



www.learninglinks.org.au

Information Sheet 65

The importance of hope

By Rebecca Dudding, Social Worker, Learning Links

Hope is the belief that future good is possible (DePalo, 2009). It is the desire for something good and the expectation of obtaining it. But does hope make a difference?

This article will outline the importance of hope to families who have a child with a disability. It will also outline how hope and hopelessness can be experienced at the same time and are not mutually exclusive and look at the role of grief in helping parents create new dreams and hopes for the future.

It will then look at how hope and hopelessness exist in our relationships with others and in what we feel, think and do. It will end with some helpful tips on how to hold onto hope.

When we look at the experience of families raising a child with a disability there is a large body of research which has found that hope is an important and strong predictor of coping well (Kausser et al, 2003).

Hope has a profound impact on a family's ability to raise a child with a disability.

Research also found that high hope individuals do better at problem solving, at managing challenging situations, at coping with illness and

disability and they feel and think more positively than those with lower hope (Weingarten, cited in Flaskas et al, 2007).

The experience of having a child with a disability can bring with it equal extremes of hope and hopelessness, courage and resilience as well as great pain and an ongoing deep sense of hopelessness which may or may not stay over time (Flaskas et al, 2007). These feelings of hope and hopelessness may be present at the same time, particularly when parents experience grief.

Many parents may not relate to the word 'grief'. Grief is simply our reaction to loss.

Parents attach to their children through dreams, fantasies, illusions and projections into the future. Disability dashes these dreams and parents may experience a loss as they separate and let go of the child they dreamed of and generate new dreams (Moses, 1987).

When separating from the lost dream parents move through the grieving states of denial, anxiety, fear, guilt, depression and anger. As parents allow themselves to grieve and experience these emotions it creates the space to start making changes, to start hoping again in the face of loss and reattach to new dreams of the future for their children (Moses 1987).

Some parents resist the grieving process because they feel that it is not acceptable – in doing so, they can get stuck and start to feel hopeless.

Another idea about hope and hopelessness is that they exist in relationships with others. Hope and hopelessness don't exist in a vacuum – our social context inevitably influences the hope and hopelessness that we experience.

Research has found that hope is strengthened by external relationships with friends, family and services

(Kausser et al, 2003).

Hope can be seen as something that we 'do' with others. This way, hope becomes more achievable, rather than expecting yourself to summon up hope on your own when you may be feeling quite the opposite (Flaskas, 2007).

In order to 'do' hope with others, families need to resist the temptation to withdraw and isolate themselves. This is no easy task – just as our relationships with others can inspire and hold hope, they can equally instil hopelessness.

Parents may find that the friends and family who they thought would be supportive are not the best people to share with. It may not be as easy as parents thought to find people that know how to support them and instil hope. Despite this, parents are encouraged to risk sharing their journey and to find people who can be supportive. This may be through friends and family members; they may also consider a counsellor or a therapist.

EMBRACING THE DREAMS OF FAMILIES FOR THEIR CHILDREN

About us

Learning Links is a charity and non-profit children's learning organisation formed in 1972 by parents and professionals to help children with disabilities and learning support needs.

Our vision is of a community where all children and families have equal access to learning opportunities and quality support.

Our services

Children under 6

- Early childhood intervention for babies, toddlers and preschoolers with a disability or developmental delay.
- Assisting children with disabilities to transition to school.
- Speech therapy, occupational therapy and physiotherapy.
- Mobile toy library service.
- An inclusive preschool.
- FREE story time sessions at Fairfield Library.

Children attending school

- Specialist assessments to determine your child's educational needs.
- Reading and maths support for children who are falling behind at school.
- Speech therapy and occupational therapy.
- Social skills and anxiety management groups.
- Transition to school groups.
- Counselling.

Parents, carers and families

- Case management services.
- Support to families who have just received a diagnosis of a disability for their child.
- Programs to help parents support their child's communication.
- A range of programs to develop parenting skills.
- Support groups for carers of children with a disability, developmental delay or chronic medical condition (MyTime).
- FREE program for parents living in Cabramatta on how to tutor children of preschool age (HIPPPY).

Workshops

Learning Links also delivers workshops for parents, carers and professionals working with children on a range of topic areas including ADHD, autism, behaviour, child development, children's learning, children's wellbeing, communication, counselling and fine motor skills.

Learning Links has services at various locations around Sydney. We also offer some services to children in country NSW, the ACT, and some programs Australia-wide and in New Zealand. A complete list of locations and contact numbers is on the back page.

Learning Links

Head Office

10 Railway Parade
Penshurst NSW 2222
Tel: (02) 8568 8200
Fax: (02) 9580 4788

Email: mail@learninglinks.org.au
Website: www.learninglinks.org.au

Learning Links News occasionally features articles written by people not employed by Learning Links. The views of these writers do not necessarily represent the views of Learning Links. Enquiries regarding this newsletter should be directed to Xiong Luong tel: (02) 8568 8221 or email: xluong@learninglinks.org.au.

© Learning Links 2011. The material in this publication cannot be reproduced without the written permission of Learning Links.



Carers' support groups can also be a great way to meet with other parents who are on a similar journey. This may be a safe place to share with others and find hope.

In our relationships with others, hope may be expressed through our feelings, thoughts and behaviour. Flaskas (2007) gives the example that 'it is possible for people to feel hopeless, but still do hope'. For example, you may feel hopeless but still express hope through your actions by taking your child to see a speech therapist. Where families move easily between these different expressions of hope and hopelessness, they have the potential to build resilience and cope well.

Parents of children with a disability can be at risk of developing fixed patterns of hope and hopelessness. For example one parent may always 'feel' hopeless – that their life is now going to be very difficult and that their child will never learn – but they may be spending more time with their child and 'doing' all they can to support their development, in the hope that it will make a difference. The other parent may 'think' positively that the child will be ok, but may not be 'doing' anything that supports development.

Generally, the study found that mothers were expressive and that fathers internalised their reactions, keeping their feelings on hold and supporting the mother through the crisis. In other words, the mother is reacting and the father is supporting by not expressing.

Both parents are experiencing confusion which results in the risk of decreased communication, lack of understanding and a pulling away from each other (Hammer 1996). This can lead to fixed patterns of hope and hopelessness which can result in further isolation. The idea that hope and hopelessness are divided up between family members through 'doing', 'thinking' and 'feeling' can bring understanding and validity to parents' different reactions and help parents realise that they are both sharing the same experience but having different reactions to this (Flaskas, 2007).

A 1996 study showed that mothers and fathers tend to react to children who have problems differently and in different time frames.

As parents start to connect more and gain a greater understanding of how each other is reacting and coping, these patterns and roles will become less fixed and more flexible.

Hope should be implicit within the relationships that parents form with early intervention professionals, including speech therapists, occupational therapists, physiotherapists, social workers, psychologists and teachers. All these professions are committed to the idea that change and development is possible, and indeed, inevitable.

Professionals and services are in the position to encourage families to have hopes, dreams and a vision for their child's future without taking away from the enormity of the family's pain and loss (Flaskas, 2007). These services have the capacity to help instil and strengthen hope as well as the capacity to instil hopelessness. Parent's interactions with these services can often be challenging.

So how should parents and therapists work together effectively to instil hope?

The following are a few ideas around this and provides a guide for therapists as well as for parents in knowing what to expect and how to engage with services.

- When working with therapists it is helpful for parents to see themselves as part of a team that is working to support their child's development. Some ways to do this are to encourage the early intervention workers to communicate together, share goals and be aware of what each other is doing. This can be done by using a communication book that each therapist writes in and/ or organising a meeting with those involved to discuss how things are going and plan for the future.
- The second is to develop goals with the therapists. Hope cannot transform reality all by itself. It needs to be anchored in action in order to become concrete (McGolrick and Heines cited in Flaskas et al, 2007). It is helpful for parents to develop these goals with their children's therapists and to think about short-term goals as well as to start developing a long-term vision of the life you would like your child to have. It is also important that these goals are written down and the steps to achieving them are identified.

- Finally, therapists should be working with parents to build their knowledge base and skills around disability, early intervention and the service system. As parents it is important to ask questions and get therapists to explain what they are doing. As parents feel more knowledgeable and in control they become more hopeful (Hammer 1996). Parents are then also able to be more in control of planning for their child's future and more involved in the decision making process for their child's life which creates hope.

As families start to find hope and create new visions and dreams for their child's future it may be helpful to remember that periods of hopelessness are likely to resurface.

Key transition times may be hard, whether this is your child starting school, starting with a new service, when your child becomes aware of their disability, birthdays or family occasions. At these times it is important to give yourself permission to experience your emotions, have realistic expectations of yourself, share experiences with people you trust and keep active.

While you may be feeling hopeless at times, it is helpful to think of the ways that you are 'doing' hope, such as supporting your child's development through activities and intervention or 'thinking' hopefully, such as holding on to the belief that they will have a good life.

Some support services for you and your family

- Carers NSW: Telephone support, provides information, referral and emotional support. This is a free service.
www.carersnsw.asn.au
1800 242 636.
- MyTime: Local support groups for parents and carers of young children with a disability or chronic medical condition.
www.mytime.net.au
1800 889 997
mytime@parentingrc.org.au
- Learning Links: Case Management, Diagnosis Support, Counselling and Parenting Groups, Mt Pritchard 9426 4300 and Peakhurst 8525 8222.
- Autism Advisory and Support Service: Run by parent volunteers who have a child with Autism, information and carers support groups.
www.aass.org.au
9601 2844 or 0432 327 096.

- Livewire: Online communities for families affected by serious illness, chronic health condition or disability
www.livewire.org.au
- For a referral to a local counsellor or psychologist speak with your GP.
- Remember that you can also speak with your existing early intervention therapists about joining a supported playgroup where you can meet other mothers with children with extra needs.

References

- DePalo, R. (2009). The role of hope and spirituality on the road to recovery: traumatic brain injury post-traumatic stress disorder: part five. *The Exceptional Parent*.
- Flaskas, C. McCarthy, I., & Sheehan, J. (Eds.). (2007). *Hope and despair in narrative and family therapy: Adversity, forgiveness and reconciliation*. London: Routledge.
- Flaskas, C. (2007). Holding hope and hopelessness: Therapeutic engagements with the balance of hope. *Journal of Family Therapy*, 29, pp.186-202.
- Hammer, E. (1996). Anticipatory guidance for parents of children with disabilities: What happens to families when a child has chronic problems? *Infant Mental Health Advocacy Conference: Birth to 3... The Critical Years*, Baylor University, Hankamer, Waco, Texas.
- Kausar, S., Jevne, R.F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities*, 10(1), pp.35-46.
- Moses, K. (1987). The impact of childhood disability: the parents struggle. *WAYS magazine*. Re-printed on <http://www.pediatricservices.com/prof/prof-15.htm> last modified March, 7, 2010.



Head Office

10 Railway Parade
Penshurst NSW 2222
Telephone: (02) 8568 8200
Facsimile: (02) 9580 4788
Email: mail@learninglinks.org.au

Maroubra

3rd Floor, Bowen Library
669-673 Anzac Parade
Maroubra Junction NSW 2035
Telephone: (02) 9349 4963
Facsimile: (02) 9349 7193
Email: maroubra@learninglinks.org.au

Mount Pritchard

Level 1, 46B Reservoir Road
Mt Pritchard NSW 2170
Telephone: (02) 9426 4300
Facsimile: (02) 9601 0058
Email: mtpritchard@learninglinks.org.au

Early Education and Care

SL, 201 Elizabeth Street
Sydney NSW 2000
Telephone: (02) 9261 8655
Facsimile: (02) 9283 0605
Email: earlyeducationandcare@learninglinks.org.au

Peakhurst

12-14 Pindari Road
Peakhurst NSW 2210
Telephone: (02) 8525 8222
Facsimile: (02) 9584 2054
Email: peakhurst@learninglinks.org.au