

Supporting fathers who have a child with a disability: The development of a new parenting program

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Abstract: *Fathers of children with a disability report both in Australia and elsewhere that they feel marginalised from communication about, and the design and implementation of, formal support for their children. They also report having few if any avenues via which they can receive support and share and discuss their concerns about the disability of their children. This article describes a new groupwork program to fill this gap – to engage and support such fathers and to complement existing support services: Hey, Dad! For fathers who have a child with a disability. Findings from an initial evaluation of a pilot of the program involving 83 fathers are also described.*

*Copies of the full evaluation report are available from:
Groupwork Solutions info@groupworksolutions.com.au*

Key words: *psychoeducational parenting program; fathers; children with a disability; 'Hey, Dad!' Program; evaluation; pilot program*

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Introduction

In 2006, Centacare Broken Bay and Uniting Care Burnside, received funding from the Australian Government Department of Family and Community Services and Indigenous Affairs (FaCSIA), to develop a new parenting program for fathers who have a child with a disability.

The program, *Hey, Dad! For fathers who have a child with a disability*, builds on workshops that Burnside has facilitated since 1998, and is designed to be delivered to groups of fathers of children with a disability using a series of workshops. An activity session involving fathers and their children is also recommended as part of the overall program. Program delivery strategies and content are set out in the *Hey, Dad! Manual*. This article describes the development of the Manual, *Hey, Dad! For fathers who have a child with a disability*, by a partnership between UnitingCare Burnside, Centacare Broken Bay, The Spastic Centre and Lifestart, as well as the evaluation of its piloting.¹

Fathers and parenting

To inform the development of the new program, a scoping study identified relevant research (Sharp et al, 2006). The study summarises American research which found that:

- When children are raised by engaged fathers, the children are more likely to have stronger coping and adaptation skills, [have] better problem-solving skills, stay in school longer, achieve better at school, [and] have longer-lasting relationships, higher work productivity, better self esteem and better control of actions, and
- Engaged fathers are more likely to have better overall health, higher self esteem, more positive self image and greater work satisfaction (Children's Trust Fund, 2004, cited in Sharp *et al.*, 2006).

Another study of 60 sets of parents of a child with severe intellectual disability assessed the extent of father involvement in the lives of their children, and both parents' satisfaction with this involvement. The study found that the fathers were most involved in playing, nurturing,

1. The program is available for purchase from info@ifp.nsw.edu.au

discipline and deciding on services. Most mothers were satisfied with the extent of fathers' help and higher levels of satisfaction were related to higher marital adjustment and lower child-rearing burden. This study reinforced the importance of including fathers in programs for families of children with a disability (Simmerman, Blacher, & Baker, 2001, cited in Sharp *et al.*, 2006).

A study of 53 mothers and 25 fathers of children with disabilities, utilising the Parenting Stress Index, found that both mothers and fathers have elevated levels of stress when compared to parents of children without disabilities. The study concludes that stress management should be addressed within therapy programs, and that programs be tailored to meet the needs of both fathers and mothers (Esdaile & Greenwood, 2003, as cited in Sharp *et al.*, 2006).

Hornby reviewed existing accounts of fathers' experiences of parenting children with disabilities. Issues identified by fathers included:

- feelings of self-blame;
- denial of the extent of the disability;
- effects on their marriages;
- uncertainty over their children's diagnoses;
- the constant strains of caring;
- restrictions on family life;
- difficulty telling other people about the disability;
- feeling guilty about having negative feelings about their child;
- negative experiences of service provision, and
- negative reactions in the community (Hornby, 1992, cited in Sharp *et al.*, 2006)

These fathers also reported benefit from meeting other families in similar situations (Hornby 1992, cited in Sharp *et al.*, 2006).

Forty-eight fathers of children with chronic illnesses completed the Family Perception Inventory and identified their concerns which included worries about the child's health (98% of fathers), feeling worn out (73%), doing enough family activities together (96%), making the family comfortable and happy (94%), the responsibility of caring for the family (81%), and extra demands on time (88%) (Hovey 2005, cited in Sharp *et al.*, 2006).

The isolation of fathers of children with a disability

Because of the stresses identified, the literature supported the provision of services to parents of children with a disability. However testimonies of British fathers of children with a disability in the 2007 publication, *Different Dads – Fathers’ Stories of Parenting Disabled Children* (Harrison et al, 2007), as well as stakeholders’ comments to the *Hey, Dad!* pilot evaluation, show that fathers continue to experience difficulties finding, accessing or receiving support particular to their needs. Common themes raised by fathers include:

- current health and community service systems for children with a disability focus heavily on mothers;
- fathers have difficulty participating because of work commitments, with most services not geared to after-hour or weekend support;
- fathers often feel excluded and report that, even when they are present, workers may still direct their communications to the mother;
- men find it difficult to speak openly and freely about their feelings and concerns;
- fathers of children with a disability have few confidantes with whom they can discuss the issues which arise for their child, their family and themselves. A common experience is that former friends fall away;
- fathers often therefore feel cut-off from services, friends and the community;
- many fathers find it difficult to speak openly about their worries and fears when their wives are present, and
- many men find it difficult to seek help or to attend their first support group.

The following reflection, by one of the fathers involved in the development of the *Hey, Dad!* Program, illustrates how men worry about their children’s well-being and about their parenting role and responsibility:

The single greatest challenge I faced as a father to a child with a disability was trying to accept the reality that I cannot ‘fix’ the ‘problem’. All parents wish to

shield their children from all harm in the world, but parents (and particularly fathers) feel like they have 'failed' to live up to this.

The feeling is: 'Not only does my child have a disability, but I'm useless, helpless, etc because I could not stop it and now I can't do anything to fix it either'.

There was nothing more painful in my life than watching my child have seizures in my arms and being completely helpless to do anything at all about them. It was not until I had professional counselling that I could focus on something other than blaming myself and acknowledge that my daughter wasn't blaming me either, nor holding it against me, that these things were happening to her (King & Coleman, 2007).

The Hey Dad! For fathers who have a child with a disability Program

The *Hey Dad! For fathers who have a child with a disability* program is a parenting groupwork program for fathers of children with a physical, emotional or developmental disability. It utilises strength-based practice focusing on building stronger connections between each father and his children and also between each father and mother. A supporting manual provides resources for two groupwork formats: *Dads and Kids Activity Sessions* plus *12 Dads' Workshops*.

The range of session content allows facilitators to possibly provide 18 months of program material, depending upon the timing of sessions. It is designed for fathers to be involved in selecting the issues most relevant to them. The program aims to support men who have a child with a disability and increases their self confidence, self esteem and parenting skills. It also reduces their and their family's isolation, promotes the important role fathers play in their family, and provides an opportunity for fathers and children to share experiences and build stronger connections.

The program strongly reinforces individual and family strengths, incorporating resources to deepen and further develop parenting skills and to foster self development, problem-solving, stress management, assertiveness and communication. It also provides support, advice and information about child development, child-care skills and community resources and allows for discussion and sharing of fathers' experiences.

Men are assisted to develop their own strategies to work more effectively with their partners in caring for the complex needs of their children.

Overview of the Dads and Kids Activity Sessions

The 'Dads and Kids Activity Sessions' are designed to build stronger connections between the dads and their children. It allows men to observe the usual type of program their child experiences during the week when they may be at work.

A number of activities are provided as a guide to assist them to plan two-hour Activity Sessions. Suggestions are provided about which activities would best suit children with particular physical, developmental, communication, sensory or other needs, by age.

Overview of the 'Dads Workshops'

The 'Dads' Workshops' provide 12 workshop-style sessions that can be used over a long period of time to promote discussion about issues that are relevant for fathers who care for a child with a disability. While this program is designed with 12 sessions, it has not been developed with the intention that the sessions will be used in a consecutive order. Priority is given to allowing fathers to choose the workshops that interest them and are most relevant. This program provides a unique opportunity for fathers to share their stories, connect with other fathers and explore ideas about caring for their child. It addresses the issue of isolation that many men face when they are caring for a child with a disability.

Fathers usually have the role in their family of 'fixing' things. Many fathers feel a sense of failure or hopelessness when they feel that they can't 'fix' the condition that challenges their child. This common issue is addressed and discussed in this program.

For many fathers, joining a group with others who share similar issues and concerns takes a good deal of courage. In the early years of their child's life this may represent an acknowledgment that they are part of a group with a label – 'father of a child with a disability' – and for many this is extremely confronting. The program is designed to gently build confidence through support, information and discussion.

The aim of the 'Dads' Workshops' is to build connections between participants so that they develop supportive relationships and are able

to normalise their own emotions and reactions to the challenges they face. Fathers and other significant family members are also assisted to regain a sense of control in their lives.

The workshop sessions were described as follows:

- *Connecting with other fathers – talking about what guys talk about least!*
Fathering today is very different to how you were fathered. This workshop will allow men to discuss with other fathers issues that impact on families where children have disabilities and to identify commonly shared experiences and feelings.
- *Working in partnership with service providers*
This workshop will explore how men can build better partnerships with the service providers who support their child or children with their disability. There will be an opportunity to share information about local resources and how the best communication for effective partnerships can be maintained.
- *Juggling the needs of your family, work and your own needs*
This workshop will explore how men juggle the challenge of balancing their family needs whilst maintaining their employment. The range of needs that a father has to manage will be discussed, as will strategies to assist fathers to effectively balance these commitments.
- *Balancing the needs of other family members*
This workshop will acknowledge the impact of a child's disability on siblings and other family members. Fathers will have the opportunity to reflect on how their child's disability impacts on brothers and sisters and also other significant family members. Ways that fathers can best support all family members in order to build and maintain strong family relationships will be highlighted.
- *Maintaining positive adult relationships*
This workshop will explore the challenges that adult relationships face due to the stress related to having a child with a disability. It explores the relationships that fathers are managing and provides strategies to keep them strong and healthy.

- *My Child and Me*
This workshop will allow men to discuss their experiences of hearing about their child's diagnosis and how the disability impacts on the child and on other family members. Strategies to assist fathers to support their families will be discussed.
- *Managing behaviour*
This workshop provides a practical session for fathers to consider the needs of their children. Strategies, which are age appropriate and considerate of their child's disability, will be discussed to help fathers manage unwanted behaviours.
- *Encouraging your child's emotional growth*
This workshop provides an opportunity for fathers to look at the challenges and limitations that their child may experience in making choices. Fathers will be encouraged to voice any concerns about their child's emotional and behavioural reactions to day-to-day situations. Opportunities to encourage the child's involvement in decision making will be discussed.
- *Building relationships through play and friendships*
This workshop provides an opportunity for fathers to explore the range of challenges faced by their child in building relationships. Ideas about ways to encourage their child through play and to form friendships will be shared.
- *Stress management*
This workshop allows men to identify stress in their daily life and its impact on our bodies, thoughts, feelings and actions. The workshop will offer practical strategies for fathers to manage their stress.
- *Finding your own strengths and solutions*
This workshop acknowledges the strengths already shown by fathers in dealing with issues relating to their child. Strategies to enhance these strengths are identified so that they can be used to find solutions to new challenges that face them, their children and their families.

- *Focusing on the future*
This workshop acknowledges the concerns faced by fathers as their child moves towards adolescence. Some young people will be moving towards greater independence whereas others will need more specialised care that might be located outside the home. The workshop will help fathers develop skills to plan for the future of their child and family.

The program pilot

Twenty-seven workers from 16 services throughout New South Wales were trained to facilitate the *Hey, Dad!* Program in February 2007, with each facilitator and service then committed to trialling at least one activity session and one fathers' workshop by May 2007. This timing was necessary in order for the evaluation feedback to be used to inform the production and publication of the final Manual by July 2007.

Of the 16 planned workshops, 12 *Dads and Kids Activity Sessions* and five *Dads' Workshops* were held in locations throughout New South Wales from Sydney to Casino in the north, Orange in the west and Kiama in the south. A total of 83 fathers attended, with 15 fathers attending both a workshop and an activity session – 98 attendances in all. The Appendix provides an example of the content of a sample session.

The pilot's evaluation

An external evaluation, to determine the extent that the new program engaged fathers and increased their parenting skills, was designed in 2006 and completed between February and June 2007 by Alt Beatty Consulting. The evaluation involved some 157 interactions with stakeholders, including 85 with fathers, via a mix of feedback sheets, interviews and group discussions. Consistent with an action research approach, progressive results were used to inform the implementation of the pilot and revisions to the *Hey, Dad!* Manual.

Engagement results

The motivation of the agencies and facilitators participating

Facilitators reported their major motivator for trialling *Hey, Dad!* was that they were looking for new ways to engage and support fathers of children with a disability.

*I've been looking for a framework to work with dads.
Our parents are requesting this constantly.*

The characteristics of the fathers attending

Information about the characteristics of 62 of the 83 participating fathers was received. Of the 62:

- the majority of participants were Australian born, with one of these fathers identifying as Indigenous. Six were born in non-English speaking countries;
- Australian born men seemed more likely to attend activity sessions or both activity and workshop sessions, than workshop sessions only. Numbers are too small to draw any inferences about the participation of men from other birthplaces;
- those who attended only activity or workshop sessions had an average age of 40, compared to an average of 45 for those who attended both types of session;
- the youngest father was 27 and the oldest 68;
- 50% of fathers had one or two children, with two fathers having nine;
- 50% of their youngest children were aged two or under;
- 92% had their children living with them full-time;
- 87% lived with their spouse/partner;
- 77% of the fathers were employed, 15% were not in the labour force and 5% were unemployed, with these characteristics varying significantly by session location; and
- the employed fathers came from a wide range of occupations and industry groups.

Delivery and participation issues

During the pilot, agencies experienced difficulties finding workshop times suitable to fathers. They reported fathers had very limited free time, having to juggle extensive work and family commitments. They suggested that the targeted families seemed to be more likely to have only one wage earner, which they argued was a result of one parent being extensively involved in the therapy and other support demands of their child with a disability.

Because of these scheduling difficulties, many of the pilot agencies reported re-scheduling sessions after fathers reported unexpected commitments which prevented their planned attendance and that, even with re-scheduling, fewer men than expected attended sessions. However, it was clear that fathers were most likely to attend sessions organised by agencies with whom they already had developed relationships. Further, once fathers attended their first session, most expressed interest in attending or at least hearing about further sessions.

Fathers' session results

Reactions to Hey, Dad! sessions

Almost unanimously, men scored their sessions positively – 98% of the 44 men providing activity session feedback and 100% of the 29 fathers providing workshop feedback scored them as good or very good.

Facilitators' rankings were also favourable, with 81% of 11 activity session facilitators and all of six workshop facilitators ranking their sessions as going well or very well.

... the Hey, Dad! sessions were the best thing I have done for a very long time. Professionally they offer something really worthwhile. Dads connected so well.

Parenting and relationship skills and understanding

Over three-quarters of the men reported that their *Hey, Dad!* participation had improved their parenting skills and helped them to better support their child. Just less than three-quarters said that the

sessions had offered them something new to help their relationship with their children.

One mother commented that she thought the sessions had made her partner have more fun with their daughter. Her partner said:

I am pursuing being more relaxed. I don't know that I have got to where I want to be yet, but I am still working towards it...I found it was a common thing for all of us to want times for ourselves. So now I don't feel as guilty about it...And I am trying different things with my daughter. I think I don't get as frustrated as often as I did before...But I do have to concentrate to put what I learnt into practice...I have tried a few different things since the session. And I think I do feel a bit more at ease with my child, more comfortable.

A number of the men reported that the sessions helped them with their relationships with their partners and to learn new relationship strategies. Some spoke of differences in their and their partners' reactions to the diagnosis of their child's disability and to their attitude afterwards, which impacted on their relationships.

I had a different way of thinking to my wife. I realised that some of the difficulties we went through resulted from me not being prepared for my wife's reaction.

Connections and other benefits

The opportunity to form connections with other fathers, in a group involving only men, was overwhelmingly the aspect of the program most valued by fathers. And overwhelmingly, the fathers expressed relief that other fathers were experiencing similar reactions and feelings, despite their children having often very different abilities or conditions.

[It was] very interesting meeting different fathers with children that have different disabilities but have the same concerns.

[It was] fantastic to meet other dads experiencing similar issues and feelings.

I found the session today very rewarding. It has been the first time that I have been able to interact with other Dads in similar circumstances.

[I liked most the] opportunity to discuss issues as fathers, with fathers only. Having done [another parenting program] I felt that this environment was more useful and I was more open and honest than [when in] an environment in which my wife and other women were present.

They also liked the opportunity, provided by the workshops, to talk about their needs and experiences, reporting that their discovery of common concerns and feelings reinforced them and made them feel “less guilty”.

Perhaps I feel more relaxed and more relieved...That there are other people going through the same thing.

It more reinforced things for me. I think we do pretty well... But it was good to have reinforcement. And it was good that the ideas were slightly different.

I felt this is a very useful way to understand and realise I'm not alone in what I'm going through and it's a great way to get things off my chest.

[What I liked most was] talking about individual situations/experiences; getting an idea of what other fathers are going through.

The men described how seldom, if ever, they had had the opportunity to speak openly and freely, without judgement, about their concerns and reactions in relation to the disability of their child and about their care of their child and other members of their family. They spoke about how significant the absence of confidantes was to them and about how alone they felt on hearing their child's diagnosis and at other times since. They believed that this was common to all new fathers of children with disabilities.

New dads have to realise they are not on their own. We have gone through it already... They will find that some people will shut doors to them and maybe some of their friends won't understand. But other people will understand.

When you first find out you are cast into some bureaucratic process – you go on a waiting list and then you go onto another waiting list. The best thing for new dads...would be to meet other dads.

They also spoke about the importance of good relationships with services and access to good information and resources.

I have realised we have to take care of ourselves. If we can't look after ourself, we can't look after our child, our partner or our family. And I have found we can't do it without external help. That is why it is good to have a place like this to talk, without fear of retribution....The first time I started to feel better was when I started to ask for help.

They particularly felt that *Hey, Dad!* groups and other ways of making contact would significantly help new dads:

I wouldn't say to new dads "Don't worry"...That can't help. Probably the message would be more "Be alert and not alarmed!"

The best thing would be to get people experiencing disability for the first time... There is a silver lining and although it is hard, it can get better.

Conclusion

While there has been a limited roll-out of the new *Hey, Dad!* program to date, the evaluation suggests that the new manual fills a significant gap in the array of programs available to families with children with a disability and that the conduct of *Hey, Dad!* sessions is likely to enhance the parenting and relationship skills and resilience of participating fathers.

Lessons in relation to running the program and engaging fathers from the pilot's evaluation have been incorporated into the final manual with the most significant being that adequate time and resources, as well as appropriately skilled facilitators, must be available for planning, promoting, recruiting fathers, and conducting sessions. *Hey, Dad!* is most effective when it builds on established relationships between fathers and the agencies running the program. Once fathers attend their first session, they will be more interested in attending others. All sessions must be individually tailored to the needs, characteristics and interests of the fathers, and, when they are involved, of their children.

Fathers greatly value speaking to other fathers who have children with a disability, sharing support strategies, and realising the extent of commonality in their experiences and concerns. And finally, the *Hey, Dad!* manual is most effective when it is used as an aid to, rather than a script for, facilitation of sessions – when facilitators complement the material with their own facilitation strengths and experience. It was also recognised that further funding was required to assist a more extensive roll-out of the program, including facilitation costs, as often disability services need external support to implement this program.

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APPENDIX: Abridged sample session: My child and me

1. WELCOME, CHECK-IN AND RECONNECTION

It is important to begin the session by encouraging participants to reconnect with each other. Since some fathers may not have attended the previous session, ask the participants to briefly reintroduce their family and share *one positive thing* and *one challenge* they have experienced as a dad since the group last met. Encourage this process to happen in a relaxed and friendly way that enables dads to choose when they contribute.

2. SHARING THE EXPERIENCE OF DIAGNOSIS

Most dads find the experience of hearing about their child's diagnosis something that is important for them to discuss. For some, this may have been a single event, while for others it may have involved a long process of fitting together pieces of a jigsaw puzzle, perhaps with continuing uncertainty. Some members of the group might have experienced this event some time ago, whereas others might be learning more about the child's condition at the present time.

For many dads, the experience of diagnosis has represented a major change in their lives. The benefit of describing this in the group is that fathers will usually discover that other fathers have had similar feelings about the event or process. Sharing these with others will help to normalise the situation for families. They will realise that they are not alone in how they have felt.

3. WELCOME TO HOLLAND

Read and discuss. This poem is written by a mother who had a child with a disability. Some fathers may feel that it does not portray a father's view of this experience.

- How similar is the story to their life?
- Does this story relate to you as a father?
- What issues highlighted in the story are relevant to parenting children with a disability?
- Does this story relate to other times in your child's and family's life – not just at the time of diagnosis?
- What other metaphors can be used to describe this experience?
e.g. a mystery flight

4. FINDING ACCEPTANCE

For many fathers, hearing that their child has a disability evokes many feelings and they can grieve for the child that they had planned for. This is a natural reaction. But this reaction can also be shrouded with many feelings that may include guilt, anger and sadness. This is an important issue to discuss and allow fathers to connect with others about this experience.

Many dads see themselves as the person who “fixes” things when they don’t go to plan. Dealing with the news of their child’s disability can challenge this view and the role they play in the family. It is important to acknowledge this issue and allow men time to discuss the impact of this.

Write the following words on cards and place them in the centre of the circle. **Discuss** the identified stages of acceptance. Some of the stages are:

- Denial
- Anger
- Bargaining
- Finding new possibilities
- Acceptance

Explain that these stages may be experienced by people at different times and we should not try to rush people through these stages.

Brainstorm ways that fathers have found helpful in acceptance:

- talking to someone else
- valuing the new and special characteristics of their child
- paying attention to the life changes
- doing new things
- working on new roles and relationships

Discuss the usefulness and challenges of each suggestion.

Discuss what do you love and enjoy about your child?

5. WAYS TO BUILD/HELP YOUR CHILD’S SELF-CONFIDENCE

The group leader may find it helpful to ask members of the group to

spend a few moments reflecting on some of the ways they already help to build their child's confidence. (If some fathers have very young children, you may want to ask how they are trying to build the foundations of their child's confidence and how they expect to further build on this in the future.)

The group leader can play an important role in this exercise by providing positive feedback to group members about what they are already doing. This can assist the father's own confidence by re-enforcing the strengths they already have in this area.

On completion of the previous exercise, fathers may find it valuable to have the opportunity to discuss additional ways of building self confidence and self esteem in children.

Ask the group:

- What is self esteem?
- What are some of the challenges in building self esteem in children?
- What are some of the ways parents can build self esteem in children?

6. HELPING YOUR CHILD TO TALK ABOUT THEIR DISABILITY

Use this section if it is appropriate to fathers' children.

Encourage dads to reflect on some of the situations their child may be likely to face, in which they need to let others know about their disability. These situations will be influenced by the nature of the child's disability. Depending on the group, there could be a wide variation in each child's ability to be able to let others know about their disability and what their needs are. It will be important to acknowledge this with the group

***In pairs**, ask the group to come up with a list of situations where their child may need to let others know about their disability and their needs. Ask each pair to share one idea with the group.*

Ask for a volunteer to share a situation in which their child needed to talk to someone about their disability. **Ask** the person if they would like to share with the group how their child was able to do this, what challenges there were for their child, and how they assisted their child. Alternatively, ask fathers to discuss how they assisted their child, in

other ways, to deal with the reactions of others to their disability.

Ask the group the question:

- *How does your child manage to let others know about their needs?*
- *What do you do already to help your child talk to others about his/her disability? (You can provide a role model for your child about how to let others know about what their needs are.)*
- *What are some of the ways in which you as parents describe your child's disability? (You can provide a role model for your child about how to let others know about what their needs are.)*