or counselling to enable them to begin to acknowledge, adjust and adapt to their situation.

### **A note of caution to helpers about the use of the word 'accept'**

In my experience, some professionals use such phrases as: *'If parents could just accept that their child is disabled, everything would be much easier.'* I would suggest that helpers should be cautious of the word 'accept'. The Oxford English Dictionary defines it as follows:

1. Consent to receive or undertake something offered.
2. Believe to be valid or correct.
3. Take on responsibility or liability for.
4. Tolerate or submit to something undesirable.

The problem is that the most commonly understood definition is the first one. However, most parents of disabled children would not see themselves as ever 'consenting to receive' being

disabled or having an impairment on behalf of their child, themselves or their family. 'Acknowledge', 'adjust' and 'adapt' are better words to describe the processes that parents go through. Parenting a sick or disabled child can be an ongoing traumatic experience. These are not processes that parents have to go through only once. No sooner have they acknowledged they have a sick baby, they then have to get used to having a toddler who has special needs, adjust to having a child who is disabled, adapt to life with a teenager who is disabled and so on. It is therefore most unhelpful for professionals to assume that, because a parent has made an initial adjustment to their circumstances, they have really come to terms with the lifelong implications.

### **Professionals' use of denial**

What about the helping professionals' use of denial? As explained above, denial, when it is used consciously, can be a really helpful way of coping with an emotionally demanding role. Problems can arise when workers lack the self-awareness to see when they are using denial themselves. For instance, a helper might not perceive his own denial of the emotional or practical impact the child's impairment is having on the family, and that this denial prevents him from empathising with parents. Comparisons with children '*much worse than yours*' are not at all helpful to families. Whilst parents themselves might have a hierarchy of 'awfulness' (I have always been relieved that my son did not go on to develop the seizures that were predicted) it is rarely effective for professionals to imply that parents should be grateful that their child is not as 'bad' as others they work with.

### **Summary**

Parents, extended family, friends and professionals use a variety of coping mechanisms in their lives with disabled babies and children. One of the most helpful, but seemingly least understood and most maligned, is denial. It is essential that parents are supported to adopt coping mechanisms or strategies which are healthiest for them and their child. Professionals need to be extremely self-aware and use supervision and support to ensure that they do not adopt coping

mechanisms that are detrimental to their effective relationships with parents. Professionals must understand why parents use the strategies they do, and work in a supportive and compassionate way to move them to those which do least harm. They must be absolutely clear about their responsibility not to support strategies that might be working for the parents but which are detrimental to the wellbeing of the disabled child or other children in the family.

### **References**

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