Carers NSW
Carers Mental Health Project
Stage One

Final Evaluation Report

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Chapter 8. *Simplifying Mental Illness + Life Enhancement Skills (SMILES)*

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Chapter 8. *Simplifying Mental Illness + Life Enhancement Skills (SMILES)*

Chapter 8 presents the evaluation of Erica Pitman's *SMILES* program. The chapter first describes the development and content of the program, its implementation within the *Carers Mental Health Project*, then presents information about the children who participated, their caring situations, and what they knew about their family member's mental illness. The program evaluation focuses on increases in knowledge and life skills, what the children liked most about the program, and parents' ratings of how the child benefited from participation. The chapter describes a longitudinal follow-up, and ends with a summary and set of recommendations.

Erica Pitman's *Simplifying Mental Illness + Life Enhancement Skills* (*SMILES*) is a three day program for 8-10 children (8-12 year olds or 13-16 year olds) who care for someone with a mental illness/disorder, most often a parent or sibling.[53] The program is usually delivered during school holidays, and at least two facilitators are required. The program is best facilitated by a professional who has a background in counselling, psychology, social work, teaching or other similar experience. Facilitating requires a thorough knowledge of, and experience working in the area of mental illness. Training and experience working with children and group facilitation are preferable.

Erica Pitman developed the *SMILES* program in 1997 as a result of the increasing recognition that children in families affected by mental illness are a population 'at risk' for developing their own mental health problems. The program aims to provide age-appropriate education about mental illness and life skills to improve the children's capacity to cope more effectively, thus increasing resiliency. It also aims to improve self-expression, creativity, self-esteem and reduce feelings of isolation.

Between 1998 and 2004, a total of 73 children participated in the *SMILES* program in NSW Australia (Fairfield, Orange, Parramatta, Central Coast, Bankstown, Bathurst, Parkes, Canley Vale) and Pointe-Claire (Montreal) Canada. Comprehensive qualitative and quantitative evaluation data has been collected from the children and their parents, and an article evaluating the program was published in July 2004.[54]

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53. Caring is defined more broadly for children than for adults, and any child with a sibling or parent with a mental illness/disorder was eligible to participate.
54. Pitman E & Matthey S. 2004. The *SMILES* Program: A group program for children with mentally ill parents or siblings. American Journal of Orthopsychiatry, 74(3): 383-388.

Three *SMILES* programs were run as part of the *Carers Mental Health Project*, one in each region.

Location	Start Date	Region	Carers	Serv. Providers
Bathurst	30 Sept 2003	Rural	11	2
Parkes	20 Jan 2004	Remote	7	2
Canley Vale	21 Jan 2004	Metro	6	1

The children were recruited into the program through a number of different sources, eg. mail-outs and referrals from mental health teams. Recruiting the children proved difficult, and one previously planned program for Parkes was cancelled.

Obviously there is also a selection factor at work in who participates – if parents are uncomfortable with the notion of children discussing mental illness and the family, they are not likely to enrol them. Thus, the children who participate are not a representative sample of all children with a parent or sibling with a mental illness/disorder.

In order to get pre-program information on the child's situation, each child was interviewed (in the presence of a parent) by one of the project staff or the other facilitators. The terms used (eg. negative, emotional health, physical health, impact, carer) were explained to the children using age-appropriate language. Theoretically the presence of the parent could have influenced the extent to which children reported being negatively affected by their caring role.

8.1 Participant Characteristics

The characteristics of the children who participated in *SMILES* are shown below.

Participants were aged 9-14, just under half lived with both parents, most families received some form of payment from Centrelink, and less than 50% had access to the Internet. Nearly 20% provided care for more than one person, and three-quarters cared for a parent and a quarter for a sibling. Three children classified themselves as the main carer, and nearly 70% lived with the consumer.

The age distribution of the consumers reflects their relationship to the child: nearly 75% of the consumers are between the ages of 26 and 45. Less than 20% of consumers are younger than 25. All of the consumers had been unwell for at least two years, with the highest percentage unwell between 2 and 5 years.[55] The most frequently cited diagnoses were depression, schizophrenia and bipolar disorder.

55. The fact that none of the children were caring for "newly" diagnosed consumers does not reflect a lack of need for those children. It likely reflects the fact that they are less likely to be known to services, or parents may be less likely to agree to send them to the program.

Table 23. Participant Characteristics: *SMILES*

Characteristic		Percentage
Sex	male	32.0
	female	68.0
Age	9	21.7
	10	8.7
	11	17.4
	12	30.4
	13	8.7
	14	13.0
Living with parents		47.8
Receives Centerlink payments		82.6
Access to Internet		47.8
Total		23

Table 24. Participants' Caring Situations: *SMILES*

Characteristic		Percentage
Caring for more than 1 person		17.4
Main carer		13.0
Live with person requiring care		68.2
Who do they care for?	parent	78.3
	sibling	21.7
Years the person has been unwell	<2	0.0
	2-5	39.1
	6-10	17.4
	11-20	21.7
	21+	21.7
Age of person requiring care	<18	13.0
	18-25	4.3
	26-44	73.9
	45-64	8.7
	65+	0.0
Diagnosis[56]	anxiety disorder	0.0
	bipolar disorder	21.7
	depression	39.1
	schizophrenia	39.1
	other	16.1
Total		23

56. The numbers do not add up to 100 because several people have more than one diagnosis.

There were some regional differences among the children in the three programs. The children from remote areas were significantly more likely than the other children to have access to the Internet (which was unexpected), and were less likely to live with the consumer. Rural children were less likely to be caring for a consumer between 25-64, and the metropolitan children were less likely to have access to the Internet, and the consumers were much more likely to have been unwell for longer periods.

When asked what they knew about their family member's mental health problem, the children generally knew there was something wrong, but they did not always know what it was or why it happened. They were able to describe the symptoms, behaviours and its impact on them:

Category	Knowledge of family's mental illness prior to *SMILES*
amount they know	• *I don't understand her behaviour* • *Understand quite a bit I suppose* • *A good bit. Lived with mum for 8 weeks* • *Not much* • *I know mum is unwell, don't know much about, hear voices* • *Bits and pieces*
symptoms, behaviours, and impact on child	• *She gets angry* • *She hears voices; unpredictable and scary* • *Dad can't do things because he's unwell; sometimes gets cranky* • *Makes him weird* • *Dad can get stressed easily, don't bother him when unwell. Takes tablets, if he gets too unwell he has to go to hospital, has to go to a counsellor* • *Sometimes she cries and gets headaches (migraine). Takes tablets* • *Sometimes gets really angry, goes psycho* • *She gets very sad, a little crazy. Angry talks fast, lots of words* • *It's scary and confusing. Worry a lot about Mum* • *Can't drive, stay away from her when she gets violent, hear voices, screams*

8.2 Impact of Caring

Figure 19 presents the means for the children's perceived time spent supporting or assisting the person with the mental illness/disorder in a number of different activities. The response categories measure the children's perception of the time they spend, rather than the actual hours. However, especially from a child's point of view, the perception is more important than the actual amount of time. Given that children are much more likely to live "in the moment" than adults, their views on the day they answered the question are likely to have been influenced by very recent circumstances.

Figure 19. Mean amount of time with which the child assists the consumer in various activities: *SMILES* (N=23)
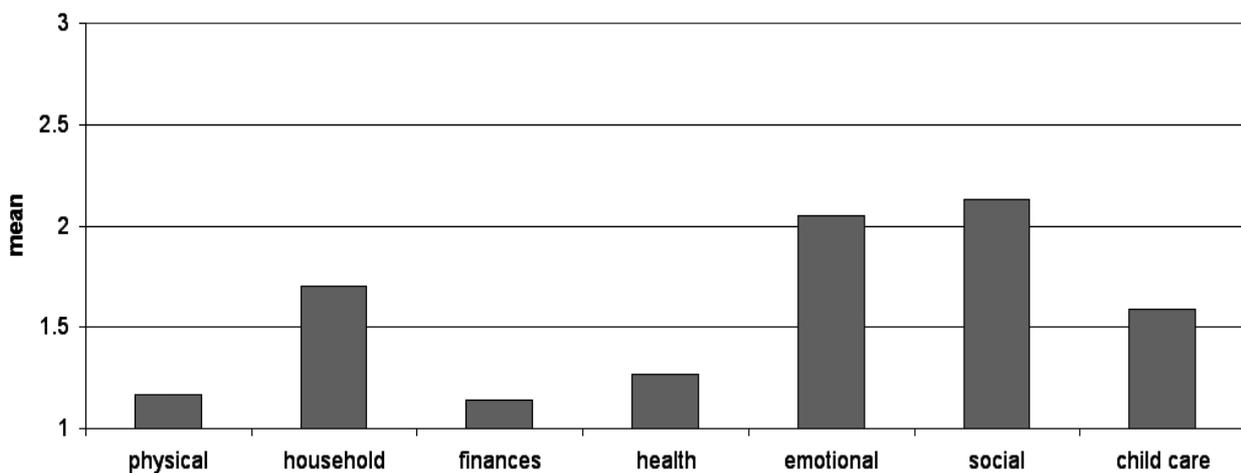

In spite of all these caveats, the figure does present some important information on the perceived amount of time that the children spent providing support to the person with the mental illness/disorder. It shows that while children do not feel they provide a great deal of practical support, they do provide a great deal of emotional and social support. There were no regional differences in the impact, but if the child cared for a parent they spent more time assisting with housework.

Even if they do not spend a great deal of time actually providing care, however, there can still be a number of negative ramifications of having a parent or sibling with a mental illness/disorder. Figure 20 illustrates the children's perception on the extent to which caring has led to a negative impact.

This chart illustrates the huge variation in the extent to which children feel they are negatively affected by having a parent or sibling with a mental illness/disorder. For all areas except for emotional health, relatively few children found their lives to be negatively affected "a lot." The majority of children did experience negative

impacts on their family relationships, peer relationships, money resources and school/work activities. What is perhaps surprising is the extent to which some aspects of the children's lives were unaffected – physical, future plans and dreams, and social activities.

Figure 20. As a young carer, how much is your life affected in a negative way in the following areas? *SMILES* (N=23)
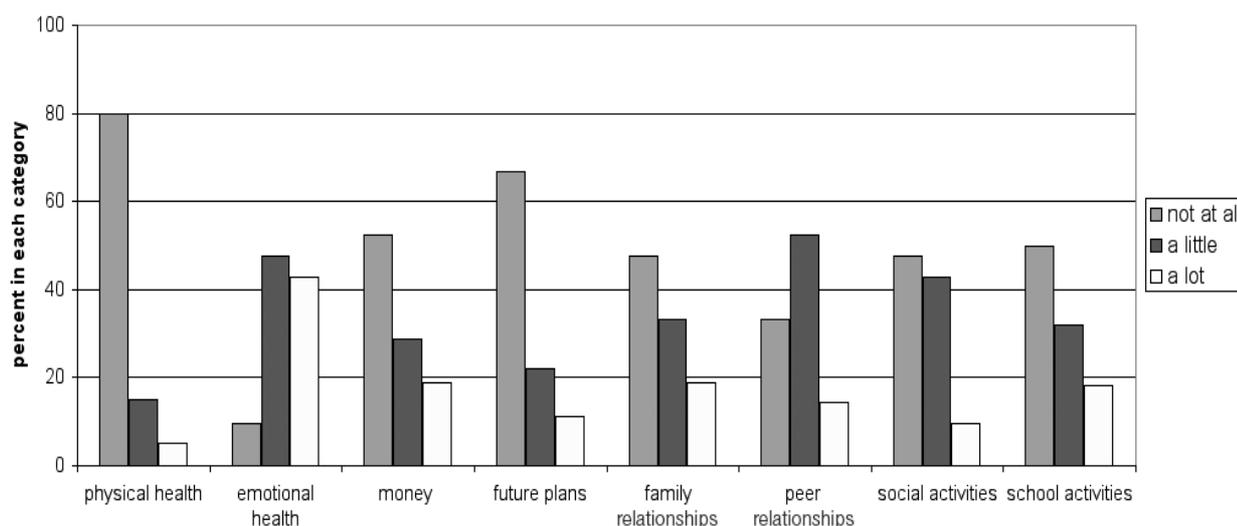

There were no differences by whether the child cared for a parent or a sibling, and the only regional difference was that the metropolitan children found their peer relationships were less negatively affected than the children from the Mid West. There were also no differences by whether the child was older (defined as ages 12-14).

8.3 Program Evaluation

At the beginning and end of the program, the children were asked to rate their level of knowledge about mental illness and some specific mental illnesses/disorders, as well as whether they felt they knew more, less, or about the same about each topic since the program began. They were also asked to rate their abilities surrounding a series of emotional and creative tasks.

By comparing the means at the beginning and end of the program, we found that the changes in all knowledge topics and life skills were statistically significant. Figures 21 and 22 present the means pre-and post-program.

Figure 21. Self-reported Pre- and Post-Program Knowledge Questions: SMILES (N=23)
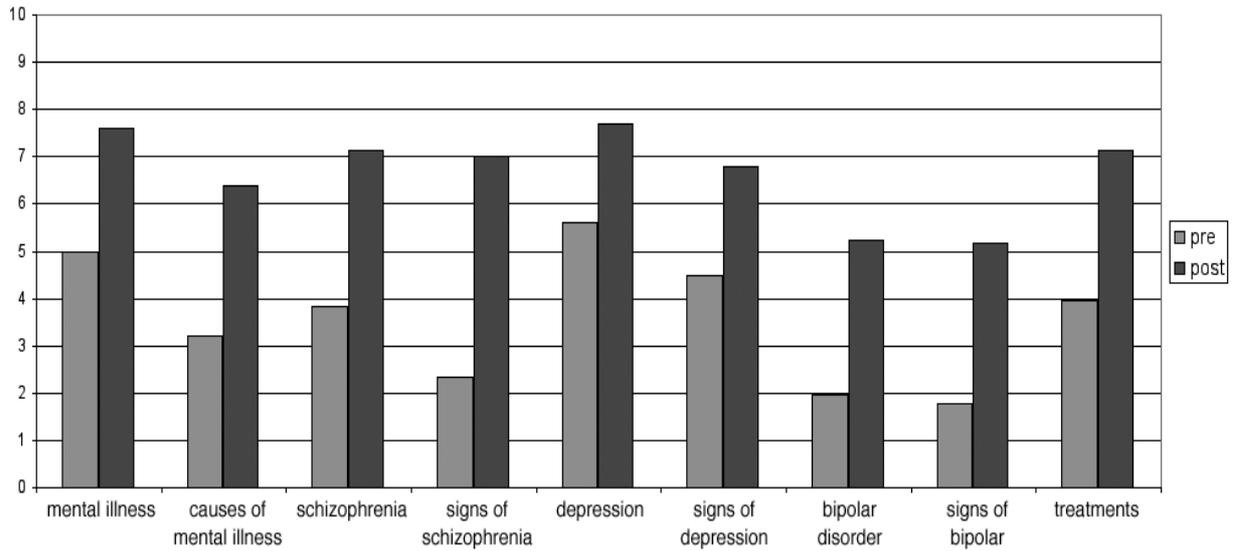
Figure 22. Self-reported Pre- and Post-Ratings of Life Skills: SMILES (N=23)
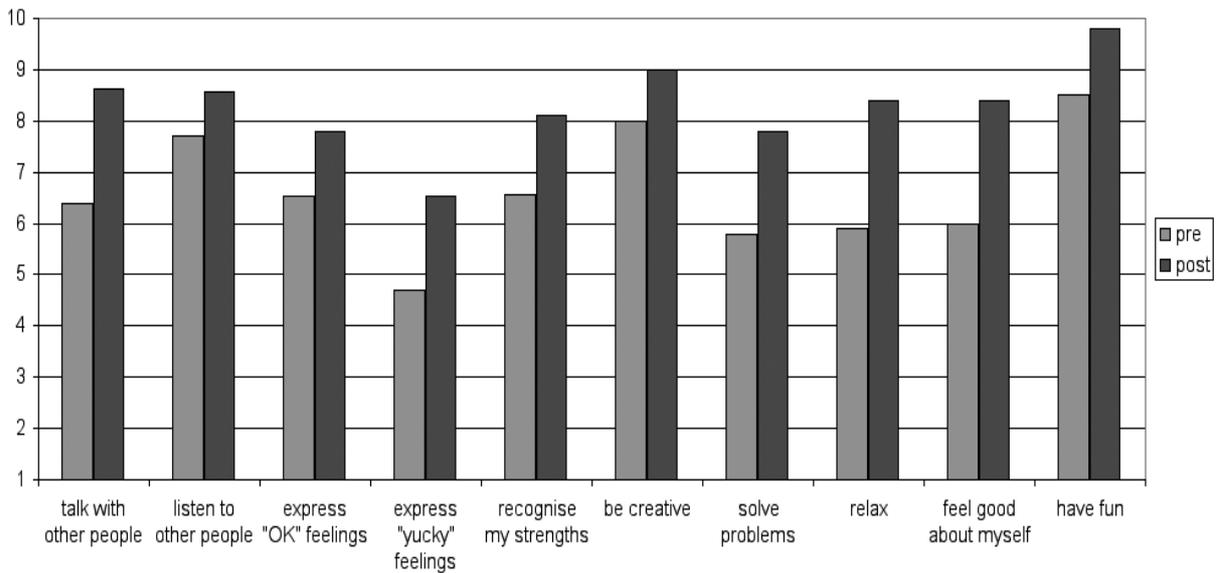
While there were some regional differences in the pre- and post-ratings, there seems to be no real pattern to them, and participants from all three regions increased their knowledge and life skills significantly.

The children were also asked whether they felt they knew the same, less, or more about each of the knowledge topics at the end of the third day. They were also asked whether they found it easier, harder, or there was no change in their ability to do each of the life skills. Table 25 demonstrates the extent of the positive change at the time the program ended.

Table 25. Percent reporting improvement in knowledge and life skills: SMILES

Knowledge		Life Skills	
Topic	**% knowing more after SMILES**	**Topic – ability to**	**% finding it easier after SMILES**
what is mental illness?	91.3	talk with people	91.3
3 causes of mental illness	91.3	listen to other people	65.2
what is schizophrenia?	87.0	express my "OK" feelings	73.9
3 signs/symptoms of schizophrenia	87.0	express my "yucky" feelings	65.2
what is depression?	95.7	recognise my strengths	69.6
3 signs/symptoms of depression	82.6	be creative	69.6
what is bipolar disorder?	76.2	solve problems	78.3
3 signs/symptoms of bipolar disorder	81.8	relax	69.6
3 treatments that help a person get better	90.9	feel good about myself	87.0
		have fun	56.5

When asked what they liked most about the program, the children answered mainly with variations about how much fun it was, how much they learned, and how much they liked meeting the other kids:

Category	What participants liked most about *SMILES*
fun and friends	• *It's fun and time out of the house* • *It was fun and I made heaps of friends and at the same time I learnt something* • *I liked singing and music and having fun (and the leaders)*
learning	• *I like everything, main thing was education of mental illnesses, problem solving and the resource plus games* • *I learnt lots about mental illness* • *The art and activities and learning more about my family's illness*

When asked what they did not like, some of the children responded that they did not like the singing,[57] the "mozzies" in South West Sydney, and having to go home afterwards.

Most (65%) of the *SMILES* participants reported that knowledge about mental illness/disorder was the most important thing they learned during the course:

- *tons about mental illness*
- *how to feel good about myself, having more fun than ever and stuff about mental illness*
- *illnesses and what cause them*
- *it's not your fault if someone in your family has mental illness*

The other important things they learned related to expressing their feelings and how to care.[58]

When asked what else would have been helpful, the children mentioned camps, having the chance to talk privately with someone and having it last longer.

Finally, parents were sent a questionnaire several weeks after the program asking about their perceptions of the impact of the program on the child.[59] The parents were unanimous in their support of the program, and all would recommend the program.

When asked about changes in the child, most parents mentioned that either there has been positive change in terms of better understanding or communication:

- *Openly communicating. Enjoying her new contact with her new friends*
- *Communicating with her mum (patient) much better*
- *She has a better understanding of mental illness, but also is hard for her to come to terms with, as she is still young*
- *Growing up a little, self confidence has improved*

Others found little to no change:

- *Nothing really. For a little while now, home life has been going steadily OK. No upheavals to test new knowledge*
- *As (her sister) has recently moved out of the house, there has been not as much tension, so it's hard to judge*

Figure 22 shows that parents[60] believed their children benefited a great deal from all aspects of the program, with only art and creative activities receiving less than 70% of parents saying their children benefited a lot.[61]

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57. This came from one of the workshops only, in which several of the adults were less than enthusiastic participants in the singing.
58. One child said he/she "couldn't remember".
59. There were no parent evaluations from Parkes.
60. Only the data from the Bathurst parents is shown.
61. One potential explanation for this is that children at this age readily access art and creative activities, and the parents may not have perceived them as being as critical as other aspects of the program which focus specifically on mental illness.

Figure 23. Parents' ratings of how much child benefitted from each area of the *SMILES* program (N=8)
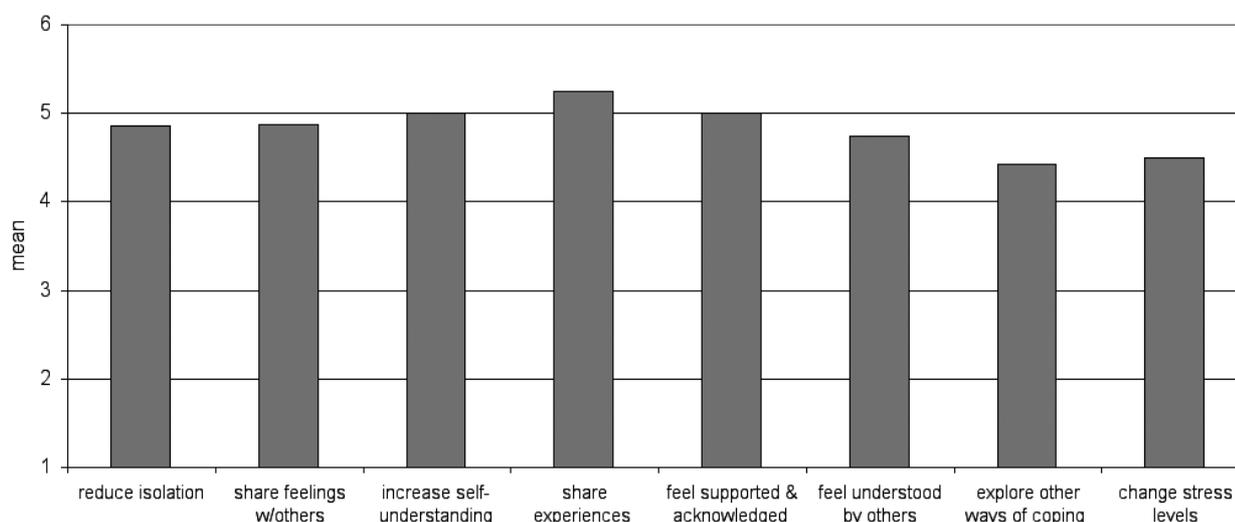
Parents were also asked what they found to be the most beneficial aspect of the *SMILES* program. From the parents' perspective, the peer support that children got from the other participants at the program was the most beneficial aspect, along with the knowledge and greater understanding they learned:

- *To learn about mental illness and to be able to share with fellow children coping with similar/same circumstances*
- *Making new friends, learning more about mental illness, being able to talk*
- *He got to speak with other kids who have 'crazy' parents*
- *Learning to deal with her own feelings/problems and understand her brother's issues in part*

8.3.1 Longitudinal Follow-Up

Because we are interested in the potential long-term impact of participation in the *SMILES* program, we are conducting a longitudinal follow-up of the participants. The topics and questions were designed following a meeting between the evaluator, Erica Pitman, and Stephen Matthey (South West Sydney Area Health Service). The topics included changes in the child's life, caring situation, impact of caring, what the child knows about the mental health problem, and then specific questions about *SMILES*: what the child remembered about it and liked about it. We also tried to get at the heart of some key long-term impacts: whether

they feel more comfortable discussing mental illness/disorder now, what they worry about and who they talk to when they worry, whether they stayed in touch with friends they made, how they have dealt with any crisis situations, gone on to any other programs or used other services, and whether they think that *SMILES* helped them (and how).

We agreed that the interviews with the children were best conducted face-to-face. The interviewers were given a structured questionnaire, and (with the parent's permission), the interviews were taped. When all the interviews have been completed, the tapes will be given to the evaluator for analysis. In the Mid West, area health service staff who had not been directly involved in the program are conducting the interviews, while in South West Sydney, the Carers NSW Young Carer Project Officer (Margaret Bourbous) has completed the interviews.[62]

8.4 Key Challenges/Issues for Program Delivery

Some of the key issues for the *SMILES* program include recruitment, support, working with children and ensuring follow-up.

1. **Recruitment** – recruiting children into the program proved quite difficult. One of the original programs scheduled for the remote area had to be cancelled because of a lack of participants. If the parents are the clients, mental health services may not immediately consider the children to be carers, and not readily refer them. Even if the children are referred, the parents may not agree to their participation.

2. **Support** – organising transportation to and from the venue (with adequate supervision) can be time consuming.

3. **Working with children** – it is important to have co-facilitators who are experienced in working with children and who are willing to participate enthusiastically in all activities (no matter how uncomfortable this may be for them).

4. **Ensuring follow-up** – someone will need to take responsibility for ensuring that any issues/problems that are identified during the *SMILES* program are followed up either by the parents or by the child and adolescent teams.

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62. She was not involved in the *SMILES* program delivery

Summary/Recommendations for the *SMILES* program

- The *SMILES* program met its goals of providing age-appropriate education about mental illness/disorder and life skills to improve the children's ability to cope more effectively with their situations. Both the children and their parents found it to be a fun and worthwhile program, and all parents would recommend it.

- The results from these three programs echo those from Erica Pitman and Stephen Matthey's research on earlier *SMILES* programs.

- The children appreciated both the fun and learning aspects of the program.

- Facilitation requires knowledge, experience and a commitment to working with children.

- While there is a large population of young carers, the project was only able to run three programs. We would recommend increasing the number of programs and enhancing its promotion throughout the schools and mental health teams.

- One drawback is that there is no specific follow-up program available to participants. Children often need reinforcement of concepts and learning. The participants are however offered the opportunity to attend Carers NSW Statewide Young Carer camps or locally based camps for children of parents with a mental illness (Children of People with a Mental Illness).