SECTION III CHILDREN WHO PARTICIPATED IN *Simplifying Mental Illness + Life Enhancement Skills (SMILES)*

This section presents the findings from a follow-up of children who participated in the three-day ***Simplifying Mental Illness + Life Enhancement Skills (SMILES)*** program. The follow-up was conducted to gain a better understanding of whether participating in ***SMILES*** led to improved outcomes for the children who attended.

This section begins with a description of ***SMILES*** along with the findings from the short-term program evaluation. We then describe the methodology for the follow-up and the characteristics of the children who participated. The findings focus on changes in the children's lives and in the well-being of the person with the mental illness, what the children remembered and liked about ***SMILES***, the extent to which the participants became more comfortable and confident in talking about and dealing with the mental illness, and whether their relationships with their families improved. Feedback from a parent/guardian of each child was also included.

1. *Simplifying Mental Illness + Life Enhancement Skills (SMILES) Program*

The ***SMILES*** program is a three day program for 8–10 children (8–12 yr olds or 13–16 yr olds) who care for someone with a mental illness/disorder, most often a parent or sibling. 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 of, working in the area of mental illness. Training and experience working with children and group facilitation are preferable.

The ***SMILES*** program was developed 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 resilience. It also aims to improve self-expression, creativity, self-esteem, and reduce feelings of isolation.

Since 1998, a total sample of 87 children has 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.[21]

Three ***SMILES*** programs were run as part of Stage One of the ***Carers Mental Health Project***, one in each region, with a total sample of 24 participants. Two more ***SMILES*** programs have been run in Stage Two (one in the rural area, organised and funded by the Mid Western Area Health Service, and one in the metropolitan area), with a total sample of 14 children.

[21] Pitman E and S Matthey, 2004, "The SMILES Program: A group program for children with mentally ill parents or siblings." ***American Journal of Orthopsychiatry***, vol. 74(3): 383-388.

The evaluation of the Stage One programs illustrated found that the ***SMILES*** program met its goals of providing age-appropriate education about mental illness and life skills to improve the children's ability to cope more effectively with their situations. The children appreciated the fun and learning aspects of the program, as well as the peer support that came from being with a group of other children dealing with mental illness in the family. Both the children and their parents found it to be a fun and worthwhile program, and all parents would recommend it. The results from those programs echo those from Erica Pitman and Stephen Matthey's research on earlier ***SMILES*** programs.

2. Methodology

The methodology for the ***SMILES*** follow-up differed from that of the adult carer and the service provider follow-ups. The content and methodology for the follow-up approved by the Carers NSW Carers Mental Health Project Evaluation Working Party. For age-appropriate developmental reasons, it was decided that face-to-face interviews with the children were the best way to collect the data, and they were conducted by service providers who were not involved in the ***SMILES*** programs. The interviewers were given a structured questionnaire, and (with the parent's permission), the interviews were taped. When all the interviews were completed, the tapes were given to the evaluator for analysis. In the Mid West, area health service staff who had not been directly involved in the program conducted the interviews, while in South West Sydney, Carers NSW Young Carer Project Officers completed the interviews.

Parents/guardians were asked to complete a different questionnaire, asking about their perceptions of the child's circumstances and changes since the child attended ***SMILES***. While ideally, the interviews were to take place approximately six months after the program's end, the time varied between six and ten months.

As shown in Table 1, participation in the follow-up was higher for the metropolitan area than for either the rural or remote areas. A total sample of 25 children participated in the follow-up, for a rate of 66%. Reasons for non-participation included the child not wanting to participate, cancelled appointments, inability to contact family, and behavioural difficulties.

Table 1. Participation in *SMILES* and in the follow-up

Region	# Participants	# Follow-Ups	% Followed-Up
Rural	18	11	61.1
Remote	7	3	42.9
Metro	13	11	84.6
Total sample	38	25	65.8

The majority of the children who participated in the follow-up (72%) were girls, which is similar to the gender distribution of participants in the original programs. Nearly all participants (96%) had a parent with a mental illness, while 20% had a sibling with a mental illness. Some had both a parent and a sibling. By the time of the follow-up, 40% of the children were older than 12.

Selectivity bias (as to who participates in a program or an evaluation) can come from two sources in this case — either the parent/guardian or the child. Thus, the extent to which the results from this follow-up can be generalised to all ***SMILES*** participants is unknown. Children or parents who may have felt particularly negative about the program may have been unwilling to participate in the follow-up, along with those who were not coping well at all.

The other source of bias might come from the interviews themselves — the children might have wanted to please the interviewer by only making positive comments about the program. The fact that children were willing to say negative things about the program and its impact increases our confidence in the findings.

3. Results — Children's Perspective

3.1 Changes in Children's Circumstances

While children are obviously affected by having a family member with a mental illness, they are also affected by changes in other aspects of their lives, such as changing schools, moving house, or having someone move into/out of their home. We were interested in the extent to which the children who had participated in ***SMILES*** experienced changes in these other aspects of their lives.

The skills taught as part of the ***SMILES*** program were designed to help the children cope with all aspects of their lives, not just with mental illness. Table 2 shows that between one-fifth and one-third of the children underwent potentially stressful changes in these other aspects of their lives since participating in the ***SMILES*** program. As was seen in the adult carer follow-up, children's circumstances are also fluid.

Table 2. Changes in circumstances

Type of Change	% Experiencing	Examples of Changes
Changed schools	20.0	• high school • moved house — had to change schools
Moved house	25.0	• we moved into our auntie's house • old house was getting knocked down
Household composition	33.3	• aunt & uncle & pop moved in • sister (with mental illness) occasionally lives with us • father moved back into home
Other changes	29.2	• mother now pregnant • changed years at school
Total sample = 24		

In addition, since ***SMILES*** 43% of the children had witnessed an episode of the person with the mental illness being unwell. These included hospitalisations, a self-harming episode, the consumer not taking his/her medication, episodes of depression, and police involvement.[22]

[22] The extent to which they were able to deal with the situation differently following ***SMILES*** will be discussed further on in the report.

3.2 Long-term Impact of the *SMILES* Program

All but three of the 25 children recalled the ***SMILES*** program positively, with most using the word "fun" to describe it. Two of the three who did not like the program thought it was "boring," while the other child said, "*I didn't really understand what was going on.*" The following themes came up when the children who enjoyed the program described what ***SMILES*** was like:

Table 3. Children's perceptions of what *SMILES* was like

Category	Examples
Peer support	• *Fun, making new friends* • *Really nice workers, friends, meeting new people*
Knowledge	• *Learn more about illness* • *Activities learning about illness & depression*
Games/social interaction	• *Play games, game where people say nice things about you* • *Played soccer in big groups*
Respite	• *Good to meet new people & get out of the house* • *Fun, let us have a break*

The venue in South West Sydney had a sensory room available which was used in the program there, although it is not a standard component of the program. The children recalled the room as a key element from their program.

When asked what they liked most about participating in ***SMILES***, the children's answers generally echoed their descriptions of what the program was like. However, some children went beyond those descriptions to talk about the impact. For one child, "*expressing myself and telling sister and mum how you felt"* was what he/she liked most. Another child said that "*I achieved something — not to be angry.*" Still another liked the "*meditation — very relaxing. Learning about other types of mental illness.*"

When asked what they remembered about ***SMILES***, the responses were divided between those who remembered the activities and games, and those who remembered learning about mental illness. One child remembered "*learning about my dad's sickness, trying to understand what it means and how to help him more, how sick he might get on some days.*" Another remembered learning how to "*take control of your actions so if your mum was unwell you would know what to do.*"

Thus, even after the passage of at least six months, the participants generally remembered the program positively, and were able to recall at least some of what they had done and learned in the program. Not surprisingly, given their developmental stages, fun activities and meeting up with other children in similar circumstances were the highlights of the program for many of the children.

3.3 Knowledge about Mental Illness

The interviewers asked the children what they remembered about what mental illness is, what causes it, and what treatments there are for it. While a few children said they couldn't remember anything about it, the majority were able to recall some basic facts about it. For one child, mental illness *"affects the brain. Just because someone has*

mental illness doesn't mean they are not human. Be there for the ill person and the carer." Another characterised someone with a mental illness as a "*person who has a disability in the head.*" One learned that it was "*a disease that can happen to anyone. That it's not my fault. It's something that can't be left alone. It has to be taken care of.*" Other children were not able to recall the facts with the same clarity. "*Schizophrenia — have a radio in their head (caused by a lot of pressure).*"

About one third of the children could not recall anything that might cause mental illness. While the other two-thirds offered answers, they were not always completely correct, but often had a kernel of truth about them. For example, "*for my mum it was her parents — kept telling her she was stupid,*" or "*when they don't take their medications.*" Several said that smoking caused mental illness (it was unclear whether they were talking about cigarettes or marijuana and other drugs). One-third were also unable to recall any treatments for mental illness. Those who did remember potential treatments primarily focused on counselling and medication.

Theories regarding causes of mental illness are quite complex, even for adults to grasp, so it is not surprising that the children had trouble recalling what some of them might be. They were able to remember what mental illness is, however, and that they were not to blame for it.

3.3.1 Worries about Mental Illness

The children were asked how much they worried about their sibling or parent with the mental illness. Only two children did not worry at all, with 52% worrying a little and 40% worrying a lot. They worried about a number of things:

Table 4. What children worry about

Category	Examples
Abandonment	• *What I'd do without her. I don't want her to go to hospital* • *She'll move away or might die*
That the person will hurt themselves	• *If she does anything silly or dangerous. Stabbing herself with knife a couple of times* • *Mum might get hurt. The medicine makes her sleepy* • *I worry that my mum might kill herself*
Impact on the consumer	• *How they are and how they are coping*
Anticipation of further episodes	• *I see her so well but I know that she can get sick* • *I worry she's going to chuck a mental when we come to visit her*
Stopping of medication	• *Not taking tablets — Mum and Dad fight when that happens*
Police involvement	• *Doing drugs. Getting caught by police, gets into trouble. She'll lose all her friends*

These are obviously quite profound sources of worry and concern for children. All but one of the children said they did talk to someone when they were worried about the person, however. Family members were the most often cited source of support, but other children also mentioned counsellors, friends, and Kids Helpline. One said they felt "*embarrassed talking to my friends*" about it.

3.4 Changes in Comfort Discussing Mental Illness

Nearly all of the children (87%) said they were more comfortable talking about mental illness with their families and other people since they participated in ***SMILES***. When asked for examples, there were several key points that arose:

- ***SMILES*** gave them more understanding about mental illness so they felt more confident in discussing it
- ***SMILES*** encouraged them to open up more about what they were feeling — *"usually worried to get it out. Now it's fine."*
- The realisation that they were not the only ones with family members with mental illness made it easier for them to raise the issue

SMILES helped one child overcome her fear of what other people's reactions might be: *"Speak to my friends. At the start didn't think they would understand and they did understand."* Thus, it was clear that the ***SMILES*** program had helped overcome children's discomfort in discussing mental illness.

3.5 Changes in Ways of Coping During Crisis

One of the goals of the ***SMILES*** program is to provide children with the resources to cope better when faced with crisis situations. As previously stated, 43.5% of the children in the follow-up had faced a time when their sibling or parent with the mental illness was unwell, since they had participated in the program. Of those, nearly 60% felt they dealt with the situation differently this time than they would have before they attended ***SMILES***.

When asked what was different this time, the children offered these responses:[23]

- *"asked for counselling"*
- *"I can cope better. I'm not the only one"*
- *"I knew what she was doing and why"*
- *"I used to stay and try to help him stop — but best not to because he pushes me down"*
- *"wasn't afraid to comfort her"*

These children were able to absorb the lessons from ***SMILES*** and apply them. Their responses illustrate that they were able to use different strategies depending on the situation. They also illustrate that having an understanding of what happens during periods of unwellness can be critically important for children.

3.6 Participation in Other Supports

SMILES is a three-day program, and can only address a certain number of issues and needs. Children also have the need for other ongoing supports, and were asked about whether they had participated in a young carer camp, talked to a counsellor or doctor about having a family member with a mental illness, and whether they had received any information on the internet about other children with family members with mental illness.

[23] The other two children were not able to provide concrete examples

Just over one-third (36%) of the children did attend young carer camps after ***SMILES***. All the children who went reported enjoying the camps, particularly the activities and peer support.[24] Nearly half of the children (42%) spoke with a counsellor/doctor since ***SMILES***, with two-thirds of those finding it helpful. Perhaps because of their ages, no one received information about young carers from the internet.

3.7 Peer Support

Like adult carers, the children continually cite peer support as one of the most important aspects of the programs in which they participate. We were interested to know whether the connections that were built during ***SMILES*** were able to be maintained over time.

Only two children said they didn't make any new friends during the ***SMILES*** program they attended. The others said they made between one and eight friends. About 20% of them reported living near the friends they had made. Only three children talked to any of their new friends on the telephone or internet since ***SMILES***. Of those, one spoke to another child once, and one talks to them once a month. The other child now goes to the same school as one of the other participants. Eight children had met up with each other, primarily through the young carer camps.

Thus, while peer support is quite important for children, it can be difficult to maintain without structured programs or follow-ups to facilitate ongoing contact.

3.8 Ways in which *SMILES* Helped

All but one child (96%) felt that the ***SMILES*** program helped them. The child who felt it did not help said *"it didn't really help because half the time I didn't understand what they were talking about."* The others felt it helped by providing them with knowledge, understanding and coping skills, encouraged open communication, gave them peer support, and focused on their self esteem.

Table 5. Ways in which children felt *SMILES* helped

Category	Examples
General knowledge or understanding	• *A little bit. Getting to know more about dad's mental illness and other people's mental illness* • *Because when I first went I didn't know anything about mum's disability* • *Explained mental illness to us. Kids Helpline number* • *Teach me stuff I didn't know before. How to handle mental illness, what to do*
Encouraged communication	• *Can talk to mum a lot more* • *In being able to communicate with others and telling them how I feel*
Social/peer support	• *Making friends*
Self esteem	• *Good tips on how to think of yourself as a good person. Boosted self esteem* • *SMILES kept my self esteem up*

[24] Except for one child who didn't like parts of it — particularly "uncomfortable beds" and having to do a bush walk.

3.9 Other Suggestions

The children were also asked whether they could think of anything else that would help them cope with having a family member with a mental illness. Seven children had suggestions, some of which were policy related (more ***SMILES*** programs, Camps, counsellors/psychologists), some support related (*"A lot more friends. Meeting more people that you could talk to about it"*), and some information-related (*"If they told the little kids and they got the picture and understood it would be ok"*). For one child, however, the only thing that would help would be if the parent didn't have a mental illness.

4. Results — Parent's/Guardian's Perspective

Because one of the goals of ***SMILES*** was to improve relationships within families through the children's improved knowledge, coping, and communication, it was critical that an adult family member give feedback on the impact of ***SMILES*** as well. Their feedback echoes that of the children, thus reinforcing the results.

4.1 Coping Abilities

When asked whether their child seemed to cope better since attending ***SMILES***, slightly more than half answered affirmatively (52%). Another 39% said they were coping just the same, and 9% said their child was in fact coping worse now. When asked to explain, parents primarily cited the child's ability to communicate better and more openly about mental illness, the child's increased understanding about mental illness, learning that they were not alone, and the actual coping skills they learned. One parent who has a mental illness said, "[He] *has learned it's not just me being difficult. Being part of a large group of 'others' whose parents aren't well is great. He fits in somewhere. He's got a better understanding and coping skills."* Another child now tells his parents to stop arguing when their interaction upsets him, while other children are able to walk away from difficult situations rather than trying to intervene in them. Most of the adults felt that the understanding about the causes and consequences of mental illness the children gained from ***SMILES*** was invaluable.

4.2 Relationship with Child

We asked the parents/guardians whether they felt their own relationship with their child had improved since they attended ***SMILES***. Of course, the extent to which it could be improved partly depends on what the relationship was like previously. Slightly less than half of the parents felt the relationship had improved (45.8%), while the same number felt that it was just the same. Two parents classified their relationships as worse. Unfortunately, we did not collect any detail on how or why it had changed.

4.3 Improvements in Communication

Most of the parents (82.6%) felt that their child was more likely to talk to them about mental illness or what was happening in the family after attending ***SMILES***. Several parents said that the child was now "*more open and understanding*" than he or she had been before the program. The children were also now more likely to ask questions about the illness or what was happening. One also talked his/her parent "*out of a panic attack.*"

We also asked the parents/guardians if they felt more confident talking with their child since the child attended ***SMILES***. Eighty-six per cent said they did feel more confident, for the same reasons that the children felt more comfortable, that is, because the child *"is more confident and so we talk more"* or *"if she asks questions, I know that she can handle answers."* Even though the emphasis of ***SMILES*** is on the children, this clearly has important implications for the family. If the adults realise the child understands more about mental illness, they are more likely to discuss it with him or her. As discussion and communication increase on both sides, relationships are likely to improve.

4.4 Ways in which *SMILES* Helped

Every parent/guardian who responded to the follow-up felt that attending the ***SMILES*** program helped his/her child.[25] The parents focused on peer support and greater understanding of mental illness as the key elements of ***SMILES***. Parents appreciated the opportunity for their child to mix with others in similar situations: *"realising that there are lots of children coping with problems"; "it helped her understand and meet children who have things in common with her."* As stated in the previous sections, the child's improved understanding of mental illness and individual family circumstances were seen as extremely beneficial — *"she understands that whatever happens — it's not her fault."* One parent summed up the impact succinctly for both the child and family: *"her own understanding of the situation helps us all."*

5. Conclusion

The results from the follow-up of participants in the ***SMILES*** program and their parents/guardians reinforced the positive findings from the short-term evaluation. The children who participated in the ***SMILES*** program found it to be helpful and some of them were able to cope better and communicate more freely after participating. While ***SMILES*** could not change the situations in which the children found themselves, it could, and did, give many of them information and skills that they used to respond differently to those situations.

The children primarily remembered the program as being fun and informative, and were grateful for the chance to meet other children in similar circumstances. Without further formal intervention, however, this peer support was unable to continue beyond the program. The impact of the program was clearly felt beyond the children. The participants and their parents/guardians were generally able to communicate more freely and confidently about mental illness following the program.

The congruence between the children's and parents' reports increases our confidence in the findings. While the participation rates for the ***SMILES*** follow-up were significantly higher than those of the adult carers and service providers, one-third of the children were not followed up. It is possible that the circumstances of the children not followed up differed significantly, and that the program may not have had a large impact on those children. What we can say with confidence, however, is that for the children who participated in the follow-up (and their families), the ***SMILES*** program had a significant and positive impact on them.

[25] This finding echoes the 100% of parents who, at the end of the initial evaluation, said that they would recommend ***SMILES*** to other families.