

# Planning group work programs for parents who have a child with a disability

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#### Effective promotion involves:

- normalising programs by using respected logos
- using action words
- · articulating clear outcomes
- identifying impact of workshop/resource
- emphasising the significance of relationships
- · being strengths based
- providing options choices about involvement
- · describing specifically what is involved
- using metaphors that are familiar.

#### Strategies to help you plan an effective program include:

- identify other workers and agencies who will assist you to plan, promote, conduct or support the program. For example, some parents may need respite to attend. Or, if your agency does not provide activities with the children, then it is recommended that you seek assistance with the planning, conduct and equipping the activities session from agencies who have experience with this context
- identify parents who are willing to help you to plan and promote the session
- meet with mums, dads and other family members or service providers to try to ascertain
  which topics are likely to be of greatest interest and what times and frequencies are
  most likely to suit the most people. (Picking a good time will be critical for parents of
  children with a disability that have extensive work and care commitments)
- recognise in the planning of each session that parents' attendance may be irregular, because of the many and varying commitments on their time
- plan your sessions by not only considering your parents' needs but also the facilitators' group work skills and strengths
- check with other major agencies to avoid picking a time which clashes with other activities for the same families
- work out what other resources you will need e.g. providing food and respite will help; using a venue in which fathers are likely to feel comfortable; making sure you have appropriate activity or training resources

## Tips for attracting members

**Important:** In developing this program, 70% of the parents at a focus group, indicated that having prior contact with the leaders was essential for them in deciding to attend the first session. This process enables them to clarify questions and build a connection with the leader.

Our experience suggests that the following tips will help you to attract fathers to your program:

- have an established relationship with the parents, or involve an agency that has direct contact with children who have special needs. The most successful programs in accessing parents and encouraging them to attend the sessions involved programs delivered in partnership with disability services
- use 'gatekeepers' in men's lives, such as partners or other key family members, to encourage their initial involvement in the program
- get parents who have already attended to tell other people about it and to promote their attendance
- explain the program to other family members and encourage them to promote attendance. Some partners may view this program as competing with the traditional role that they play in the family
- request other agencies supporting targeted families to promote your program and encourage parents' attendance
- paint an accurate picture as possible to all of these people of the broad content and structure of the session, what parents are likely to get out of the session
- use quotes and reflections from other parents who have attended other sessions in your promotional material
- be clear about times, locations, dates, structure, content and the availability of respite, that food will be provided, and that the program is free, in all promotional material (a draft flyer is included at the end of this section for your consideration)
- ring all the participants and speak to them individually about the program (very important). Explain the overall content and likely process involved and working out ways to remove any barriers to, or anxieties about, their attendance
- check whether the family need respite to allow the father to attend and arrange this, preferably at no cost to the family
- for families where they are a high level of needs, meet them before the group occurs
- allow lots of time to plan and develop trust with the dads. If it is difficult to recruit some
  parents to attend, organise some social events, like a BBQ to enable the them to slowly
  get to know other parents
- provide a map to make finding the venue simple

provide details about transport, parking etc

### Tips for keeping members

It is important to portray a welcoming impression:

- welcome new parents, find out what they would like from the group, explain what will happen in the sessions and introduce the new members to other members
- arrange seats in a circle
- · allow time for talking and listening to each other
- avoid jargon and don't refer to people without explaining who they are
- remember and use people's names

Groups need members who will share in the workload of the group. For example:

- everyone should help decide on the group's activities
- members' views should be heard
- members should identify roles or activities they are happy to help with
- rotate jobs regularly and involve new members
- share information and make use of existing networks is important
- give everyone a chance to contribute with the skills they have
- do not let older members dominate (Contact a Family, 2006a)

#### Successful groups have the following features:

- a positive group climate stressing the strengths of children
- focus on what can be accomplished, rather than obstacles
- the group meets the needs of members, whether that be emotional support, information, education and/or advocacy
- require leaders who motivate/organise and provide contacts (King, Stewart, King, & Law, 2000)

## The emotional world of men who have a child with a disability

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 disability
- effects on the marriage
- uncertainty over the diagnosis
- · constant strain of caring
- benefits of meeting other families in similar situations
- · 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
- dealing with negative reactions in the community (Hornby, 1992)

Forty eight dads of children with chronic illnesses completed the Family Perception Inventory and identified their concerns. Concerns included:

- child's health (98% identified as a concern)
- 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%)
- extra demands on time (88%)
- sexual relationship with spouse (87%)
- having enough fun and relaxation (85%)
- enough time alone with spouse (83%) (Hovey, 2005)

Understanding the emotional world of men as fathers is integral to the successful inclusion of them into groups. The reflection below, of one of the fathers involved in the development of this program, highlights what many men think about as parents, and may rarely express to other people:

"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"

Sample wording for different session topics...

## 1. 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.

#### 2. 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.

#### 3. 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.

#### 4. 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.

#### 5. 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.

#### 6. 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.

#### 7. 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.

#### 8. 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.

#### 9. 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.

#### 10. 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.

#### 11. 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.

#### 12. 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.