

Meeting the Needs of Women through Workshop Weekends

Margaret Cole

From childhood on, women's moral sense emphasises caring for others. This orientation to the experiences, needs and wishes of others leads women to attend to and nurture other human beings and to provide them with what has become known as "social support" (Belle, 1982). This provision of crucial support is often at a cost to the women involved. This paper describes a community outreach project which has been running for nine years with the primary aim of renewing and reinforcing women's feelings of self worth. The project involves twice-yearly residential weekends attended by an average of one hundred and twenty women. The history and evolution of the groups and some possible reasons why they work will be discussed.

Workshop weekends for mothers of special needs children have been held in Western Australia twice a year since 1983. This paper describes their history and evolution; their structure and content; and the importance they have for the women who attend.

Reference is made also to a documentary video, currently in production, where mothers of special needs children describe the impact of having a child with disabilities has on their lives, and what the weekends have meant to them. Finally, there is some discussion on what might be the reasons for the continued appeal of these weekends.

In 1978, when I was working as a developmental psychologist at the Princess Margaret Children's Hospital, I was approached by the physiotherapy department to make time available to mothers who had some questions about the effect of the child with disabilities on the rest of their families and indeed on the rest of their lives! This was the beginning of mothers' support groups which are still running and have been the forerunners of lots of other mutual support groups both within and outside the hospital.

In 1983, the mothers in one of the groups expressed concern for other mothers in the community who had special needs children and no support group. Members of these groups also identified their need to spend some

time away from their 24 hour-a-day family responsibilities, and their desire to learn new skills and develop their self-awareness.

The first camp was held at the Scout Associations camp at Lancelin. Thirty-seven mothers attended. Since then the numbers have slowly risen and at the last four weekends we have had between one hundred and twelve and one hundred and seventeen participants. In the early years about half the participants were new and approximately half were repeaters. We estimate we now have a pool of about five hundred mothers who have attended at least once.

A questionnaire survey of the participants at the November 1990 camp showed the 29% of the women who replied had attended six or more weekends, and 8% have attended almost all the weekends since their inception.

Cost

The weekends are self-supporting and cheap. The first camp cost the participants \$12.00 each, and for that they received two nights accommodation and basic food, i.e. coffee, tea, cereal, cheese, bread and fruit which I took up in the boot of my car. Once the weekend had more than sixty participants we arranged catering and the price rose accordingly. However, the last weekend in May 1991 cost \$45.00 each, which included two nights accommodation and five meals plus access to all workshops.

This reasonable cost can be achieved because the weekends have been seen as a community outreach project of firstly, Princess Margaret Hospital and now of Selby Child and Adolescent Clinic. I take time-in-lieu for the weekend and other presenters apply to their agencies for similar arrangements or donate their time. The clinic covers the secretarial and mailing costs and there is generous co-operation from about thirty-six community agencies who either print information and application forms in their newsletters or photocopy the details and send them out individually to their members.

Venues

We tend to use venues where the accommodation is around \$7-\$8 per night and there are a surprising number of them around. Sometimes we book a year ahead if a venue is very well received, but we also have been asked by some of the participants to vary the venues. We usually go to Kingston Barracks on Rottneest in November, but this year, we are going to Club Capricorn at Yanchep which is much more up-market accommodation than we usually have. The first camps were in twenty-four and twenty-eight bed sheds with pigeons flying in and out and wind coming up through the floor boards. This November, we will be in four or six bed chalets with all facilities, including TV!

I don't know if cost is a major factor but we have always assumed that it was

Margaret Cole, Clinical Psychologist Co-ordinator, Selby Child and Adolescent Clinic, 2 Selby Street, Shenton Park, WA. 6008

for most women and often 'carry' mothers who are unable to meet part or all of the cost. A city Lioness club gave us five scholarships for the last weekend and we shared them out between six mothers. A parent group in Albany is organising a first ever weekend in their area towards the end of the year and they are possibly planning to have it at the Karri Bank Lodge with twin share rooms, all meals served and still only charge \$90.00 for the two days. They looked at a cheaper alternative but discovered there had to be rosters for the washing up and a siren sounding thirty minutes before meals! They decided that was definitely NOT what they wanted for a weekend and are pursuing the more expensive option. I am very excited to be associated with this 'daughter of Kalparrin' weekend and am very interested to see if the rural experience is different from our essentially urban one.

Participants

The weekends are open to any mother who has a child with special needs. This means that over the years we have had participants whose children had been diagnosed with almost every known syndrome and disability. We have regular attenders from groups of mothers whose children have Down's syndrome, muscular dystrophy, cerebral palsy and spina bifida. The weekends are generally well-supported by the Authority for Intellectually Handicapped Persons and a wide range of diagnoses and syndromes are represented by its clients. In addition, mothers of children with heart problems, hearing impairments, epilepsy and cystic fibrosis attend. Recently, I was approached by the Tourette's Syndrome group here to see if they were eligible to attend. Anyone with a child with special needs of any age can be part of the weekends. We have had mothers of intellectually handicapped persons in their 20s; we regularly accommodate mothers who are themselves registered as clients of AIH and who have children with intellectual delay. The only children who can attend are breast-fed babies and we usually arrange for baby minders if there are more than two babies so that the mothers can feel free to attend workshops. At one weekend we had

fifty-four mothers, four facilitators, four babies under ten months of age and two baby minders. We do rely heavily on the good nature of some of our own children in this regard!

Workshops

The workshops are to a large extent determined by the feedback from the participants of the previous camp. It is emphasised that none of the workshops is compulsory and that there is no pressure on any one in a workshop to participate actively. Examples of workshops topics are given in Table 1.

<p>Table 1 Examples of Workshops presented</p> <p>Journal Process Dance Dreams and Dreaming Loving Your Body Learn to Massage Tai Chi Relaxation Dealing with Anger Conflict Resolution Attitudinal Healing You and Your Family's Health Planning for Your Child's Future Stress Management Behaviour Management with Children Self-Appreciation Siblings and the Child with Special Needs Yoga Cardio-Pulmonary Resuscitation Grief and Loss</p>

There is a mix of informational and educational workshops with programs aimed more specifically at self knowledge and personal development.

Between four and six workshops are offered each weekend. There is always a Journal Process workshop, as the principles of unconditional regard and respect, safely to deal with issues, and the luxury of being listened to without comment are implicit in the whole approach to these weekends.

Format

The format for the weekends is very simple. Friday evening is devoted to a session where everyone introduces themselves in whichever way they

wish. If there are over one hundred participants this takes quite a long time, but it is integral to the development of a sense of belonging and of shared joy and pain. In addition, every mother is looking for someone not only with an experience close to hers in having a special needs child, but perhaps also a more specific affiliation such as being the mother of a surviving twin or having a child with a rare chromosomal abnormality or someone who has tried or found a method for working with some difficulty in their child's development. The introductions allow women to note, not only their friends' progress, but also other women that they would like to catch up with later in the weekend for whatever reason.

The remainder of the weekend is devoted to workshops or to rest and recreation or a combination of both. No workshops are compulsory and the weekends are for the participants to use as they wish.

Why do women make the effort to attend these weekends?

Almost every weekend we ask for anonymous feedback in order to be able to evaluate and develop the weekends. At the November 1990 weekend, I asked some new questions because I was interested in why women came and if their reasons for coming had changed over time. I am using the 1990 returns for the following information because there was such a good return rate - eighty-six from one hundred and ten participants which is 78%.

I asked them first what feelings they had about coming if this was their first weekend. They answered in their own words and at least half of them were fairly anxious - they used words such as 'scared', 'apprehensive', 'terrified', 'fear and trepidation'. One fifth were ambivalent saying they were 'scared and excited', 'nervous but keen'; and over one quarter were really pleased, happy or looking forward to it. Among the responses that I categorised as "other" were 'guilt', 'desperation' and statements such as 'I felt it may be able to help me come to terms with my special needs child'.

A reply that seems to me to epitomise the complexity of women's roles and their response to such an opportunity was given by one woman attending for the first time: 'Was it worth it? Guilty leaving kids! Would I mix with others? Could Dad cope? Were the workshops above me? I'll be mortified if I cry.'

We asked the mothers to rank what were the most important aspects of the weekend for them in order, the most important being ranked one. Table 2 shows their responses using only their first choices. The total comes to more than one hundred because a number of respondents chose more than one aspect as being equally important.

In the "other" responses were aspects such as being able to cry without a red face; being able to belly laugh without inhibition, and being with special friends. It is interesting to note that these are the responses from November 1990 and May 1991 weekends, but little has changed over the nine years. In 1984, a masters student on placement at PMH, evaluated questionnaire returns for the first two weekends. I had collected subjective ratings for each of the weekend activities including the workshops and dinner at the local tavern! The most highly rated feature of the weekend was the contact with other mothers aspect. In recent years, there has been a marked increase in the recognition of the importance of mutual support to these families and in the growth of self-help groups, but it is obvious that these two factors alone do not necessarily mean that the needs of these women to meet together and share their joys and sorrows are being met.

The student wrote in his report, 'in terms of the self-appreciation aspect of the weekend, and the mothers individual responses, it is impossible to make generalizations which do justice to the richness of the responses offered' [when asked what they learned about themselves over the weekend]. He felt that a quote from one mother served to reflect the general sentiments expressed. 'I appreciate my inner strength and ability to refuel it through my sense of playfulness and humour. I appreciate also my need to reach out to other people, to get to know them better - not their children's problems - but what they did

Table 2

MOST IMPORTANT ASPECTS OF WEEKEND

	First choice percentages	
	November 1990 [N=86]	May 1991 [N=43]
Chance to rest	26	16
Contact with other mothers	30	49
Opportunity to learn more about self	16	19
Opportunity to be away from family responsibilities	38	30
Time to enjoy yourself	21	19
Chance to learn new skills	5	9
Other aspects	7	7

before they had children and I have a great need to communicate my love of life to others. I appreciate that I'm no longer self-denying but am taking time for myself at last'. I find that I too would rather let the women speak for themselves than give you all these figures, as I find the richness, insightfulness and poignancy of their writing conveys their point of view much better than I can.

I asked if the women got something from the weekends that is difficult to get otherwise, and asked for some detail. Responses are roughly classified in Table 3.

Table 3.

DO YOU GET SOMETHING FROM THE WEEKEND THAT IS DIFFICULT TO GET ELSEWHERE?

Belonging
Safety
Time/Space
Sharing
Information
Rest and Relaxation
Fun

The responses are in order from the most frequently mentioned to the least. A number of women mentioned more than one aspect as being unavailable elsewhere. A number of women wrote

'Yes' and several expressed the difficulty of putting into words what it was that they found unique in their weekend experience.

Over half of the respondents referred to a sense of being part of something. They used words like 'camaraderie', 'sisterhood', 'not being alone', 'a unique undercurrent of love and caring', 'special friends'. Almost as many women referred to a safety aspect - an opportunity to experience trust, to not be judged, 'permission to be real', 'a chance to be myself', to cry and laugh, to release.

Another aspect of the weekends that women felt they couldn't get elsewhere was time and/or space. This included time to be alone, time to talk without interruption, time to think, time to be selfish, 'time to see my situation more clearly', and, as one mother said 'time to go to the toilet on my own!' Space seemed to be used interchangeably with time as in 'space to deal with issues' although one respondent wrote 'Space! Big space, little space, any space!'

Other women referred specifically to the joy of sharing, of being understood, of empathy. Someone wrote of this as the 'tremendous energy and compassion from other mothers'.

Information, personal growth, fun, rest and a chance to learn new skills without having to pay were also important to many participants. One of the mothers who has been to fourteen weekends wrote in reply to this question of

whether she gets anything from the weekend that is difficult to get elsewhere: 'Yes, always. Out of each camp you go home feeling a little stronger and feel like you have learnt something. There is a common bond amongst us all. A feeling of friendship and understanding and you don't have to explain the reasons why you do and think things eg. about your handicapped child, because we all just understand, some by a small degree and others have very similar problems and can relate quite well. I come to these camps just for me. I talk very little now on camps about my disabled son, I don't feel the need any more. It's nice to forget about the realities of life for awhile'.

Someone else summed it up by writing only one sentence on the whole of a two-page questionnaire: 'I love coming here it mack me felle good'[sic].

The Documentary

In 1989 while I was on exchange in England, two of the mothers who had attended a number of camps, put forward a proposal to make a documentary about the mothers' camps. They asked for mothers to volunteer to 'tell their stories' and received overwhelming support from the mothers at that particular camp. They went looking for funding and approached the Film and Television Institute who immediately were very interested. In particular, a director who had attended the introductory session with his wife on the Friday night, was convinced of the importance of making this documentary. The proposers original aims were:

1. To share and celebrate the humanity and spirit of mothers of handicapped children
2. To sensitise the public to the hardship and issues associated with disability in families
3. To provide a training resource for people working with disabled children and their families
4. To commemorate the Mothers' camps as a record for those who have taken part and to encourage attendance by others who might benefit from taking part

The director, Andrew Wiseman, has obtained just under \$190,000 to make a

50 minute documentary. The funding has come from the Australian Film Commission, Film Victoria and the Western Australian Film Council. Filming has taken place at two camps and in the lives of four or five women whose stories have been selected.

Two years later the film is likely to have a first "draft" ready for comment in August this year. The format may be different from that envisaged by the original proposers, but Wiseman still sees its primary aim as giving voice to mothers who have special needs children. Wiseman hopes that the documentary will be ready for release in May 1992.

What is maintaining the appeal of these weekends?

The Approach

Implicit in the choice of workshops and explicit in the introductions and the teaching of writing as a therapeutic tool is the desire to avoid professional imperialism and the divine right of experts. Even for over one hundred participants there are rarely more than six professionals present during the weekend. We have often been asked by professionals as they hear of the weekends from their clients, whether they can attend. However, unless they have something to share, ie. unless they can facilitate a workshop that they already know will be of benefit to the women attending, they cannot just come and be part of the experience. The main reason for this is respect for the uniqueness and privacy of what these women share. This is sometimes a pity as the format lends itself to nurturing and supporting any human being and lots of mothers who don't have children with disabilities tell their friends ruefully that they would kill for an opportunity to attend. Part of the reason that I have prepared this paper is because I hope that the idea may be taken up by other groups, or someone will pay my salary just to organise and run these weekends!

Part of this non-didactic approach is that it is made clear that attendance at workshops is voluntary and that if participants wish to spend the whole weekend asleep or power-walking the Bibbulmun Track, then that is perfectly in keeping with the aims of the weekend.

Another aspect of the approach is the explicit belief that those attending have the power to have the life they have dreamed about. This is underlined by the choice of the song that is used as the theme, and is implicit in all the workshops. The weekend aims to give them back their belief in their own competency and some skills and insights into how they can achieve this competency.

The final aspect of the approach is that to a large extent, the workshops are shaped by the feedback from the participants. There are often suggestions for suitable workshops or workshop facilitators, requests for changes of venue or ways in which newcomers could be made more comfortable or recommendations and/or gifts of suitable theme songs. These views are always taken into account when planning the next weekend.

I found it very interesting that a big American conference on Developmental Disabilities in 1990 had two whole sessions devoted to empowering families and a one-hour presentation was entitled 'Developing Community-friendly Systems that provide Family Supports (or learning to stop administering and start listening).' I believe we listen and we are community-friendly.

Permission to grieve

We all have issues of grief and loss which we may or may not have worked through. These women have a clearly identified loss issue - that of the loss of their perfect child, but they are also not exempted by this loss from other catastrophic grief situations, such as the loss of their marriage, the death of their adult daughter in a car smash, the lingering death of a parent, or the loss of a life of their own. The weekends provide a conducive yet structured setting in which they can become aware of varied views of life and death, different styles of coping with loss, and an awareness of the grief process and how it impinges on them. All of us would like to avoid our own and others suffering - we hide our true feelings and our vulnerability for fear of exploitation and betrayal and trivialisation of our pain. We hide or deny or struggles to come to terms with our losses in an attempt to protect others or to save face ourselves.

Irene Rezenbrink (1989) quotes Judith Tatelbaum:

Having the courage to grieve leads to us having the courage to live, to love, to risk and enjoy all the fruits of life without fear or inhibition'

The number of women who mentioned the safety or time to cry as an important aspect of the workshop attests to the difficulty of grieving in today's society.

Relief from the stress of caring

Contemporary theories of women's psychology emphasise their embeddedness in social relationships. As Belle (1982) points out

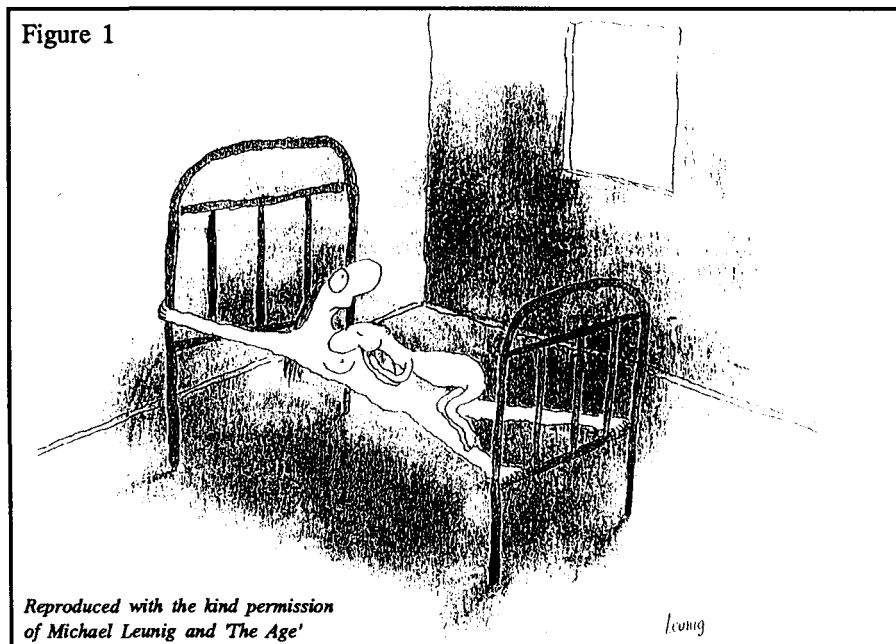
...from childhood on, women's moral sense emphasizes caring for others....Women's orientation to the experiences, needs and wishes of others can, in extreme form, entail a loss of self in overwhelming responsibility for and connection to others....This sense of connection to and responsibility for others also leads women to attend to and nurture other human beings and to provide them with what has been called "social support".

Strictly speaking, social support should be reciprocal and genderless, but this does not square with what we know about sex roles in families or in the larger society. Women have almost as a part of the definition of their role the provision of social support to others. Michael Leunig's drawing (Figure 1) epitomises to me the asymmetrical nature of many supportive relationships. The woman is not only providing warmth and comfort, but is holding the bed together and is indeed the only support available! Because she has no resources left, she cannot reach out to obtain any succour that might be available.

Mothers, especially mothers of special needs children continually describe this feeling of being the main support of their spouse, children, parents, and if they are very caring, often their work colleagues and friends. A woman is at greatest risk of demoralisation and depression when she bears the entire responsibility of child care and **when she does not receive adequate nurturance herself.**

It is interesting to note that at the request of some women who attend the weekends, we have changed the name

Figure 1



Reproduced with the kind permission of Michael Leunig and 'The Age'

from the formal title of "a workshop weekend for mothers of special needs children" or the informal "mothers camp" to "Kalparrin weekend". Kalparrin is an Aboriginal word meaning "sharing the load" and I believe that is a good description of what happens. I was happy to change the name because the weekends were often trivialised by male professionals as "bikie weekends" or drinking sprees! Taking the "mother" out of the title appeared to upgrade the concept societally!

The major importance of the contact with other mothers is the fulfilment of women's drive for relatedness. Here they can "be themselves" without being labelled weak by a patriarchal society. Women must struggle with a number of paradoxes in their lives. They are expected to be caring but being caring is being weak; they are expected to be strong, and hold the family together, but are also expected to be weak and soft as feminine women are supposed to be. Mothers and wives are automatically expected to be "good at listening" and it is only recently that the skills of empathy and good listening are now being valued in the fields of counselling and management training, whereas when they were labelled "feminine skills" they were dismissed and devalued while at the same time being taken for granted.

For 48 hours the participants at the camp can use all their feminine skills

and have them valued explicitly and implicitly. Gloria Steinem said that women need to mother each other, and I think the weekends become a powerful vehicle for women to experience nurturance, care and relatedness. They often report either that the euphoria of the camp lasted for a week or a month or alternatively that it disappeared the moment they got home!

Ritual

There seem to be elements of ritual in the continued participation of many women in these weekends. The ritual themes that appear most clearly are those of membership, healing, identity definition and celebration. When it was suggested that because of the quite extraordinary numbers attending that we should perhaps have four weekends per year but restrict people to attendance at only two, there was deep concern expressed by many mothers that it wouldn't be the same and they might not see the people they wished to.

What do we have here?

I like the psychoanalytic idea of a "free" (? safe) place within a structured boundary. The weekends provide a firm boundary in time, place and persons within which the women have the freedom to participate in whichever way they choose. So in a way, we are a therapeutic community.

I believe the closest similar phenomenon I have found in my reading is the person-centred approach to large groups provided by the Facilitator Development Institute in Great Britain which are residential summer workshops that have been held since 1975. They have as an aim to create a learning community where individuals can experience the large group as an environment conducive to personal and professional development.

Probably because these weekends could be considered as a learning community or a therapeutic community it is interesting to finish off by looking at what therapeutic factors are considered to operate in groups. (See Table 4)

I believe that the women themselves have defined these factors clearly and poignantly in their own words in their description of what the weekends mean to them. ♦

Table 4

POSSIBLE THERAPEUTIC FACTORS

1. Self-disclosure
2. Self-understanding (insight)
3. Acceptance (cohesiveness)
4. Learning form interpersonal action
5. Catharsis
6. Guidance
7. Universality
8. Altruism
9. Vicarious learning
10. Instillation of hope

Aveline & Dryden (1988)

References

Aveline, M. and Dryden, W. (eds) (1988) *Group Therapy in Britain*, Open University Press.

Belle, D. (1982) "The Stress of Caring: Women as Providers of Social Support" in Goldberger, L & Bresnitz, S. (eds) *Handbook of Stress: Theoretical & Clinical Aspects*, The Fress Press: London.

Bloch, S. (1988) "Research in Group Psychotherapy" in Aveline, M. & Dryden, W. (eds) *Group Therapy in Britain*, Open University Press.

Renzenbrink, I. (1989) *Community Responses and Responsibilities in Bereavement*. Paper presented at A.C.T. Hospice Society Annual General Meeting, 17 April 1989.

CHILD PROTECTION

2 DAY CONFERENCE

11 and 12 March 1992

OUR CHILDREN - OUR FUTURE

GUEST SPEAKERS:

Dr Richard Krugman and Professor Don Bross
- Kemp Foundation U.S.A.

Professor Kim Oates
- Children's Hospital NSW

Brian Burdekin
- Human Rights Commission

TOPICS:

Consequences and Cost to the Community of Child Abuse and Neglect; Child Abuse and Neglect in an Australian context; Progressive Strategies; Issues of Co-ordination of Child Protection; the Child and the Law

VENUE:

Campbelltown Catholic Club, Camden Road, Campbelltown.

COST:

\$50.00 per day; \$90 for two days; early bird registration by 16.12.91 \$80.00 for two days

FURTHER ENQUIRIES:

The Cottage Family Care Centre
Marilyn Lawlor or Dianne Wagg
(046) 28 1855