



**Paying Attention to Self (PATs):
An evaluation of the PATs program for young people who
have a parent with a mental illness**

John Hargreaves, Matthew O'Brien, Lyndal Bond, Danielle Forer,
Amy Basile, Liz Davies

**Final Report
December 2005**



© Centre for Adolescent Health 2005

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced without prior permission from the Centre for Adolescent Health.

ISBN 0-646-46217-2

Centre for Adolescent Health

The Centre for Adolescent Health was established in 1991 with support from the Victorian Health Promotion Foundation and the William Buckland Trust. It is an initiative of the Royal Children's Hospital, significantly supported by the Murdoch Children's Research Institute and The University of Melbourne. The Centre is recognised for advancing knowledge that has influenced adolescent health practice and policy internationally. The integration of adolescent health practice with research underpins good policy development and forms the basis of the Centre's education and development programs.

Suggested citation:

Hargreaves, J, O'Brien, M, Bond, L, Forer, D, Basile, A, Davies, L, & Patton, G 2005, *Paying Attention to Self PATS: an evaluation of the PATS program for young people who have a parent with a mental illness*. Centre for Adolescent Health, Melbourne.

Acknowledgements

This 3-year study was funded by Victoria and the Victorian Health Promotion Foundation (VicHealth), beyondblue, a national depression initiative, and the Victorian Department of Human Services, Mental Health Branch.

Evaluation Team:

Coordinator John Hargreaves

Matthew O'Brien, Dr Lyndal Bond, Danielle Forer, Amy Basile, Liz Davies,

Professor George Patton

Evaluation Partners:

Paul Leeves - Goulburn Valley Child & Adolescent Mental Health Service, Shepparton

Sally Ryan & Elise Willersdorf - Inner South Community Health Service, Melbourne

Katharina Verscharen - Shire of Yarra Ranges, Youth Services, Lilydale

Allison Wolf - Wimmera Uniting Care, Horsham

The evaluation team and partners would like to thank:

PATS participants

PATS Reference Groups

PATS Peer Leaders

CONTENTS

CONTENTS.....	4
TABLES	6
FIGURES	6
EXECUTIVE SUMMARY AND RECOMMENDATIONS	7
Aims	8
Methods	8
Findings.....	9
The impact, outcomes and experience of PATS participants.....	9
Implementation of the PATS programs	10
Recommendations.....	11
1 PATS PROGRAM BACKGROUND, OVERVIEW AND THEORETICAL UNDERPINNINGS	12
1.1 Background.....	12
Children of Parents with a Mental Illness.....	12
The need for prevention and early intervention	13
Informing young people for coping and caring.....	13
Adolescents as young carers	14
1.2 Program Overview	15
Aims and Objectives	16
Target Group	16
Pre program Interview.....	17
Eligibility Criteria	17
Exclusion Criteria	17
Peer Support Groups	18
Co- Leadership	19
Leadership Training and Advocacy	19
PATS Socials.....	19
1.3 Theoretical Underpinnings of PATS	21
Youth Participation.....	21
Why a peer support model?	23
Mental Health Literacy	24
Stigma	25
Depression.....	25
Homelessness	26
2 EVALUATION.....	27
2.1 Impact and Outcomes of Participating in the PATS Program	28
Research design	28
Methods.....	28
Measures.....	29
Impact measures	29
Outcome measures	30
Other descriptive measures.....	32
Comparison data.....	32
Assessing the experience of PATS	32

Data analysis	33
Results.....	33
Participation and attrition	33
Socio-demographics.....	33
Impact and outcomes of living with a parent with a mental illness.....	34
Experiences of school, extra curricular activities and substance use	36
Trajectories of impact and outcome measures from pre-intervention to 12 months post-intervention	37
A consumer’s perspective: PATS participant feedback	43
Discussion	53
Limitations of the study.....	53
Strengths of the study.....	53
Conclusion	53
2.2 PATS Program Implementation, Capacity Building and Sustainability.....	55
Methods.....	55
Interviews	55
Journal	55
Case Studies	56
Telephone interviews with key agencies.....	56
Additional data sources	57
Results.....	58
Capacity building and partnerships - PATS coordinator perspective.....	58
Capacity building and partnerships - PATS partners’ perspective.....	67
Sustainability	69
Worker impact	69
Structure and content of the PATS group sessions.....	71
Engaging adolescents and families	71
Access.....	73
2.3 Case Studies	79
A parent’s perspective of PATS	79
A participant’s perspective of PATS	80
3 CONCLUSION.....	83
3.1 PATS Participants.....	83
Description of participants.....	83
Young Carers.....	83
3.2 Impact and outcomes of the PATS program.....	84
Implementation of the PATS programs	85
4 RECOMMENDATIONS	88
4.1 Peer Support.....	89
4.2 Capacity Building	90
4.3 Coordinating Role	91
5 REFERENCES.....	92
6 APPENDICES	96
5.1 PATS Participant Questionnaire	96
5.2 Prompts and questions used in the two rounds of semi-structured interviews with PATS site coordinators.	114
Round 1 November – December 2003.....	114
Round 2 November - December 2004.....	115

TABLES

Table 1 The demographic characteristics of the PATS participants34
 Table 2 Impact and outcomes of living with parent with a mental illness35
 Table 3 School experience and risk behaviours.....37
 Table 4 Burden of care, social support, problem solving and mental health for those who completed pre, post and 12 month follow up (n=64)38
 Table 5 Comparison of participants who completed pre- and post intervention with those who completed all waves42
 Table 6 Referrals IN: % of participants at each site referred by self, family, school or health or welfare agency in 2004.....64
 Table 7 Mode of access: Participant to group sessions in 2004:.....74

FIGURES

Figure 1 PATS Program Model.....20
 Figure 2: Number of participants in the study who completed each wave of data collection29
 Figure 3 Burden of Care39
 Figure 4 Mental Health Literacy40
 Figure 5 Reported Levels of Stigma, Risk of Homelessness and Depression40

EXECUTIVE SUMMARY AND RECOMMENDATIONS

Paying Attention To Self (PATS) is a peer support program for young people aged 13 – 18 years who have a parent with a mental illness. The program aims to reduce the likelihood of the development of mental health difficulties in young people who have been identified as having an increased risk for this outcome; to decrease the risk factors for these young people; and to increase their coping skills to help them meet their needs and challenges. The eight-week peer support program facilitated by a health professional and a peer leader provides groups with ongoing opportunities for support through social, education and recreational activities. As a capacity building program, PATS focuses on workers, organisations, and the broader community, creating awareness of issues affecting children of a parent with a mental illness.

In June 2002 the Centre for Adolescent Health received three-year funding to pilot the PATS program and evaluate its implementation in five locations across Victoria. Funding bodies included the beyondblue national depression initiative, the Department of Human Services, Victoria and VicHealth. The lead agency, the Centre for Adolescent Health, coordinated and facilitated the dissemination of the program across five sites, and undertook evaluation of program implementation, and of the impact and outcomes on PATS participants. The partner sites were:

- 1 Youth Services, Lilydale, Shire of Yarra Ranges
- 2 Inner South Community Health Service
- 3 Goulburn Valley Child and Adolescent Mental Health Service, Shepparton
- 4 Wimmera Uniting Care, Horsham
- 5 Centre for Adolescent Health, Royal Children's Hospital, Parkville.

Aims

The aims of this evaluation were to:

- provide information about young people and their families, where a parent has a mental illness
- investigate the impacts and outcomes that arise for young people who participate in the PATS program
- document the participants' experience of the PATS program
- investigate the implementation and sustainability of the PATS program
- investigate the broader organisational and community capacity building aspects of the PATS program.

Methods

There were two major components to the evaluation. The first described the PATS participants and assessed their experience of participating in PATS. The second component comprehensively and systematically documented and evaluated the implementation and capacity of PATS programs across the five sites.

PATS participants were surveyed at the commencement (wave 1) and completion (wave 2) of the group sessions and six months (wave 3) and twelve months (wave 4) after completing the program. The structured questionnaire included demographic information about the young people, and a range of measures and questions to investigate the impacts and outcomes of the PATS program on participants. On completion of the structured questionnaire at waves 2, 3 and 4, participants were also asked for feedback on the program, and to reflect on their experience of PATS.

A variety of methods were used to evaluate the implementation of the PATS programs and capacity building in the five sites. Program coordinators were interviewed at the beginning and end of the project. They also kept a journal designed to capture worker details, networks of organisations contacted, contact log, participant referral sources and attendance and session plans. Workers were asked to write a reflective piece about their involvement and, where they deemed appropriate, to ask a PATS participant and/or parent to write a reflective piece about their experiences of PATS.

Findings

The impact, outcomes and experience of PATS participants

- 60% of PATS participants reported having depressive symptoms. This was significantly higher than would be expected of young people in the general population (18%).
- The prevalence of depressive symptoms for males was similar to that for females, contrasting dramatically with the Victoria wide figures, in which only 12% of males report symptoms of depression.
- PATS participants reported higher levels of risk of homelessness and school suspension than those in the general population.
- Only 25% of PATS participants' parents live together, compared with 70% from a state-wide school-based representative survey
- PATS participants reported significant reductions in:
 - depressive symptoms (60% pre-intervention, 38% 12 months later)
 - risk of homelessness (44% pre-intervention, 17% 12 months later)
 - stigma (30% pre-intervention, 15% 12 months later)after their involvement in the program.
- Over the 12-month period, no differences were found for reported substance use or measures of social support and social problem solving skills.

Reflecting on their experiences of PATS, participants reported:

- learning more about their parent's illness
- reduced feelings of isolation resulting from meeting people with the same issues as themselves
- increased confidence in seeking help
- understanding and empathy with their parent's experience
- reduction of blaming themselves – greater self acceptance
- increased ability to deal with feelings
- development of coping strategies.

Overall, these results indicate that young people coming into the PATS program are experiencing high levels of emotional distress, and a clear need for some form of intervention or support, such as that offered by the PATS program. Furthermore, the reduction in levels of depression and risk of homelessness after completing the PATS

program, and stigma associated with having a parent with a mental illness amongst PATS participants, show promising indications that the PATS program can impact favourably on risk factors known to be experienced by this group of young people. The young people's own reflections of their experience of PATS supports and strengthens these findings.

Implementation of the PATS programs

A range of advocacy approaches was necessary to raise awareness and understanding of issues experienced by young people with a parent with a mental illness, and develop skills to better meet the needs of these young people.

Integrating PATS into organisations was seen as an effective way of decreasing the workload necessary for coordinators in supporting young people, however resources did not always facilitate this option. Limited resources were also an issue in the establishment of reference and advisory groups.

It was perceived that there was greater potential for many more referrals to be received from mental health services. Reasons identified for the relative lack of referrals included: adult mental health service workers tending to be sceptical about non-clinical prevention programs; lack of time and expertise in exploring the needs of non-adult family members; and lack of regular promotion of PATS to these services.

Access was the most significant issue for most of the sites in terms of burden on the worker. Such issues included driving, picking up, and dropping off participants; costs, for example of taxis and young people's safety.

The personality and skill levels of the workers were regarded as significant factors in contributing to the success of the PATS program in each of the sites. Embedding the program within the host organisation, however, reduced the impact of workers leaving the position, so capacity within the organisation was maintained.

Involving families as much as possible was the most effective strategy to achieve successful engagement and ongoing involvement in the PATS program, including having an initial meeting with the parents and young person or going to the family home for the meeting. Important factors in encouraging young people to participate included: provision of transport; discussion; reminder calls and emphasising that the program was voluntary.

Recommendations

Recommendation: Peer support programs such as PATS are recommended as an effective intervention in improving the health and wellbeing of adolescents who have a parent with a mental illness.

Recommendation: Capacity building is recommended to raise awareness and develop the skills and knowledge of workers, organisations and communities in relation to young people who have a parent with a mental illness.

Recommendation: Strong links need to be formed across community and mental health sectors to ensure the success and sustainability of peer support programs for adolescents who have a parent with a mental illness.

Recommendation: Adolescent peer support programs such as PATS are most appropriately located in community-based environments, so as to provide a non-stigmatising setting that will attract young people.

Recommendation: It is recommended that adolescent peer support programs such as PATS be linked with other groups that benefit children, young people and families where a parent has a mental illness.

Although not as effective as peer support, alternative pathways need to be considered for young people who have a parent with a mental illness and cannot, or do not wish to, attend groups.

Recommendation: A peer support program for adolescents who have a parent with a mental illness needs to be integrated into the host service to ensure support and sustainability.

Recommendation: Mental health services need to build on family sensitive practices to identify, resource and refer young people who have a parent with a mental illness.

Recommendation: A statewide co-ordinating role is essential for the further development of supports for young people who have a parent with a mental illness.

1 PATS PROGRAM BACKGROUND, OVERVIEW AND THEORETICAL UNDERPINNINGS

1.1 Background

The following sections outline the issues faced by young people who have a parent with a mental illness, and provide the rationale for the development of the PATS program.

First onset of mental illness often occurs in adolescence. Young people with a parent with a mental illness are at significantly increased risk of developing mental health problems. Apart from this increased risk, having a parent with a mental illness has a significant impact on all family members. Daily, children and adolescents in the family can face the stresses of caring for the parent. Stressors include the fear of being developing a mental illness themselves; coping with the stigma of mental illness; and trying to manage the ordinary challenges of growing up, including managing school and work. Given these increased risks and daily stressors, preventive or early intervention programs for young people in these situations are warranted. In recognition of these needs the PATS program was developed to provide a supportive group experience through which young people could learn more about mental illness develop coping strategies and, importantly, have fun with other young people in similar situations.

Children of Parents with a Mental Illness

In adolescents depression is common and it is estimated that by the age of 18, as many as 25% of adolescents will have had at least one depressive episode (Clarke et al. 2001). Adolescents who have parents with a mental illness are at increased risk and are more vulnerable to developing depression, bipolar disorder and other psychopathologies, including anxiety disorders, than offspring of non-ill parents (Lieb et al. 2002; Clarke et al. 2001; Chang et al. 2000; Beardslee et al. 1998).

Estimates of increased risk for young people vary across studies. Lapalme (1997) stated offspring of those with mental illness are four times more at risk of developing a mood disorder compared with offspring of healthy parents. Chang et al. (2000) reported that half the offspring of parents with bipolar disorder will have psychiatric conditions. Using life table estimates, Beardslee et al. (1993) predicted that by the age of 20 a child with an affectively ill parent has a 40% chance of experiencing an episode of major depression, and by the age of 25, that percentage rises to 60%. Severity of parental mental illness also

indicates a greater risk (Beardslee 1998), and leads to an earlier age of onset for offspring, and a more complicated course of illness (Lieb et al. 2002; Chang et al. 2000). Lieb et al (2002) found no gender difference in familial transmission of maternal or parental depression.

Approximately 27,000 Australian children have a mother with a mental illness (Cowling et al. 1995). This represents a significant number of young people at increased risk for experiencing mental illness at some time in their life.

The need for prevention and early intervention

Most adults with recurrent depression have their initial depressive episodes as teenagers, suggesting that adolescence is an important developmental period in which to intervene (Clarke et al. 2001). Preventive interventions for depression are often targeted at adolescence and are generally delivered in schools.

Given the increased risk of developing mental illness for those young people with a parent with a mental illness, a targeted intervention would appear to be warranted. Early detection of mental health issues in this group may lead to treatment of early manifestations before they develop into categorical mental illness (Lieb et al. 2002; Chang et al. 2000). There is some evidence that psychosocial intervention for offspring of parents with a mental illness may prevent depression (Beardslee et al. 1993). A recent study by Clarke et al (2001) trialled a cognitive intervention for offspring of depressed parents and found positive effects on its participants.

However identifying children whose parents have a mental illness is can be difficult. Firstly, the parents must be identified. Hospitals often do not enquire or record information regarding the dependent children of those admitted. It is also difficult to identify children of parents who do not require hospitalisation and are unknown to health services. While there is a need for improved recognition of these children in order to implement such interventions (Ramchandani & Stein 2003), there may need to be a broader focus than just depression.

Informing young people for coping and caring

While the increased risk of developing a mental illness is an important consideration, young people need skills and information about how to cope with and care for their parent with a mental illness. These parents often perceive their children, including older children, as too young to understand their illness (Handley et al. 2001). While this may be true to some extent, children worry about their parents and want to take care of them. However

they may find it difficult to talk about their parent's illness, and can feel embarrassed by it. While they struggle to understand and recognise the signs of their parent's mental illness, it is significantly more difficult to cope when they are uninformed, and/or receive conflicting information from different members of the family (Handley et al. 2001) about the illness. Therefore, there is the potential to enhance the coping and caring skills of children through programs that address the needs of all family members (Handley et al. 2001).

Adolescents as young carers

A young primary carer is defined as 'someone up to 25 years of age who is the main provider of care and support for a parent, partner, child, relative or friend who has a disability, is frail aged or who has a chronic mental or physical illness' (Department of Family and Community Services, 2001, 6). It is estimated that there are 388,800 carers under the age of 26 years in Australia, representing 17% of all carers in Australia, and that 18,800 of these are primary carers. It is estimated that a further 6 - 10% of young people under 26 are informal carers. One quarter of young carers provide care for someone with a mental illness (Australian Bureau of Statistics, 1998). These figures probably underestimate the total number of young carers in Australia, as many young people are not identified as carers.

The Young Carers study also found that 60% of young primary carers aged 15 – 25 years were unemployed, or not in the labour force (compared with 38% for the general population in this age group). Only 4% of young carers aged 15 – 25 years were still at school compared with 23% of the general population in this age group (Carers Australia September, 2001).

Young carers have been a hidden and unsupported group in Australia. Carers Australia believes the primary contributing factors to this are a complex range of social and cultural values, beliefs and attitudes that result in a lack of self identification, and a general lack of awareness of young carers by: the government; key professionals in sectors such as health, welfare, community care, education and disability; and the wider community.

The literature concerning young carers indicates that, 'if the basic rights and needs of young carers were met, the negative effects associated with their caring role could be significantly reduced' (Carers Australia, 2001, 3). Recommended supports for young carers include:

- Recognition, understanding and respect

- Age appropriate information on illness and disability and about their rights as young people and carers
- Informal and formal support, most critically from a person who they can talk to and trust
- Access to appropriate, flexible and affordable services, such as respite that meets their specific needs
- The opportunity to enjoy their childhood and youth, and reach emotional and social maturity through having choices and access to full social and economic participation.

The PATS program recognises the caring role that many participants take on within their families. PATS provides the opportunity for young people to explore their caring roles within the eight-week group, and assists young people and their families to access community supports.

1.2 Program Overview

Young people caring for a parent with a mental illness face an increased risk of emotional difficulties. The PATS program is designed to equip young people with strategies and experiences that foster resilience.

In response to an identified gap in the nature of services available for young people with a parent with a mental illness, the PATS program was piloted in 1996 by the Centre for Adolescent Health, and funding was obtained to continue the project in 1997. PATS is a prevention/early intervention strategy using peer support for young people who have a parent with a diagnosed mental illness. PATS is not designed as a traditional therapeutic intervention – rather it is a support program incorporating:

- an eight-week group work program, with a maximum of eight 13 – 18 year old participants
- a mental health worker and a peer leader
- a combination of structured content on mental health/illness literacy, coping strategies and help-seeking information; and participant guided issues, experiences and activities
- sharing personal experiences, rather than receiving professional advice
- post program extended involvement: recreational and social activities; leadership training; group leadership; and planning and program implementation.

Aims and Objectives

PATS is a peer support program that aims to provide young people who have parents with mental health issues with the opportunity to:

- share their experiences
- be supported by other young people in a situation similar to their own
- reduce their risk of developing mental health difficulties
- focus on mental health promotion and illness prevention.

The objectives of PATS are to:

- increase young people's knowledge of mental health and illness
- improve their help seeking behaviour and coping strategies
- improve their sense of connection to their peers, family and community.

The Centre for Adolescent Health has developed PATS based on a model of peer support that has been evolving over a number of years. The Centre's concept of peer support is the bringing together of young people who share common health and wellbeing concerns. Using adolescent development and youth participation principles, young people and health professionals work in partnership to generate a sense of community, belonging and acceptance. Peer support occurs in groups and with individuals through discussion, reflection, exploration, skill development and socialising.

Target Group

PATS is targeted to young people aged 12 – 18 years who have a parent with a mental illness such as schizophrenia, bi polar disorder, depression, anxiety disorders or borderline personality disorder. It is a diverse group for which Falkov (2004) identified a spectrum of need. Some young people:

- appear well
- are resilient but need support
- are vulnerable and need services
- are vulnerable and in need of protection from risk of injury.

Young people may move in any direction along this spectrum of need across their lifetime.

Pre program Interview

The pre program interview is an important opportunity for engagement, and to ascertain if the program is appropriate for the young person. PATS facilitators meet individually with each young person and their families or workers prior to their entry into the program.

Eligibility Criteria

The key questions for workers in ascertaining if PATS is appropriate for a young person include:

- *Is the young person interested in coming to the group?*
PATS is a voluntary program in which participants need to have some degree of interest in taking part in the group. It is important for the young person to make a choice about participating in the program. They should not be forced to participate.
- *Does the young person have support outside the program?*
Young people need some stability in their life in order to take part in PATS. Supportive structures can be derived from their school, family, or youth and community services.
- *Will participation in PATS benefit this young person or is there potential for their participation to result in family conflict?*
A parent may be reluctant for their child to participate in the program or the unwell parent may deny experiencing mental health problems. It is advisable in these instances to address the parent's concerns, and if the issues are not resolved, to postpone the young person's involvement. Increasing tension within the young person's family would be counterproductive to the goals of PATS.

At times it may be recommended that the young person take part in individual counselling, and the family be linked into support services, as a first step towards accessing the program.

Exclusion Criteria

If the young person has their own mental health or behavioural issues the following should be considered:

- The young person needs to have some capacity to be able to reflect on their own and others' situations.
- PATS does not have a clinical treatment focus, therefore, support for a young person experiencing their own mental health problems needs to be addressed prior to attending the group.

- The young person's developmental level is important in terms of relating to the other participants in the group. Assessment regarding each individual should take into account their age, cognitive abilities and social skills.

Peer Support Groups

The core focus of PATS is the peer support group. Groups comprise six to eight young people who meet weekly for eight weeks. The groups are facilitated by a peer leader (a young person whose parent has a mental illness) and a health professional.

Topics covered in the group include:

- Understanding your parent's illness
- Improving your relationship with your parent
- Communication and problem solving skills
- Dealing with the stigma associated with mental health
- Strategies for coping with your parent's condition and staying mentally healthy.

The focus is on healthy thinking and healthy coping strategies. Group activities include discussion, games, role-plays, art and craft, guest speakers and social outings.

PATS takes a flexible approach to planning and delivering the content of each session. The young people are involved in generating the topics and focus for each weekly session. No two groups, therefore, are exactly the same. Peer led programs acknowledge young people's skills and their role in finding solutions and supporting each other through the challenges in their lives. The role of workers and peer leaders of PATS groups are to facilitate the young people in supporting each other, and to provide education around mental health and illness. The focus is on building connectedness in the groups between young people by:

- *Normalisation* recognises that many families are affected by mental illness and that acknowledging the range of reactions, emotions and effects of this can have a positive effect on a young person and their family.
- *Acceptance* focuses on assisting the young person to come to terms with their parent's illness.
- *Decreasing isolation* ensures the young person no longer feels alone in their situation.

Co- Leadership

The role of the peer leader is a crucial component of the PATS program. The peer leader can be given responsibility for the social aspects of the groups, organising activities and getting the participants mixing and talking. They act as a positive role model for the group and are able to share their own experiences and coping strategies.

Leadership Training and Advocacy

PATS leadership training gives young people the opportunity to further develop their skills and confidence. The training covers such areas as peer support, mental health and illness, communication skills, group dynamics, leadership skills, public speaking and activity planning.

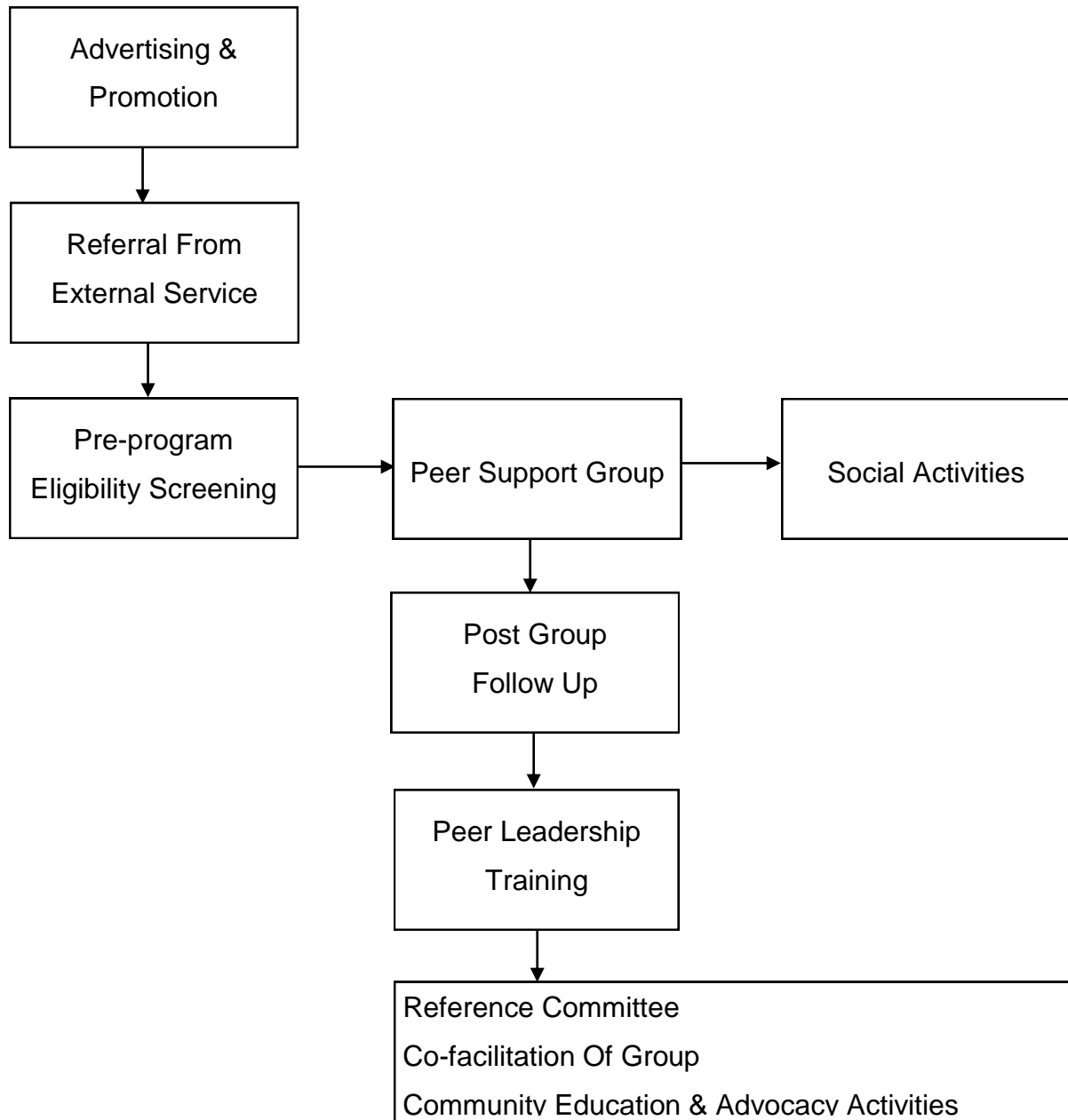
Peer leaders are provided opportunities to educate the community and advocate on behalf of other young people. This includes speaking at conferences and co-facilitating workshops with the health professionals. PATS also has a strong commitment to advocacy on a broader political and community level. In addition to community perceptions and stigma, the program recognises the many contextual factors in our community, such as access to housing, employment, financial assistance and health care, which impact on the experience of mental illness. PATS empowers young people and their families to work towards change in community perception of mental health and illness and to advocate for change in the way services support these families. Each program site is encouraged to form a young person's reference group to assume a role of advocacy, consultation and feedback in the wider community.

PATS Socials

Each school term social and recreational activities are held for PATS participants. These provide the opportunity to continue friendships and support after the eight-week group has been completed, and to meet young people from other groups.

Below is the model of the PATS program. The program works at a number of levels including individual, group, and community.

Figure 1 PATS Program Model



1.3 Theoretical Underpinnings of PATS

Youth Participation

A core practice framework of the PATS program is youth participation. A common definition used to describe youth participation is that of the Australian Youth Foundation (1996):

'Youth participation is about developing partnerships between young people and adults in all areas of life so young people can take a valued position in our society, and the community as a whole can benefit from their contribution, ideas and energies.'

The Youth Affairs Council of Victoria and the Office for Youth state that 'youth participation involves young people being active in decision making processes on issues that affect them'. In any democratic society it is important that all members have opportunities to participate in the decision making processes that affect them and their communities (Office for Youth, 2004).

There are numerous benefits to both young people and organisations from involving young people in youth services. For young people this includes:

- Recognising the rights of all people to be involved in decision making that affects them
- Respecting young people's citizenship *now*
- Recognising the capacity of young people and building their capacity
- Building connectedness with their community
- Empowering young people
- A sense of belonging
- Provision of supportive adult relationships
- Contributing to their community and developing a sense of mattering
- Building confidence in one's abilities to master one's environment (Australian Youth Foundation 2000; Wierenga et al. 2003; Eccles and Gootman 2002).

Recently, nationally and internationally, there has been increasing and renewed emphasis and interest in youth participation. Commonly federal, state and local governments involve young people in Youth Roundtables, Youth Advisory Committees and Youth Councils, or seek input from young people on specific issues. In these roles young people take on an

advisory function to the department or council, and often initiate their own projects (Wierenga et al, 2003).

Similarly, schools generally have a student representative council to provide advice to the school on issues affecting students. More recently Student Action Teams, in which students undertake projects of wider community concern using the school infrastructure, are being established (Wierenga et al, 2003).

In the community sector there are examples of young people taking on governance roles, such as in the Foundation for Young Australians, in which young people are actively involved in decisions with regard to the allocation of philanthropic funds. Canteen, an organisation for young people who have cancer, involves young people in a range of roles.

In 2004 the Department of Health and Ageing contracted the Australian Infant Child Adolescent Family Mental Health Association (AICAFMHA) to develop a strategy for the voice and perspective of young people to be incorporated into the development and implementation of national programs funded under the National Mental Health Strategy (NMHS) and the National Suicide Prevention Strategy (NSPS).

Wierenga et al (2003) identify some key elements of successful youth participation projects:

Meaning: Young people are involved in doing something in which they can believe, and has a bigger purpose. It is about recognising young people as able to make a meaningful contribution, and as co-creators in their community.

Control: Young people are able to make decisions, be heard, and are equipped with the skills and resources to do the task well.

Connectedness: Young people work with others and are part of something bigger (Wierenga et al. 2003). Youth participation has the capacity to build connections between young people and their communities.

Thus youth participation is not just a matter of working with young people. There needs to be work undertaken with adults as well as young people, to promote the rights of young people to participate. Holdsworth (2001) stated that participation and teaching and learning new skills, needs to be undertaken using a transformative approach, to transform, and support the learner in transforming the world. Equally, for youth participation to be effective, a strong commitment needs to be built into organisational structures.

In reviewing youth participation it is equally important to consider the challenges, for both young people and organisations, associated with involving young people in decision making. As Kirby and Bryson (2002 cited in Wierenga et al. 2003) stated, 'involving young people badly may do more harm and cause more cynicism than not involving them at all'.

PATS is committed to engaging with and developing opportunities for participation with young people who are marginalised and disadvantaged. Many participants in PATS, because of the chaotic nature of their home situation or lack of attendance at school, may miss out on traditional opportunities for participation and leadership. PATS aims to provide opportunities for skill development and participation within the program, which may be attractive to well functioning and resourced young people.

Hart (1992) developed a widely used conceptual model for considering the different levels of participation. It recognises that what can appear to be participation may be more tokenistic, and may not involve much participation for young people.

The model is as follows:

8. Youth directed and initiated
7. Youth initiated, shared with adults
6. Adult initiated, shared decisions with youth
5. Consulted and informed
4. Assigned but informed
3. Tokenism
2. Decoration
1. Manipulation

In PATS the program generally moves through the stages of consulted and informed, through to level 7, youth initiated and shared with adults. The issues outlined need to be considered to enable participation for all young people.

Why a peer support model?

Peer interventions have been used in many areas with adolescents including drug and alcohol prevention, HIV/AIDS awareness, school bullying, chronic illness and now for adolescents who have a parent with a mental illness. Clear definitions of peer support are lacking in the literature, with peer support and peer education often used interchangeably. Shiner (1999) outlined a number of problems surrounding the literature of peer

interventions, stating that the concept of 'peer' is often not clearly defined, and that programs often fail to define the nature of peer involvement in interventions.

While there are many advocates of peer based interventions, and many descriptive studies have been written detailing projects, there has been a lack of formal evaluation and evidence relating to their efficacy (Ward et al, 1997 in Shiner, 1999). Hence the importance of the PATS study.

Peer support programs are based on the premise that bringing young people together in a group format can reduce feelings of isolation, provide an opportunity to meet new people and establish friendships. They assist young people to be aware that there are people their own age with similar experiences and issues. It is hoped that this awareness increases the sense of belonging and social connectedness (Bettencourt et al, 1998; Milburn, 1996; Olsson et al, 2005).

Projects commonly report that through their sharing, participants are able to see how others deal with problems. They are able to see alternative perspectives and solutions to problems and learn to develop and apply coping skills. Potential outcomes for peer based interventions include learning social skills, learning to share, comfort, help and empathise with others (Bettencourt et al, 1998; Milburn, 1996; Turner, 1999; Olsson et al, 2005)

It has been documented that peer leaders also gain from their involvement in peer based interventions. Peer leadership provides participants with leadership experience, offers young people participation in meaningful roles and assists their personal development. Consequently, young people learn about themselves and may feel a sense of worth from contributing to and helping the lives of other young people (Bettencourt et al, 1998; Milburn, 1996; Olsson et al, 2005)

Mental Health Literacy

'Mental health literacy' traditionally refers to people's level of knowledge about mental illness. It consists of several components and relates to a person's primary knowledge and beliefs about risk factors, causes and types of professional help available. Mental health literacy is focused on empowering people who experience mental health problems, and enabling them to seek help for themselves. It is important, as the more knowledge people have about mental illness, the earlier they are able to identify mental health issues in themselves and in others around them (Jorm 2000; Jorm 1997).

Mental health literacy is extremely important for adolescents who have a parent with a mental illness, particularly due to the increased risk of them developing their own mental health problems. By increasing their knowledge and awareness of the risk factors, causes, services available and how to access them, they are in a stronger position to help themselves should issues arise. Mental health education also fosters better relationships within families by increasing the young people's understanding of their parent's illness.

Stigma

Stigma surrounding mental illness is created by misunderstanding, misinformation and myths. People with a mental illness are often viewed as dangerous, distrustful and to be avoided. These labels and stereotypes create negative attitudes towards people with mental illness and lead to fear, embarrassment and avoidance. Experiencing reactions of this nature, people with a mental illness are more likely to disengage with the community, thus creating feelings of isolation, and limiting opportunities for employment and social interaction. This impacts negatively on their cognitive, emotional, social and behavioural development and functioning (Ramchandani & Stein 2003; Pinfold et al, 2003; Ostman & Kjellin, 2002; National Mental Health Awareness Campaign, 2005).

Stigma does not only affect those with a mental illness, it also affects their family and friends. Research has found that stigma by association can have lasting psychological effects on those around a person with a mental illness. Relatives of those with a mental illness have reported difficulties in having friends come to their home and maintaining and developing relationships with others (Ostman et al, 2002). Further, young people experience difficulty disclosing that they have a parent with a mental illness to teachers and friends at school, thus creating a level of isolation for themselves.

By increasing education and awareness of mental illness in the community, the level of stigma and discrimination experienced by people with a mental illness and their family could be dramatically reduced (Commonwealth Department of Health and Family Services, 1997).

Depression

Depression can be characterised by a low mood, lack of energy, decreased enjoyment and interest in activities and general living, lack of concentration, sleep disturbances, and diminished appetite. People with depression often have low self esteem and self-confidence, and find it hard to function from day to day (Australian Institute of Health & Welfare, 2004). Depression has also been associated with increased levels of alcohol, cigarette and illicit substance use (beyondblue, 2004). In Australia depression will affect

one in four females, and one in six males (beyondblue, 2004), and 2-5% of young people will experience depression.

Children of parents with depression are at increased risk of a number of mental health problems. Half the children of parents with depression will at some point experience depression themselves during their childhood or early adulthood (Hammer et al. 1998; Weissman, 1997 in Olfson et al, 2003). Parental depression is associated with adverse effects on children's mental health, and depression is twice as likely in children of parents with depression as those without (Olfson et al. 2003).

Homelessness

At the time of the 2001 Census 99,900 people in Australia were homeless. 26,000 of those homeless were young people between the ages of 12 and 18 years (Australian Bureau of Statistics, 2001). Homelessness is a transition that occurs over time and the reasons for young people's homelessness are as varied as they are complex.

Studies have shown that conflict within the family is a significant factor in young people becoming homeless (Hyde, 2005; Mallett et al, 2005). In a Los Angeles study, Hyde (2005) found that 75% of homeless young people reported being raised in single parent households for much of their childhood. The majority of those had experienced reconfiguration of the family home through parents re-partnering or blended families. Conflict can arise due to differences in expectations between young people and their step-parent. Mallett et al (2005) found that young people often felt alienated and marginalised, if not victimised. Differing expectations between young people and step-parents in relation to participating in blended family life, school and employment, were also sources of conflict within the home (Mallett et al, 2005). Young people from single parent and blended families are at seven times higher risk of homelessness than adolescents from nuclear families (Chamberlain & MacKenzie 1998). Additionally, Hyde (2005) found that abuse and conflict within the home could also be attributed to parents' substance abuse (30%). Often leaving home is a measure young people take to protect themselves from further emotional and physical danger (Hyde 2005).

2 EVALUATION

In June 2002 the Centre for Adolescent Health received three-year funding to pilot the PATS program and evaluate its implementation in five locations across Victoria. Funding bodies consisted of the beyondblue national depression initiative, the Department of Human Services, Victoria, and VicHealth. The lead agency, the Centre for Adolescent Health, coordinated and facilitated the dissemination of the program across five sites and undertook evaluation of program implementation, and of the impact and outcomes on PATS participants. The partner sites were:

- 1 Urban/rural fringe of Melbourne: a local government agency on the urban/rural fringe, with extensive and active youth focus, serving the eastern suburbs out to rural areas in the Great Dividing Ranges.
- 2 Inner/middle suburban Melbourne: a State Government funded community health organisation located in the inner southern suburbs with a small but active youth focus, serving the south east inner to middle suburbs.
- 3 Regional centre: a State Government adolescent mental health service located in a major regional hospital with dedicated youth specialists, serving a large area of north-central Victoria.
- 4 Regional centre: a large non-government community support organisation with a very small youth focus, serving a large area of Western Victoria.
- 5 Inner city Melbourne: associated with large central hospital, a multi disciplinary state-wide centre comprising clinical services, education, research, community programs, focus on the western and inner northern suburbs. Dedicated youth focus.

The aims of this evaluation were to:

- provide information about young people and their families, where a parent has a mental illness
- investigate the impacts and outcomes that arise for young people who participate in the PATS program
- document the participants' experience of the PATS program
- investigate the implementation and sustainability of the PATS program
- investigate the broader organisational and community capacity building of the PATS program.

2.1 Impact and Outcomes of Participating in the PATS Program

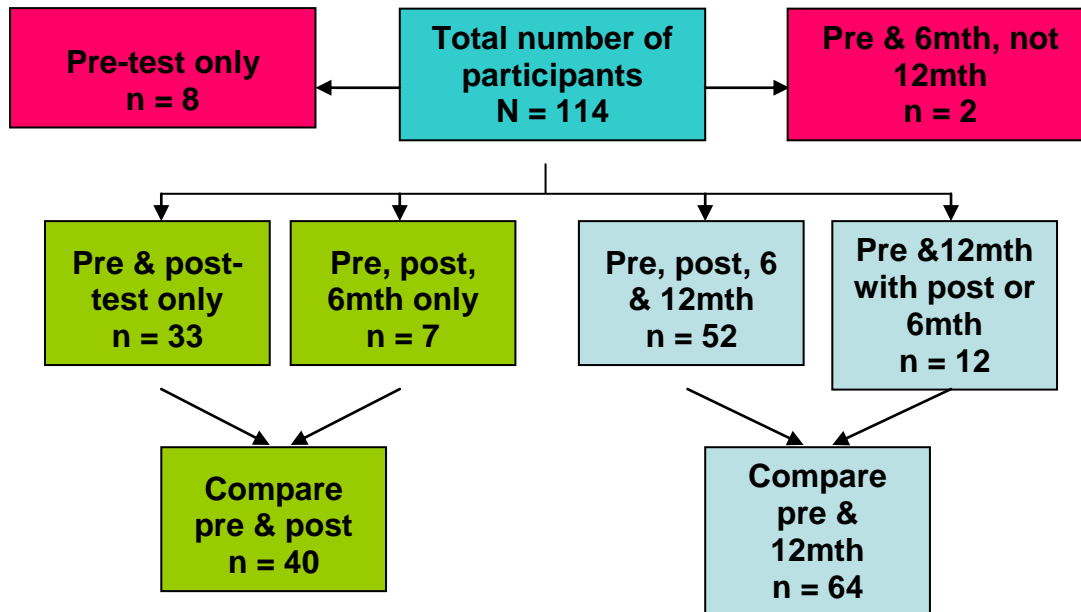
Research design

The study design to assess the effect of the PATS program on participants was a simple pre and post test, with six and twelve month follow up after participation in the PATS program. While recognising that a controlled trial would provide stronger evidence of effect, a wait list control design was not feasible at the time of the study.

Methods

Participants were surveyed using paper and pencil questionnaires, designed to be completed in no more than 30 minutes. The pre-PATS questionnaire was administered on the first night of the group session and the post PATS questionnaire on the last night of the sessions by the site coordinators and facilitators (see figure 1). The six-month and twelve-month follow-up questionnaires were mailed out to participants for completion and return, with some questionnaires being administered by phone when responses were not received. Figure 1 shows the number of participants in the study who completed each wave of data collection. The structured questionnaire included demographic information about the young people, and a range of measures and questions to investigate the impacts and outcomes of the PATS program on participants. On completion of the structured questionnaire at the post intervention, six-month and twelve-month follow up, waves 2, 3 and 4, participants were asked for feedback on the program, and to reflect on their experience of PATS using a format of Likert scales and open-ended questions.

Figure 2: Number of participants in the study who completed each wave of data collection



Measures

Where possible, all measures were chosen to be relevant to, and have been trialled with young people. For some aspects of the program, however, there were no existing measures. From discussions with program leaders and previous PATS participants, several measures, such as self-care and mental health literacy, were developed to assess the impact of specific components of the program. The impact measures included to assess the effects of specific program aims included mental health literacy, stigma, burden of caring for a parent with a mental illness, social support and social problem solving skills. The major outcome measures were depressive symptoms and positive emotional wellbeing. Risk of homelessness and substance use were also assessed. To be able to describe the PATS participants, socio-demographic measures and questions about school and work experiences were also collected.

Impact measures

- To assess **mental health literacy** the project team constructed a set of questions asking about young people's ability to access mental health services for themselves and their parents. Participants were also asked if they could name their parent's mental illness.
- **Stigma** has been identified as a major issue faced by this group of young people. PATS specifically targets reduction of stigma. To assist in developing participants' skills in dealing with stigma, participants were asked how much they agreed with the following statements:

1. I worry about what my friends think about my parent's mental illness.
2. I have no problem telling people about my parent's mental illness.
3. I feel uncomfortable when people ask me about my parent's illness.
4. Sometimes I feel embarrassed about having a parent who is affected by mental illness.

Responses to these questions were collated to provide a total score. Participants were also categorised as high, moderate or low on this scale.

- The Montgomery Borgatta Caregiver Burden Scale (Montgomery and Borgatta 2000) was adapted to measure the **burden of caring for a parent with a mental illness**. Subscales included: an assessment of tangible aspects of caring (for example, time taken); how demanding the responsibilities were; and the emotional impact on the carer. For each subscale, participants were categorised as having high, moderate or low demands as described by Montgomery & Borgatta.
- **Social support** was measured using the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al. 1988). This includes three subscales: family, friends, significant other and a total score.
- **Social problem solving skills** was assessed using the Social Problem-Solving Inventory-Revised-Short and Modified Self Report Coping Scale (SPSI-R-S); (Chang and D'Zurilla 1996). This scale produces four subscales assessing different types of coping skills and a total score. The total score was standardised as per the manual, where the average score is 100 with a standard deviation of 15.

Outcome measures

- **Depressive symptoms** were measured using Angold and Costello's Short Mood and Feelings (SMF) self-report questionnaire designed for epidemiological survey research with adolescents (Angold et al. 1995). This single dimension scale correlates substantially with the Children's Depression Inventory and the Diagnostic Interview Schedule for Children (DISC) depression scale. The SMF has been shown to discriminate between clinically referred psychiatric subjects and DISC diagnosed children from controls (Angold et al. 1995). As recommended by the authors of the scale, high levels of depressive symptomatology were defined by a score of 12 or greater on the SMF (Angold et al. 1995).

- **Positive emotional wellbeing** was assessed using a 13-item subscale of the Psychological distress and well-being measure developed by Veit and Ware (1983). This measure has good psychometric properties.
- Anecdotal evidence from PATS Coordinators suggested that many young people with a parent affected by mental illness can have issues concerning their security and happiness at home. PATS specifically targets improving participants' connectedness to home and family. **Risk of homelessness** was assessed using the questions developed by Chamberlain and McKenzie's National Census on Homelessness (1998). Participants were asked how much they agreed with the following statements:
 1. I get into a lot of conflict at home.
 2. I would like to move out of home soon.
 3. I feel happy at home.
 4. I feel safe at home.
 5. I have run away from home.

Possible and high risk of homelessness was calculated according to the criteria defined by Chamberlain and McKenzie (1998).

- Participants were asked about **substance use** including, drinking, smoking, cannabis use, and other drug use for non-medical purposes. The alcohol questions included frequency of drinking in the last school term, and frequency of binge drinking (defined as having five or more alcoholic drinks within a couple of hours).

Other descriptive measures

- Participants were asked a number of **socio-demographic questions** including age; ethnicity; family structure (parents living together or not); parents' employment; which parent is affected by mental illness; and whether they live with that parent. Participants were also asked to name the mental illness affecting their parent(s) to help ascertain the level of knowledge of mental illness:
- Participants were asked a number of questions about their experience of **work and study**. Work and study environments can be either stressful or positive for young people. These questions included an assessment of positive or adverse experiences of study environments, their attendance and academic achievement. Participants were also asked about their involvement in co-curricular activities in school and out of school and leisure activities outside work.

Comparison data

Where possible, data from the Adolescent Health and Well-being Survey conducted in 1999 by the Centre for Adolescent Health has been used to compare the PATS participants with a representative state-wide school-based sample of young people (Bond et al. 2000). This study provides information from a large representative sample of approximately 9,000 secondary school students aged between 13 - 17 years. It shares many of the same questions and measures used in the PATS survey, including demographics, risk of homelessness and depression.

Assessing the experience of PATS

At the completion of the questionnaires for waves 2, 3 and 4, each young person was asked for feedback on the program, and to comment on the outcomes they perceived they had gained from their participation in PATS. This section of the questionnaire asked open ended questions, and presented a series of statements with a 4-point Likert scale (strongly disagree, disagree, agree, strongly agree). Questions focused on areas such as the usefulness of the program, knowing more about parents' illness, and enjoyment. The open-ended questions enabled the participants to provide more detail on what they learnt from the program.

Data analysis

Data were analysed using STATA statistical software system release 7 (StataCorp. 2001). To assess change over time, for categorical variables, McNamar's test was used. Repeated Measures ANOVA was used to assess change over time for continuous measures.

Responses to the open questions were analysed for themes emerging. These are summarised below. Quotations from the participants are included to illustrate the themes, and allow the young people's voices to be heard.

Results

Participation and attrition

The total number of participants was 114 for the period Term 3 2003 to Term 2 2005. Sixty-four (56%) provided data for all 4 surveys (pre-intervention, post intervention, 6 months and 12 months later). Forty completed the pre and post intervention surveys only. Figure 2 (above) shows the number of participants who completed the questionnaires for each wave.

Socio-demographics

Table 1 provides information about the participant's age, ethnicity, family structure, level of parent employment, and includes comparable information from the Adolescent Health and Wellbeing Survey (Bond et al. 2000). There are significant differences between the PATS participants and the school sample in terms of parents living together (25% PATS participants versus 70% Victorian sample) and in parents' paid employment.

Table 1 The demographic characteristics of the PATS participants

	Females	Males	Total	Victorian school sample
	n=78	n=36	n=114	n=8,809
Age (mean, se)	14.6	13.9	14.3 (1.7)	14.0
Ethnicity				
Australian born (%)	96.1	91.7	94.7	n/a
Aboriginal or Torres Strait (%)	6.5	2.9	5.4	n/a
Language other than English spoken at home (%)	5.1	8.3	6.1	5.4
Family structure (%)				
Parents live together	26.0	22.2	24.8	69.7
Separated/divorced	53.3	66.7	57.5	17.1
Other	20.8	11.1	18.4	2.3
Parent employment (%)				
Mother in paid employment	29.2	45.7	34.6	52.0
Father in paid employment	59.7	44.1	54.7	75.0

Impact and outcomes of living with a parent with a mental illness

Table 2 provides details about the impact and outcomes of living with a parent with a mental illness. In the majority of cases, it is the mother who has a mental illness. For about 10% of participants, both parents are affected. The majority of participants live with the parent who is affected.

Table 2 Impact and outcomes of living with parent with a mental illness

	Females n=77 %	Males n=36 %	Total n=114 %	Community or school-based representative samples			
Who in family is affected by a mental illness (%)							
Mother	60.3	70.59	63.6				
Father	11	23.53	15				
Both parents	15.07	2.94	11.21				
Other	12.33	2.94	9.34				
Lives with parent affected by a mental illness (%)							
	81.33	64.71	76.15				
Burden of care for young person							
Tangible aspects of care (e.g. time)							
Moderate	59.4	78.8	65.7				
High	37.7	18.2	31.4				
Burden of responsibility							
Moderate	41.7	44.4	42.6				
High	37.5	25.0	33.3				
Emotional impact on carer							
Moderate	16.4	33.3	22.0				
High	76.7	63.9	72.5				
Mental health literacy							
Able to ask for help for self	86.4	81.3	84.7				
Able to ask for help for parent for services	69.9	69.7	69.8				
Have an emergency plan	33.3	38.3	34.9				
Stigma							
Moderate	20.3	16.7	19.2				
High	21.6	30.0	24.4				
Social support (mean, sd)*							
Family	4.6	(1.4)	4.7	(1.3)	4.7	5.8	(1.1)
Friends	5.0	(1.6)	4.4	(1.4)	4.9	5.9	(0.9)
Significant other	5.4	(1.5)	5.0	(1.1)	5.3	5.7	(1.3)
Total	5.0	(1.2)	4.8	(1.0)	5.0	5.8	(0.9)
Social Problem Solving (mean, sd)*							
Converted to standardised score**	9.8	(2.9)	10.3	(2.1)	9.9	11.2	(2.5)
	91		94		92	100	
Risk of homelessness**							
possible risk	26.7		20.6		24.8	11.0	
high risk	13.3		11.8		12.8	4.0	
Depressive symptoms (%)**							
	54.6		50.0		53.2	18.0	
Psychological wellbeing (mean, sd)							
	46.1	(14.0)	49.7	(13.7)	47.2	(14.0)	

*Normative data from manual or originating sample

**Victorian school-based representative sample

Following is a list of some mental illnesses by which participants report their parents are affected:

- bipolar disorder
- schizophrenia
- multiple personality disorder – disassociative identity disorder
- post traumatic stress disorder
- obsessive compulsive disorder
- social phobia
- anxiety, panic attacks
- depression
- borderline personality disorder

In context of mental health literacy, a large majority of participants report being able to seek mental health services for themselves and their parents prior to participation in PATS.

For social problem solving the PATS participants score lower than the reported norms, but fall within the average range (D’Zurilla et al. SPSI-R Manual 2002).

Table 2 also reports levels of risk of homelessness, prevalence of depressive symptoms and stigma at baseline. The percentage of PATS participants who are at possible or high risk of homelessness is significantly higher compared with that of a representative sample of young Victorians. The percentage of participants reporting depressive symptoms is three times higher than that for a representative sample of young Victorians. Unlike the population estimates, the prevalence of depressive symptoms for male PATS participants is similar to that of females. This contrasts sharply with the Victorian data, where females at 23% were much more likely to report symptoms of depression than males at 12%

Experiences of school, extra curricular activities and substance use

Table 3 summarises participants’ experience of school, involvement in extra curricular activities and their substance use at baseline. About 30% reported having worries or problems with school. A large proportion, compared with the Victorian sample, report suspension from school. Substance use did not appear to be very different from their peers.

Table 3 School experience and risk behaviours

	Females n=77	Males n=36	Total n=114	Victorian sample 9000
School experience				
At school (%)	86.7	90.9	88.0	100.0
Further study (%)	5.3	0.0	3.7	
Left school, no full time work (%)	8.0	9.1	7.4	
School is a good part of life	33.8	20.0	29.7	n/a
Problems & worries at school	29.6	20.0	26.7	n/a
On average good/very good marks at school	60.3	51.6	57.7	n/a
Have been suspended from school	23.0	54.3	32.7	10
Have been expelled from school	1.3	11.4	4.5	
Extra curricular activities				
Organised by school	57.9	57.1	57.7	n/a
Organised outside school	52.7	54.3	53.2	
Go out with friends	83.3	88.0	84.8	
Alcohol use				
Never drink	50.7	65.5	54.7	30.7
Binge drink	35.1	16.7	29.9	18.6
Cigarettes				
Never smoked	61.3	76.7	65.7	45.2
Regular smoker	22.7	16.7	21.0	22.8
Marijuana				
Never tried	76.0	75.0	75.7	81
Tried once or twice	16.0	14.3	15.3	nc
Regular use (1-2 a month or more often)	8.0	10.7	8.7	nc

n/a not available

nc not comparable

Trajectories of impact and outcome measures from pre-intervention to 12 months post-intervention

Table 4 presents the data from the 64 participants who completed all waves of data. There were significant reductions in levels of stigma, risk of homelessness and depressive symptoms over the 12-month period. Scores on psychological wellbeing increased on average by 5 points over that time, indicating a moderate effect (a third of a standard deviation), however this was not found to be statistically significant.

Table 4 Burden of care, social support, problem solving and mental health for those who completed pre, post and 12 month follow up (n=64)

	Pre	Post	6 month	12 month	p-value*
	%	%	%	%	
Burden of care					
Tangible aspects of care (e.g. time)					
High	29.8	50.0	39.6	27.0	.157
Responsibility burden for carer					
High	36.7	37.5	39.6	28.6	.648
Emotional impact on carer					
High	76.7	69.1	70.9	64.1	.100
Mental health literacy					
Able to ask for help for self	87.5	90.2	88.2	86.0	-
Able to ask for help for parent	70.5	82.1	80.4	80.3	-
Have an emergency plan	32.3	35.2	35.7	34.4	-
Stigma					
High	29.8	26.9	23.5	14.5	.017
Total score	8.2 (3.4)	7.9 (4.1)	7.3 (4.1)	6.1 (3.9)	<.001
Risk of homelessness					
Possible risk	27.9	20.4	15.7	9.5	.002
High risk	16.4	11.1	7.8	7.9	
Social support					
Family (mean, sd)	4.6 (1.2)	4.4 (1.2)	4.9 (1.1)	4.5 (1.3)	.311
Friends (mean, sd)	4.6 (1.7)	4.4 (1.5)	5.0 (1.4)	4.9 (1.4)	.021
Significant other (mean, sd)	5.1 (1.5)	5.0 (1.7)	5.4 (1.3)	5.3 (1.4)	.399
Total (mean, sd)	4.8 (1.3)	4.6 (1.3)	5.1 (1.0)	4.9 (1.1)	.084
Social Problem Solving (mean, sd)					
	10.0 (2.3)	9.9 (3.0)	10.4 (2.3)	10.5 (3.0)	.171
Converted to standardised score**	93.0	92.0	95.0	96.0	
Depressive symptoms (%)					
	60.0	55.8	52.7	37.5	.006
Psychological well-being (mean, sd)					
	45.8 (13.3)	45.6 (14.1)	48.4 (14.1)	50.2 (15.1)	.155
Alcohol use					
Binge drink	26.7	16.7	23.64	31.25	.424
Cigarettes					
Smoker	29.3	29.1	32.7	36.51	.226
Marijuana					
Regular use (>twice a week)	3.5	4.4	5.45	6.35	.688

*Categorical variables assessed using McNemars test comparing pre-test with 12 month post intervention. Continuous measures assessed using repeated measures ANOVA

**Where population has mean 100, sd 15

There were no major differences in mental health literacy, burden of care, social problem solving or substance use. There were small increases in the friends social support subscale.

Figure 2 shows the burden of care on participants of living with a parent with a mental illness, in terms of three dimensions: tangible aspects of care (such as time taken to care for parent), the burden of responsibility on the carer and emotional impact on carer.

Figure 3 Burden of Care

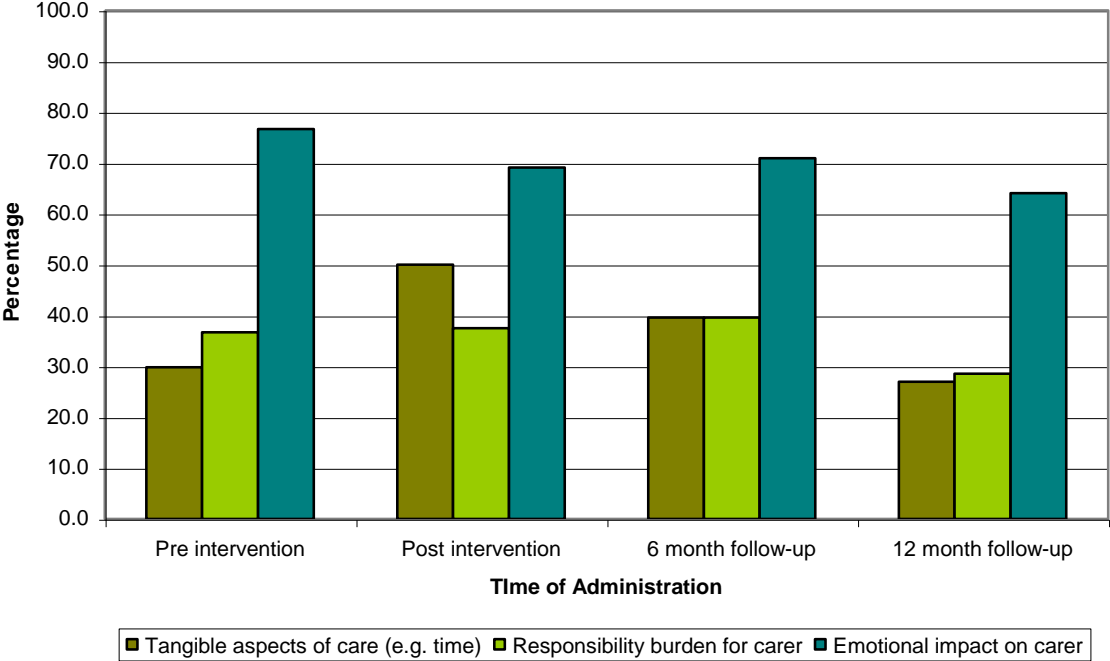


Figure 3 provides details of participants' mental health literacy, in context of participants' ability to ask about help and services for themselves, for their affected parent, and if they have an emergency plan.

Figure 4 Mental Health Literacy

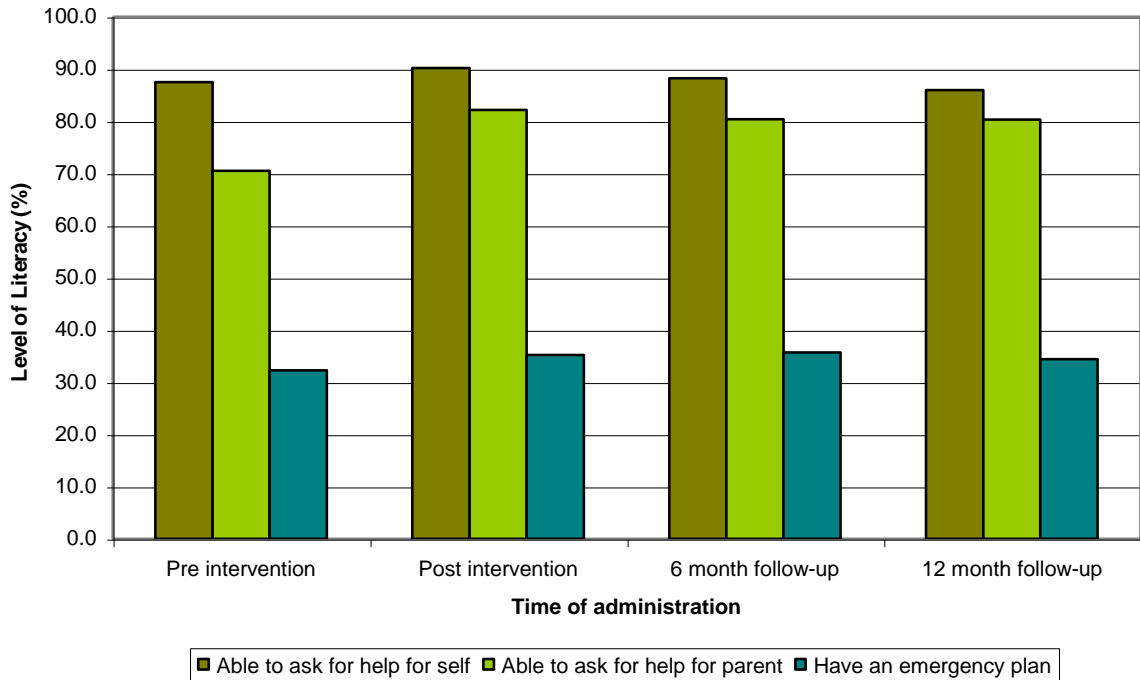
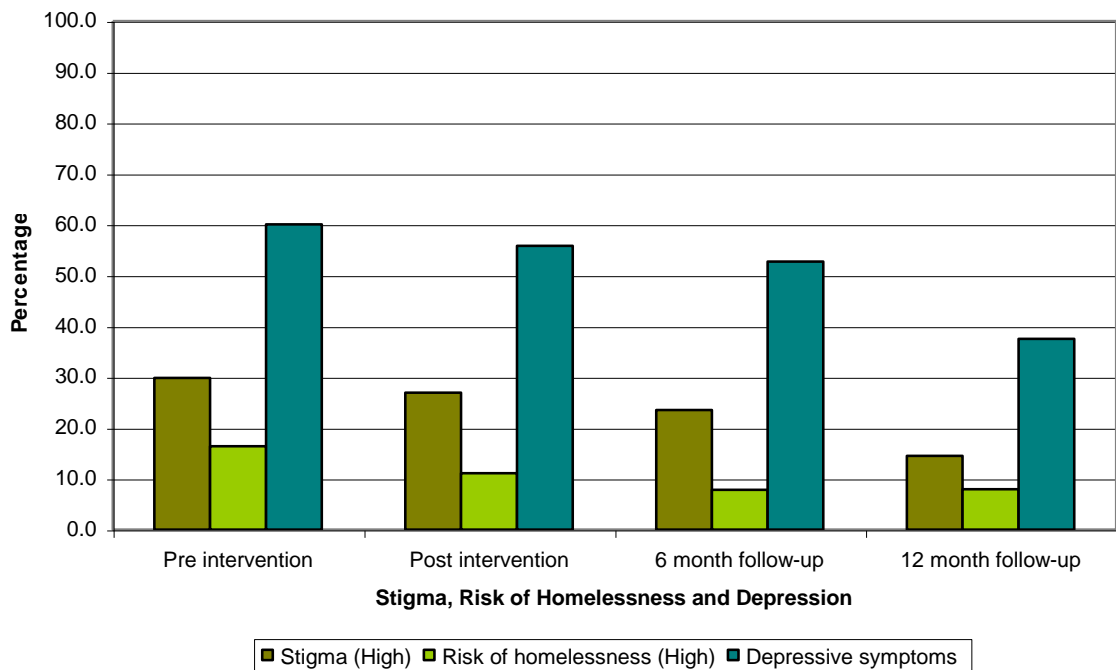


Figure 4 records participants reported symptoms of depression, risk of homelessness and levels of stigma associated with mental illness.

Figure 5 Reported Levels of Stigma, Risk of Homelessness and Depression



To determine if there were differences between participants who completed all the surveys, and those who only completed the pre and post-tests, some sociodemographic factors, some impact measures and assessment of mental health at baseline and at follow-up for the two groups were examined. These comparisons are reported in Table 5. Those who completed only the pre and post measures report fewer depressive symptoms, higher emotional wellbeing, lower stigma and decreased risk of homelessness.

Table 5 Comparison of participants who completed pre- and post intervention with those who completed all waves

	Completed all questionnaires n=64		Completed Pre and Post only n=40	
	Pre	Post	Pre	Post
Age (mean, se)	14.3	-	14.0	-
Ethnicity				
Australian born (%)	95.3	-	92.5	-
Language other than English spoken at home (%)	90.7	-	97.5	-
Family structure (%)				
Parents live together	26.6	-	28.2	-
Parent employment (%)				
Mother in paid employment	31.7	-	38.0	-
Father in paid employment	66.7	-	70.3	-
Mother affected by a mental illness (%)	64.5	-	61.1	-
Burden of care				
High tangible aspects of care (%)	29.8	50.0	33.3	29.7
High responsibility burden for carer (%)	36.7	37.5	29.0	35.9
High emotional impact on carer (%)	76.7	69.1	69.2	61.5
High stigma (%)	29.8	26.9	15.8	5.3
Risk of homelessness (%)				
Possible risk	27.9	20.4	15.8	23.1
High risk	16.4	11.1	7.9	10.3
Social support (mean)	4.8	4.6	5.2	4.9
Depressive symptoms (%)	60.0	55.8	46.0	38.9
Psychological well-being (mean)	45.8	45.6	50.2	51.8

A consumer’s perspective: PATS participant feedback

As described previously, at the completion of the questionnaires, each young person was asked for feedback on the program, and to comment on the outcomes they perceived they had gained from participating in PATS. This section of the questionnaire asked both open ended questions and used Likert scales to rate their experiences.

1. Participant Satisfaction with the program

Table 6 summarises participant satisfaction with PATS. It is evident that at the completion of the eight-week group, the majority of the respondents gave positive responses about their participation in PATS.

Table 6. Participant satisfaction and experience of the PATS program

	Wave 2	
	Strongly disagree or disagree	Agree or strongly agree
After the PATS program	%	%
I found PATS useful	3	97
Know more about parent’s illness because of PATS	1	99
I enjoyed being in PATS	5	95

2. Helpful things learned in PATS

At the end of the program, 84% of participants agreed or strongly agreed with the statement that they had learned helpful things in PATS. Positive responses to the program continued to be reported 6 and 12 months later with 81% and 78% of participants continuing to report that they had learned helpful things during the PATS program. The following provides a summary of the ‘helpful things’ that participants identified:

- *Learning more about my parent’s illness*

A strong theme emerging was the help PATS provided in learning more about their parent’s illness. Young people wrote about an increased ability to recognise the signs and

symptoms of their parent's illness, to understand why their parents were unwell, and that PATS helped them to recognise the 'things that trigger mum'. As one young person stated:

When she has her attacks I know what it is so I can be more prepared not scared like I used to be.

Another young person wrote:

[I learned] more about other illnesses and realising I'm not the only one.

- *Normalisation and reduction in isolation*

The theme of normalisation and reduction in isolation was consistent throughout the feedback. Knowing that there were other young people in a similar situation was seen as a positive outcome of the group for many participants. I learned:

...the knowledge that other people go through the same sort of things.

One young person wrote:

[PATS helped by] explaining mental illness to others and understanding it myself.

- *Increased confidence in seeking help*

Many young people wrote that PATS had assisted them to understand when and where to go for assistance, and increased their confidence in asking for help, as the following quotes illustrate:

- *Just to ask for help if I need it.*
- *What to do in situations when my mum is unwell, and emergency numbers.*
- *How to cope better when my mum gets angry, an episode, how to calm her down and ask for help.*
- *Dealing with issues, & services and how they can help you. Places to go, support, services.*

- *Understanding and empathy of their parent's experience*

A number of young people wrote that PATS had helped them to understand things from their parent's perspective, which in turn, they felt had helped them to communicate more with their parent and manage the situation better. PATS helped me 'see how mum feels and what it's like to be in her shoes'.

- *Reduction of blame*

Following on from the theme of increased empathy, it was found that an increased understanding of mental illness was also connected with the theme of not blaming their parent or themselves. This theme was mentioned by a number of young people. PATS helped me:

...understand more of my mother's illness and helped me to limit the amount of blame I put on her for the things that go wrong.

I learned:

Its not my fault.

- *Development of coping strategies*

Participants wrote that PATS had given them concrete strategies for managing their situation. Learning new ways to problem solve, and skills to cope with their situation were highlighted by many of the respondents. 'Things in life (like school) will not letting having a parent with an illness taking over my life. I can balance my life between school and relaxing. It is a really good time to have a break from home and you learn how to cope better.' What was helpful? 'Discussions in the peer group about different situations and the feelings associated with them.'

Concrete ways that PATS was seen as helping young people included:

- *I'm not fighting as much.*
- *Believing in myself.*
- *We're (parent and young person) communicating a bit more.*
- *Helped me to stay calm and more focused on school work.*

- *Ability to accept and deal with feelings*

Young people wrote that PATS had helped them to deal with strong feelings like stress, anger and guilt, and assisted them with feeling better about themselves and their situation.

There was a sense from many of the young people that PATS had given them permission to focus on themselves.

- *I learnt that I can have fun. I learnt how to be more open minded in general, and to be more calm when my mum (with the illness) was showing symptoms of the illness, more at peace.*
 - *I learned to think before you have a angry spurge.*
 - *I learned how to improve the way I feel about myself.*
 - *You realise there are others who share the same feelings that your experiencing.*
 - *It helps let out feelings that you feel about the illness and how to cope.*
- *Maintaining contact with PATS*

Important aspects of PATS are the opportunities to continue involvement through social outings, camps, leadership training, reference groups etc. At each wave the young people were asked if they had been involved in any of these other activities with PATS, outside of their eight-week group.

Table 7 Involvement in PATS activities by wave

	wave 1	wave 2	wave 3	wave 4
No other PATS activities	84	64	28	27
Outings	10	8	20	32
Leadership	4	3	13	14
Peer leader	3	2	6	8
Presentations	2	8	2	3
Reference group	1	1	5	8
Newsletter	2	2	2	8
Courses	0	0	1	0
Other group	13	12	17	22

Young people were able to identify multiple options, therefore the figures do not correspond to the total number of participants.

Many participants reported becoming involved in other activities with PATS, and for most the involvement increased over the 12 months post PATS completion. However 28 young people at wave 3, and 27 young people at wave 4 had not been involved in other PATS activities post the 8 week group. This is important given that 90% of participants at the 6 month follow up stated they wanted to keep in contact with PATS. At Wave 4, this figure dropped, with 80% of respondents stating that they wanted to maintain contact with the program. While the majority of young people stated they wanted to maintain contact, the reality is that many were not maintaining contact or involvement with the formal aspects of the program.

Participants were asked if they had individually maintained contact with other members from the program. 53% of respondents said they had maintained contact with people from the program. 47% had not kept in contact with others.

The young people who had not maintained contact with the program or other participants were asked their reasons for not maintaining contact. The following reasons were given:

- “Don’t know”
- “Didn’t get phone numbers or addresses (when in the group)”
- “No time – too many other commitments”
- “New interests, can’t fit PATS in”
- “Couldn’t be bothered”
- “Didn’t hear from anyone, so I didn’t try”

- “People moved”
- “Didn’t think they’d want me to (make contact)”

The responses reflect the reality of young people’s lives. For some, other commitments were a barrier for becoming involved, or took priority over PATS. For other young people who wanted to maintain contact, the importance of the PATS leaders providing the opportunity for young people to swap contact details if they wanted, was important. As one young person suggested, ‘We need contact numbers of people in my pats group. A business card with my pats leaders name & business hours phone number on it’.

The importance of providing opportunities for the young people to meet and see each other after their 8-week group was also highlighted. For some, providing them with each other’s numbers did not necessarily equate with the young people keeping in contact with one another. As one young person stated:

[there was] ... just one person I was friends with, we both had each other’s number, just never rang.

And another young person stated:

I’ve given them my email & no one has emailed me.

Each of the PATS sites varied in how communication between the young people was maintained and in the activities offered post the 8-week group. This is reflected in the feedback from participants.

Keeping in mind that the majority of young people want to maintain contact with the program, but only 53% have, the barriers to participation, such as transportation and geographic isolation, which were highlighted in young people’s access to the 8-week group, could also be factors limiting involvement in wider PATS activities. The opportunities provided may not be of interest to all members of the program, and other opportunities may need exploring.

3. Improvements to PATS

Participants were asked, ‘What could be done to make PATS better for you?’

There were a variety of responses to this question, with some themes emerging in the recommended improvements. Many of the young people stated that there were no improvements needed:

It's perfect the way it is.

- *Food*

Food was a popular topic for comment. Some young people stated that they really appreciated the food provided, and thought this was important. Others made suggestions for other food including: pancakes, chocolate and ice cream. Food did appear to be an important part of creating a comfortable atmosphere in the group.

- *Mental illness information provision*

Some differences occurred in the participants' opinions regarding the provision of information about mental illness. Some young people liked that feature of the group, stating that they received lots of practical information and handouts on mental illness.

Others stated that they would have liked more information to be provided, and more guest speakers addressing the group. This was potentially a reflection of the different sites, with each site providing different levels of information and speakers. It may also be a reflection of the varying needs of the young people for information provision. Whereas some were satisfied with how much they received, others wanted more. Ensuring the participants knew where to access more information if they wanted it, was seen as important.

- *Length of PATS*

The timing and length of PATS was a theme emerging a number of times in the responses. Some young people felt that the program should run for a longer time, with two terms a suggestion from a few participants. Others wanted the opportunity to take part in more than one group. Again this was a reflection of the different ways in which the program is provided in the different sites. Some sites provide the opportunity for young people to repeat the group, while others provide ongoing recreation and leadership opportunities for keeping in contact with the program. Clearly it was important for the young people to have opportunities to remain involved.

- *Structuring the group*

Maintaining a good balance between discussion times, and outings and activities, was a theme emerging for a few respondents. Some young people wanted more time for discussion, whereas others wanted more time for fun activities such as games and outings. These suggestions may be a reflection of the age range and gender mix of the groups, and highlight the importance of carefully planning the composition of participants in a group.

Some participants commented that they thought the age range in a group should be closer together, so that people who want to talk can, and people who want to 'muck' around can be in different groups. The complexity of planning the composition of the groups is shown in this recommendation from one of the young people who suggested that the facilitators have 'groups of the same ages, but still mixed groups to give the younger children a chance to have someone older to turn to'. In some rural sites geographic distances, and the smaller referral base, meant that age specific groups were not possible. This proved challenging for meeting the needs of the different age groups within the one program.

The young people appeared to want the size of the group to be a minimum of four young people. On the other hand, one young person stated that there were only three people in her group, and whilst it was good, she would have liked more people to participate.

- *Advocacy*

Young people saw advocacy and awareness raising as an important role of PATS in the community. One young person suggested that PATS:

... try and include the whole community about what we're doin.

- *Suggestions from young people who didn't like the group*

The 5% of young people who did not like PATS, and who stated that they did not want to maintain contact with the program were asked if there were improvements that could have been made to make it better for them, and why they didn't like it.

The comments show a variety of reasons. Two of the young people were quite pragmatic in stating that they didn't think there was anything wrong with the program, it just wasn't right for them. The facilitators of PATS recognise that the program is not necessarily going to meet the needs of all young people in this situation. As one young person stated:

Just because a solution is right for one person doesn't mean it's right for all.

Another young person stated:

PATS was great, I just didn't enjoy it and I don't know why. Everyone else seemed to enjoy it lots. There seemed to be a lot of effort put into it but I just found it a little boring. I don't know why I didn't enjoy it. I think it was because I didn't have any friends.

This comment also shows the importance of creating connections between the young people during the group process.

Another young person identified that the group was not fun enough. When asked how we could make PATS better, the response was:

Me not coming. There is nothing you can change to make it better, more fun less work.

The final reason identified for not liking or needing the group was a sense of having already dealt with the issues covered in PATS. As one young person wrote:

I joined PATS too late in my life [i.e. I'd already worked through the issues covered].

In summary, it is important to assess the needs and motivation of the young people prior to the group's commencement, and to ensure that young people are aware of the group's focus.

4. Recommending PATS to others

Using the Likert scale, young people were asked to respond to this final statement: *I would recommend PATS to other young people who have a parent affected by a mental illness.*

This statement was seen as a good indication of the strength of the young person's satisfaction with the program. There was consistency across the three waves, with 97.6% of respondents stating that they would recommend the program to other young people.

The young people were asked to write what they would tell other young people about PATS. A selection of quotes is presented below reflecting their perceptions of the program, and highlighting the themes, which have been addressed in this feedback section.

- *It's fun, you get to meet new people, and learn lots of useful things about your parent's mental illness and yourself.*
- *It's a great opportunity to meet people in your situation and learn about mental illness. You learn that you need to put YOURSELF first.*
- *It is a really good time to have a break from home and you learn how to cope better.*
- *It's a great program and if you want to sort things out with your parents it's the way to go.*
- *That we make friends who understand our position, get a better understanding of the illness and have fun and eat great food!*

Finally, one young person when asked what they would tell other young people wrote:

E.V.E.R.Y.T.H.I.N.G.

Discussion

Limitations of the study

The capacity for this study to assess the effects of the PATS programs on participants is limited by the study design. Without a control group, it is difficult to confidently attribute the changes observed over time to participation in PATS. This evaluation does contribute to our understanding of the issues these young people experience, and the state of their mental health.

A further limitation of this study was the sample size and the rate of attrition across the twelve-month follow up. Only half of the participants were able to complete all four questionnaires. Interestingly, the participants who did complete all questionnaires reported higher levels of depression and lower levels of wellbeing at baseline, than those participants who only completed pre and post tests. These data would indicate that those most in need continued to contribute to the study.

The study was limited in choice of measures that would be most relevant to the aims and objectives of the PATS program, and also to the sensitivity to change of these measures. This was particularly the case for mental health literacy and coping/problem solving measures. The qualitative data, however, in which the young people were asked to reflect on the PATS program, provided valuable information about what they believed they had learned, and how the program has helped them to understand, deal with the situation and their feelings, and to have confidence in seeking support.

Strengths of the study

This study is the first to document the mental health, family, school and social issues faced by young people living with a parent with a mental illness, and to provide longitudinal data on these aspects. The questionnaires were designed to cover the important areas that the program hoped to address, in addition to measures of mental health. Without a comparison group, we cannot confidently say that the reductions in depression, stigma and risk of homelessness are due to participation in the program, however these reductions are very promising.

Conclusion

This evaluation gathered valuable information about the prevalence of mental health issues for young people who have a parent affected by mental illness and provided some data about their school and social experiences. These data support the notion that young

people who find themselves in families with one or more parents affected by mental illness, certainly have high needs, particularly in regards to effective means of support and targeted intervention and prevention programs, such as PATS.

2.2 PATS Program Implementation, Capacity Building and Sustainability

Methods

A variety of methods was used to evaluate the implementation of the PATS program in the five sites. Program coordinators were interviewed at the beginning and end of the project. They kept a journal designed to capture worker details, networks of organisations contacted, contact log, participant referral sources and attendance, and session plans. Workers were also asked to write a reflective piece about their involvement and, where they deemed appropriate, to ask a PATS participant and/or parent to write a reflective piece about their experiences of PATS.

Interviews

Through semi-structured interviews, each site coordinator was interviewed twice; once at the end of the first year of the program in November-December 2003, and then again twelve months later in November-December 2004. In consultation with PATS workers prompts and questions (see Appendix 1) for these interviews were developed to elicit workers' perspectives on the establishment and maintenance of the PATS program. Additionally, issues and topics that arose during the course of meetings, discussions and support sessions with PATS workers, were raised in the interviews. Conversations were taped and the first round transcribed, while the second round comprised extensive notes and quotes. Data was entered into NVivo qualitative analysis software and analysed for themes and issues.

Journal

A journal was designed in consultation with PATS workers to record data about routine day to day activities associated with running the PATS groups. To aid the process of note taking, the documents were carefully designed to minimise the time taken to record this information. Part of the purpose of the data collection was to encourage worker documentation and to promote reflective practice. The journal comprised five sections:

1. Worker details.
2. Network of organisations contacted during the running of PATS.
3. Contact log for noting number, medium and duration of contacts.
4. A group roll to record participants' attendance, referral source, destination, and transport mode used to attend PATS groups.
5. A session planner where details of issues and activities were recorded.

Workers were asked to fill in section 3 for Term 1 2004, sections 2 and 4 for the period of questionnaire data collection (Term 3 2003 – Term 4 2004). Section 5 was to aid in the production of a manual, and to encourage resource sharing among the PATS workers. Resource sharing proved particularly successful at quarterly partnership meetings.

Case Studies

Workers were asked to contact one or two PATS participants and their families, if appropriate, to write about their experiences of participating in the PATS program. It was left to the discretion of the worker to ask the participant, a member of the participant's family, to write a worker perspective themselves and any combination of these they deemed appropriate. The following suggestions were submitted to the worker as a guide to issues of interest for the writers and workers:

1. Demographics: age, gender, school level/work, region, wider interests and activities, trajectory before PATS.
2. Family: issues, structure, support and demands.
3. Referral into PATS: why, where from, hopes and impressions.
4. Experience with PATS groups: memories, highlights, criticisms.
5. Experience post PATS: what they got out of PATS; how it helped at home, school etc., what information/strategies were useful, what was not so useful.
6. Involvement in wider PATS activities.
7. PATS related highlights and experiences (activities, breakthroughs, advocacy etc).
8. Life experiences, highlights and challenges.
9. What's ahead?
10. PATS worker perspective (if appropriate).
11. Referring worker perspective (if appropriate).
12. Parent perspective (if appropriate).

For information on parent and participant perspectives of PATS, see the case studies at the end of this section.

Telephone interviews with key agencies

To assess capacity building impact of the partnerships, telephone interviews were undertaken with key agencies. Questions included:

- Why did you agree to support the PATS program?
- What benefits has the partnership brought?
- Does your manager support the link? (between PATS host and partner agencies)

- Have you promoted PATS?
- Does the collaboration facilitate service agency responses to community needs?

What is in place to maintain the collaboration?

Additional data sources

In addition to the above primary data sources, the following documentation was gathered:

- meeting notes and telephone conversations recorded by both the Evaluation Coordinator and the Program Manager
- a forum held by one worker for parents
- articles written by participants and workers
- agency promotional material and websites.

Results

Capacity building and partnerships - PATS coordinator perspective

Implementing PATS in the community produced a range of challenges for those agencies participating in the program. For PATS coordinators addressing these challenges often meant reviewing and developing partnerships in order to build capacity for promoting mental health for young people in the community.

Developing new links with service providers for sources of referrals, as well as consolidating existing relationships, was a major focus for PATS workers throughout the project.

1. Agency networks and links

To some extent, existing networks and links between the PATS host agency and external agencies in the region, determined the success of initial groups. The established pattern of links also had an enduring impact on the course of the program. One site experienced difficulty in promoting PATS to a new source of potential referrals beyond its existing client base:

There's a lot more private. That's something that I need to address, because I'm so used to focusing on working with the public schools, that all my promotion has been there, and I've contacted only one private school. I would be the only person in this agency that would be working probably with private schools and families connected to them, because generally they're virtually excluded from our services.

In contrast, one site further developed an already close existing partnership as a result of offering the PATS program. They had been working together to respond to families affected by mental illness. The external agency offered carer respite and the host agency offered individual counselling. With the advent of PATS there was an additional option to offer wider support to young people in these families, both where the severity of the case did not warrant individual counselling and to augment individual counselling for those young people who required counselling. As a result of this partnership, places in the initial groups were filled out before the program was even up and running. As well as providing an initially rich source of referrals, this relationship resulted in the other agency providing ongoing funding to cover extensive transport costs for PATS participants throughout the region.

2. Establishing reference groups

A great aid to networking adopted by most sites during the course of the evaluation period, with varying degrees of success, was the establishment of a PATS reference or advisory group of representatives of other service providers in the region. The main reasons for convening these bodies was to promote the PATS program to a range of services dealing with or encountering young people from families affected by mental illness to secure incoming referrals, and to give these agencies some input into the direction that PATS was taking in their region.

It was really about providing an opportunity for them to have a good understanding about what we do, how we run it...how could we run it in a way that gives good access for people and families, and what is it they're wanting from us to be able to get this happening in a way that would give them a reason to refer.

Another reference group produced a mission statement that focused on the referral process, and anything that could be done to secure, develop and streamline this process. The primary functions of the Service Delivery Reference Group identified by workers were:

- engender a thorough understanding of PATS among key organisations and individuals in the region
- provide regular updates on services
- identify the needs of young people with a parent affected by mental illness within the region, and develop PATS options to respond to this need, for example, relocating venue to referral clusters
- identify support for wider adolescent and family needs encountered during recruiting for PATS
- encourage external agency input
- provide a venue for a meeting of the minds to brainstorm and problem solve issues
- contribute to the development of responses to the needs of young people with a parent affected by mental illness in the region.

One site was particularly successful at developing partnerships through the establishment of a highly effective reference group composed of representatives of related services that were to provide the bulk of ongoing referrals throughout the evaluation period. To achieve this, the make-up or representation of the group and its ongoing viability were of critical importance. The make-up of this group comprised representatives from:

- respite services
- family services
- youth services
- adult mental health services
- community health services
- the major hospital based regional health service.

Other sites chose to include other strategic agency representatives, including workers from Department of Education and Training, Child and Adolescent Mental Health Service, Juvenile Justice, Child Protection and Mental Health Promotion Officers. Most sites included other workers from the host agency, particularly if this agency was large and complex with units providing services in different domains.

Despite its success, experience showed that the effectiveness of the reference group tended to wane over time. In fact, one worker reported that it was extremely difficult to keep up the level of information and interest of this group. It was not always possible for workers to simply apply more time and effort to recruiting and maintaining the reference group:

Awareness and referrals could be higher if I was out there educating. This is a resource issue.

Individual representatives were lost and the effectiveness of the group sometimes became marginal. This was thought to be for several reasons. There was a tendency for the meeting to become a PATS progress report, which was seen as a waste of time as this could be achieved by other means, for example, email. Staff turnover and movement in represented agencies resulted in loss of interest and connection with the PATS reference group. Competing demands for time and resources resulted in the constant review of individuals' schedules and commitments, and some loss to the reference groups after initial interest and engagement. The issues of worker access and the geographical size of the regions serviced, discussed in detail elsewhere, were equally pertinent to organising a location and frequency of reference group meetings. It was impossible to meet everybody's needs:

We've lost representation. I think it's the climate here in terms of lots of demands on resources, a huge demand on services, and we just can't even move. And so

things like reference group just gets put by the by because you just don't have the time.

Several workers identified the difficulty of selecting a time and place to hold meetings that suited everyone. Attendance at the meetings waned in several sites over the course of the investigation. One worker noted that 'we lost a few of the ones that travelled the longer distance' of two hours. Another worker, after initially convening the reference group quarterly, experienced a drop in interest and attendance. It was agreed to meet only annually and maintain regular contact and updates by email. This group also relied on the equivalent of 'corridor' catch-up conversations when they met at youth health and mental health events organised on a regular basis in their region. Furthermore, the same worker was very active on a number of committees across their region, where members of the PATS Service Delivery Reference Group were also represented. This provided a situation of mutual support for each other's projects, and further opportunity for the promotion of PATS. It should be noted that this approach was aided by the worker's managerial position in the host agency, necessitating simultaneous work on a range of programs and tasks. This spread the call on resources across several funding sources.

3. Connection with the wider community

One observation highlights important aspects of the disseminated PATS model that had profound implications for workers and participants alike, and wide application to promoting the program. This stressed the benefits derived from promoting the PATS program as a community wide activity across the state of Victoria. This was reinforced by the program's association with a widely recognised and respected leading institution:

When I mention Centre for Adolescent Health, it seems to sit well with my colleagues and the kids. It creates an identity that you are connected with other people, not a horrible departmental name. The kids love hearing that there are other people out there. It's about that isolation; other sites and people out there ... It's really important to be part of something bigger.

The countering effect on isolation of the combined factors, above, has implications that go to the very core of the PATS approach to combating the effects of living with mental illness, stigma and the perception of isolation in the individual. It is clear that these characteristics made the PATS program very appealing to young people and health professionals and was a powerful promotional asset.

4. Resources

One of the largest calls on workers' limited resources was promoting the PATS program, a complex and time consuming task that involved a wide range of strategies and activities. Other major time commitments were categorised as maintaining young people's engagement in the program, supporting them and their families during the group and follow-up, planning and running the groups, organising youth participation and wider PATS activities. The sites were allocated 0.4 EFT throughout the project, and although this was considered enough to run the groups, it was not considered sufficient to cover effectively all the other major time consuming and equally important aspects of the PATS program. Not surprisingly, running the groups was always the priority in terms of worker resources:

Sometimes there's not enough time. The promotion really tends to go by the wayside when you're running a group.

Most workers recommended an extra 0.2 EFT as a minimum to cover the other demanding tasks required to keep PATS a viable program:

To do this effectively, we needed more of a promotional focus....At 0.4 EFT the program can only ever be an add on to something else. It is only slightly more time than you need to do the group but not enough to do all the responsibilities that go along with it.

Not all of the agencies hosting PATS had sufficient resources to support young people on an individual basis before, during or after coming into the program. In some cases, workers found that young people needed support before doing the group, but because this was not always available or possible, these individuals were lost to the group:

Another issue here is the lack of continuity or follow up of issues. There is nothing here I can link kids into who need individual support. That means that there are a few kids that we lose because some kids need individual support before they come to the group. There are kids at the end of the group that I would like to keep engaged in the program and other things but there isn't the individual support. There is only short-term assessment stuff. I end up doing that anyway. The other sites have staff that can do case management or counselling.

Two agencies had sufficient youth service resources to enable the development of a team approach to running the PATS program, in which the tasks around promoting PATS and interviewing potential participants for the groups was separated from facilitating and running the groups. This was seen as a significant advantage for those agencies that had the focus, resources and personnel to enable this approach. It allowed the tasks to be broken up and performed in conjunction with wider agency responsibilities. In fact, one worker stated categorically that running PATS would not have been possible had this pre existing level of commitment to youth services not already been in place:

We work in an integrated model. I have been able to utilise members of the team. Someone else facilitates the groups. The council has supported this and allowed us to put in a lot more hours than what the funding covers. You can see the benefits of this and the outcomes of the young people have been significant.

Unfortunately, one agency's commitment to youth services received a setback when the number of youth workers was reduced by half. This was a contributory factor to this agency's decision to discontinue with PATS on the grounds that it would not be viable beyond the current funding period. Difficulty in attracting referrals has also played a part in this decision. This maybe attributed to low numbers of young people living in this inner-city area, and the transport issues associated with making the program available to suitable participants residing further from the city centre. Initially the program was located in a mid-suburban area, but the adult focussed agency was unsuccessful in appealing to young people and their potential referrers.

One promotion strategy discussed by workers, but not attempted, was to dedicate the first part of the year to recruiting participant referrals. Several sites reported the difficulty of securing sufficient numbers to run a group in Term 1. Nor was it possible to establish a waiting list late the previous year as the Christmas break made continuity of promoting the program difficult. This was particularly the case where sites were dependent on schools as sources of referrals. The busy lead up to examinations followed immediately by a long summer break, and then time taken to return to routine, meant that schools were not always reliable sources of referrals for Term 1 groups. It was therefore proposed that it might be possible to forego offering a group in Term 1 and instead concentrate on recruiting referrals for the groups held during the remaining three terms. It must be noted that not all sites reported difficulties raising numbers for the beginning of the year. One site was almost always booked out at least one group ahead.

5. Referral Patterns

Where did PATS workers in the sites source participants for the PATS program? Table 6 displays the sources of PATS participants during Term 1 and Term 2 2004. Total percentages across all the sites are given in addition to a breakdown for each site. The agency categories that were the sources of the referrals were defined as follows:

- Self: a participant contacted the program directly requesting further information
- Family: a member of the participant's family (usually sibling or parent) contacted the program directly requesting further information
- Schools: participants were referred by school personnel (e.g. Student Welfare co-ordinators, school nurses, Student Support Services officers, DE&T. personnel)
- Mental Health service agencies in the region
- Community Health services in the region
- Family Support agencies
- Local Government health or youth services
- Juvenile Justice, Department of Corrections
- Non government Organisations (e.g. Uniting Care)
- Hospital

Table 6 Referrals IN: % of participants at each site referred by self, family, school or health or welfare agency in 2004

	Self	Family	School	Mental Health	Community Health	Family Support	Local Government	Juvenile Justice	Ngo	Hospital	Total
	%	%	%	%	%	%	%	%	%	%	
All sites	16	5	14	27	3%	6	15	6	6	2	100
Site 1	3	3	7	28			42	3	14		100
Site 2	27		27		27	19					100
Site 3	17		17	49		9		4	4		100
Site 4	33	33		17		17					100
Site 5	22	6	17	22			6	17		10	100

Site 1: Local Government Youth Services

Site 2: Community Health Service

Site 3: Adolescent Mental Health Service; located in large regional hospital

Site 4: Community Care Services

Site 5: Multi-disciplinary Centre; Clinical Services and Community Health Promotion Programs; located in major hospital.

It is interesting to note that young people, or their families contacting the program directly, accounted for more than one in five of total referrals. This was usually the result of seeking or encountering promotional information about PATS:

- in brochures/fliers at host agencies, other local agencies, schools
- in notices in local community paper or newsletters etc.
- as a result of mental health promotion at school where PATS information has been available.

6. Engaging adult mental health services

Mental health services accounted for a quarter of all referrals. Families where a parent received attention from adult mental health workers were identified as prime sources of potential referrals into PATS. Adult mental health services, however, were reported as being consistently difficult to secure as a consistent referrer of young people, with great potential for many more referrals than were actually received. Opinions about the reasons for this included: adult mental health service workers tending to be sceptical about non clinical prevention programs; and the prospect of discussing prevention options for non adult family members - a sensitive and potentially difficult task in an already difficult situation - was an added burden when the priority was to treat the adult.

There were successes in securing regular referrals from adult mental health services. Most workers reported that consistent active promotion of the project to adult workers was required. As soon as contact waned, so did the number of referrals. Many workers agreed that to be successful you had to be 'in their faces' all the time, and that you had to establish a favourable reputation both for yourself and the program:

As well as persistence, you have to offer a professional service, be consistent about your approach and you have to show them (mental health workers) what you can do. You have to know what you are talking about... You have to work at building a relationship. They rely on reputation. If they know someone who does a good job, then that is what they hold onto. I think that is what we have been able to establish. They are not good at communicating with services outside clinical. This takes up a

lot of time.... I'm on several committees, so that I am on the inside. They get to know you through the system.

To summarise desirable attributes of the host agency, and the workers' strategies for securing referrals from adult mental health services, included:

- the host agency had a clinical mental health focus (note that this factor might have mitigated against needs of young people in some cases – see 'Venue')
- the host agency was well known and credible, more so if it was perceived as a sizeable bureaucracy, with which adult mental health workers and other health professionals could identify
- a combination of time, opportunity and persistence; one worker reported spending two years developing a partnership with the adult mental health service before an opportunity to collaborate on a project arose
- participation in committees and events where adult mental health sector workers were represented, to enable the PATS worker(s) and the PATS program to become known and identified with the relevant services.

7. Intra-agency

One of the prime motives for seeking funding to set up the PATS program was to respond to an identified need to support individuals or family members encountered in other programs and activities already running within the host agency. This was a source of initial referrals in the PATS groups once set up, but this was not always a base of referrals sufficient to sustain the program beyond the first few groups, as the internal needs of the agency were met.

8. Capacity building within service agencies

PATS has been particularly successful in drawing together workers interested in providing a more coordinated response to family and youth issues. This has occurred both within the host agency and externally. One example was within a host organisation that contained a Youth Team and a Mental Health Team:

It's been really positive for relations between programs in our agency. Like, we've got a mental health worker who's going to be facilitating one of the groups, and she's part of a steering group and we're doing joint work with the mental health

program that we weren't doing before. We're inviting speakers from that program to come along to the groups. There's co work happening.

Representation on agency committees and attendance at a range of team meetings were other responses to this challenge. Another approach was to engage a key management individual or group in the program, keep them updated, and involve them where possible. One worker's response to the program's isolation and lack of support within the organisation was to relocate to a specialist division that dealt more directly with the community and families affected by mental illness. Consequently, the program was not only located within a like minded group rich in referrals, but also physically located in a more appropriate setting that provided the venue for the groups.

Capacity building and partnerships - PATS partners' perspective

Those interviewed consisted of a range of workers from mental health services, schools and community support services. The establishment of PATS programs has resulted in the significant promotion of the issues confronted by young people who have a parent with a mental illness. Partners associated with the PATS program in the five sites clearly reflect this broader impact.. All those who participated, perceived PATS as a very worthwhile program for young people to be referred to, and felt that it had been a positive experience for all those involved. The summary below provides insights not gathered elsewhere in the process evaluation.

1. Perceived benefits of PATS by partners

All those interviewed could quite clearly outline benefits of the PATS Program and saw the group as a positive experience: 'Fantastic service! Great support.'

Workers also noted the strength of the program in terms of educating the community. One worker saw the program as offering additional support for young carers and that it has helped to raise their profile: 'They're placed in the position of being young carers but often they don't have the skills'. PATS 'deals with a particular issue that's becoming more and more prevalent'. Additionally, PATS 'raises the profile of mental illness as a community health concern'.

At one rural school, some Year 12 students had helped to run groups as peer leaders. The worker noted that this responsibility helped build their confidence and leadership skills. At another school, two students had also been encouraged to become leaders. They became 'mentors' in that the leaders talked to potential referrals, thus becoming 'ambassadors' for

the program. The PATS peer leaders were observed to be 'taking leadership skills to the school' and the worker had 'seen real growth in their confidence and self-esteem'.

Most workers interviewed saw the PATS program as important in providing somewhere for these young people to be referred, and as expanding links in the community and forming new partnerships. One worker found that contact with the PATS program resulted in a closer relationship with the host organisation, and a better understanding of how programs work together. Other collaborations arose, such as joint conference presentations, PATS peer leading on children's camps and the possibility of mentorship roles for PATS peer leaders. Generally, the partners' relationship with the PATS Program provided resulted in increased resources, a greater ease of referral, and the sharing of new information.

2. Fostering interagency responses to community needs

In one region, in response to the provision of the PATS funding, a network was established that met regularly to discuss the needs of families in which there is parental mental illness. The network consisted of a number of workers from a broad range of services from a wide geographical area. In another region, PATS had become very well linked with a range of local non-government support organisations and community support services. One of the regional partners stated that they now had a better relationship with the mental health services in the area and were planning to work together to facilitate mental health education sessions in schools.

Another worker believed the program would 'give a voice to the young' in the region. Two school workers saw the program as creating more awareness about mental health and illness, as it was becoming more discussed in class and the school in general. The schools were now more aware of the services being offered by the PATS host organisations in the region. One worker, however, considered the waiting lists for young people needing to access community mental health services still to be an issue of concern.

A partnership between a school and the regional PATS host organisation was used to provide a whole range of services to its student body. The relationship involved joint submissions to help run programs in the school. The partnership was mutually beneficial in that the host organisation had access to the youth population of the school and the school provided support for its young people.

3. Sustainability of the collaboration

All those interviewed looked forward to continuing their partnership with the PATS host agency and believed they had built good relationships through the program. Many agencies discussed the PATS Program regularly both in team meetings and when meeting with other services. One organisation considered the PATS Program to be one of the mainstream services they now provide. All staff at two mental health services supported their local program and there was a strong relationship between management of both organisations.

Sustainability

In addition to the sites funded during the evaluation, many regions have expressed interest in the program, and a few have managed to use limited local funds to participate in training and set up and run PATS groups. The most successful thus far has been in Geelong, the largest centre outside of Melbourne, by forming a partnership between the government health service and a non-government family support organisation. Despite the future of this program being in jeopardy due to a scarcity of funds, a number of young people have been able to participate in the program, and a great deal of work has been done to increase community knowledge concerning the issues faced by children of parents with a mental illness.

Training for workers and young people has also taken place in the southern, Gippsland region of Victoria. Subsequent funding was not available to provide programs as hoped, however two programs have been run in the short term in two towns. One was run through a government school and the other through a youth support agency.

There has also been significant interest in the establishment of PATS Programs in various regions around Australia. These have included both metropolitan and rural locations. Often in these cases awareness has arisen concerning the need to support these young people and funding has become available to provide an effective program.

Worker impact

When workers establish themselves in a region, they become associated with the particular issues at the centre of their work and the programs they promote. Professional networks of workers are partly based on a history of face to face contact, collaboration, and shared or overlapping duties, interests and directions. This was certainly the case for PATS workers, who came to be identified with issues around young people with a parent affected by mental illness in their regions. There are benefits and costs to this

phenomenon. On the one hand, if a worker becomes identified with a program they promote it by default wherever they go; perform the role of overt contact and consultant on issues related to that program; and are generally a very visible beacon for referrals and issue resolution. If, however, the individual moves on to other responsibilities or another agency, these advantages can be lost, and a new worker might encounter difficulty in rebuilding some contacts and collaborations. The sites had a number of responses to this issue. Once again, agencies that had the resources to organise a PATS team were potentially better off, as they could progressively train workers in promotion and other aspects of the program, involving them in meetings and interviews so that both greater coverage, skills development, and less reliance on one individual was achieved:

There is no doubt (personality) has been a booster in establishing the PATS program in our region, especially the relationship building. I'm known. But I get all the facilitators to attend the network meetings and do the pre interviews that I do. So there is that contact.

Once again, the ability of workers to attend to this aspect of promoting PATS can be related directly to resources and worker time:

It's taken such a lot of energy to get the small numbers that we've had that there hasn't been a lot of time left over to do all the other health promotion aspects of PATS. That's been a disappointment and a challenge, because I think they go together. We haven't been able to do as much of the educative and profile raising stuff as much as we would have liked.

It should be noted that alternative means of communicating the PATS message, such as telephone, emails, flyers and so on, were not considered by workers as effective as face to face contact.

In some cases, identifying a project with a particular person had some drawbacks. One worker was introduced from another region specifically to run the PATS program. The worker was new to the region and had to establish a reputation and 'track record'. Initially, the worker detected some reticence in workers from agencies from which referrals might otherwise have been expected. The worker attributed this to being an outsider and being little known in the region, resulting in the PATS program being overlooked:

Something that was highlighted to me was that people concentrate more on the personality of the person in the job and not so much the job that's been done....I think people need to get over that....and embrace change.

It should be noted that the worker successfully overcame this initial obstacle.

A similar situation can develop when personnel changes occur in key places in any network. A successful response to personnel change in external agencies was to prioritise promoting PATS with the new individual(s) to familiarise them with the options offered by the program.

Structure and content of the PATS group sessions

The minimally structured and participant driven aspect of PATS was perceived to be a difficulty for some host agencies. PATS has a strong emphasis on youth participation principles, requiring workers and host agencies to work in consultation and partnership with the participants in each group to structure the content of the groups. It is therefore not a straightforward package that has set content and structure. Each eight week group and each site varied in the content covered, and in the management of the sessions. The rationale for this is that it allows for workers to be flexible; to utilise their own group work styles; and enables the young people to have input into the themes and activities that are covered. It was found that some sites had quite structured plans, with clear outcomes stated for each activity. They used these from group to group. Other sites had minimal documentation of their session plans keeping the content flexible according to the young people's needs.

The lack of a set program at times was a challenge for workers, especially those new to the program, and has implications for worker training and support. Having time to engage with the young people and peer leaders around what they would like covered, and how they would like the PATS sessions to be structured, was a challenge. This was not always practicable, particularly for those workers who were required to transport participants before and after the group sessions.

Engaging adolescents and families

Successful referral into the program is the first part of the process of realising a young person's participation in a group. The young person and family often needed considerable attention to achieve successful engagement and ongoing involvement in the PATS program. A range of obstacles to participation was encountered, and measures were taken to overcome them by the workers running PATS.

1. Engaging the Family

Selling the program to the family was a constant challenge. This process was often very sensitive, involving building trust between the worker and parent, worker and young person, and sometimes parent and child. Much of this comprised allaying fears around the very sensitive subject of mental illness, after-hours transport, and other issues. Parents had misgivings about their children's participation in PATS, fearing what might be said to them and by them, and the implication that participation represented a failure of parenting:

I want your little girl to come and be a part of this group where she can talk with other peers about mum or dad's mental illness. The parent just thinks: 'What will she say about me? ... Does that mean I'm a bad mother?' So we had to be very careful about how we worked with some of those issues.

One worker's solution was never to see a young person alone, and to include as many members of the family as possible during the engagement phase interviews and discussions around PATS. Parents and siblings could then feel safe about a family member participating. Other strategies included seeing families in their own homes, presenting prepared (and funded) transport options, and relating anecdotes about other families' experiences with PATS (see the extract from a parent's story below).

If the worker or young person was able to secure permission from a parent for their child to attend PATS, this gave the young person an overt message that it was all right to attend the groups, and there was no necessity to cover up involvement with PATS from the family, as experienced by some participants (see Lyric's Story). It should be noted that in some cases, usually at the older end of the age range, young people requested that their families not be informed. Occasionally this was not possible or advisable anyway, as the young person was homeless or not living with either parent.

2. Engaging the Participant

After receiving a referral and engaging the family (if appropriate) the real test sometimes was establishing and maintaining a participant's level of engagement in the program. Common initial negative reactions of potential participants were along the lines of 'It's not cool to come to this group' or 'She felt everyone would know because it was her local community and her peers would find out that she had a parent with mental illness'

I think it's still a big issue just getting adolescents to come to a group, any kind of group, any kind of appointment ... Invitations ... hanging around ... that kind of thing can happen. Getting a central meeting point and getting people to it. And fitting in with people's schedules.

For PATS workers, the use of multiple strategies such as discussion, persuasion and reminder calls to encourage the more reticent individuals to go along and at least try the first night, was essential to the success of the PATS groups.

Once individuals were engaged in PATS and attending groups, most of the difficulties (but not all) associated with engagement, were resolved. For many participants, the first nights of the PATS group allayed fears, doubts and prejudice, and formed a connection with other young people and the group. One very important aspect of the road to PATS was that young people participated because they had chosen to, not because they were told to or forced into the program. This not only resulted in good retention rates (see Participation rates) but according to this worker's comments also contributed to them being 'rewarding and useful' to work with:

There's a really positive feel about the group in general.....the kids who actually come to the group want to be here on the whole, and that's different to all of the other groups that I work in with young people ... I do other groups where kids get told they have to go, and there's a very different feel when people come together to support each other and get support themselves. They've made a choice to do it.

Attrition from the program, however, could still occur. The phenomena of personal or family crises, or simply a change in the participant's priorities were not uncommon. Following up, supporting and keeping these young people engaged in the program was often successful, albeit time consuming. Last minute withdrawal from a scheduled group as the first night approached was experienced by some sites and was difficult to plan for. For a young person withdrawing from the current group, the offer of a group running at another time often resolved the problem, but usually there was not time to recruit a suitable replacement young person to participate in the current group, thereby reducing numbers and affecting the make-up of the group.

Access

Access was an issue for most of the sites with implications in terms of burden on the worker, young people's safety, parental commitment and need for infrastructure support.

1. PATS sites: Catchments, venues and mode of transport

Table 7 shows how participants got to the PATS group sessions. Overall a third could rely on being driven in the family car. Almost 50% relied on either an agency vehicle or taxis funded by the agencies. This indicates that without such infrastructure and/or funding available, PATS groups would not be accessible for a significant number of young people.

Table 7 Mode of access: Participant to group sessions in 2004:

	Family car	Agency vehicle	Agency funded taxi	Public transport	Family organised taxi	Walk or bicycle
	%	%	%	%	%	%
All sites	30	23	24	17	5	1
Site 1	7		93			
Site 2	25			50	25	
Site 3	35	55		5		5
Site 4	40	60				
Site 5	45		25	30		

Site 1: Melbourne metropolitan fringe.

Access was almost exclusively through agency funded taxi. The group venues were in a central location, locations in neighbouring outer suburban centres, and a small town in a neighbouring rural area. There was minimal public transport servicing these areas. The agency had a vehicle available.

Site 2: Melbourne metropolitan inner suburban.

Group venues were rotated between three inner suburban locations. There was a moderate level of public transport available, and there was an agency vehicle available.

Site 3: Regional centre.

Access depended on the worker being able to pick up and drive participants home using the agency vehicle. Group venues were located centrally, with several in smaller towns. Some public transport was available to the central venue. An agency vehicle was available.

Site 4: Regional centre.

Access was dependent on the worker being able to pick up and drive home participants using the agency vehicle. Group venues were located centrally and several in smaller towns. There was negligible public transport service. An agency vehicle was available.

Site 5: Melbourne metropolitan central. Most groups were run in a central venue. One group was run in an outer suburban location. The venue was well serviced by public transport. There was no agency vehicle available.

2. Participant and family access to service agency and PATS venue

Across the sites, difficulties relating to the isolated nature of many of the families attempting to access services from geographically distant locations was well recognised before PATS was introduced. In fact, servicing the more remote areas of their respective catchments is an ongoing issue experienced by all the agencies running the PATS program. Time and resources taken to travel considerable distances, for most country families and agency workers, is a part of everyday life and simply expected. This is reflected in the workers in the two rural sites having access to, and devoting considerable time to personally transporting participants. However, the issue of isolation and transport is not restricted to sites located in rural regions. Many PATS participants attending groups in Melbourne had to overcome considerable transport difficulties. PATS groups were usually run during weekday evenings after school and before the evening meal, the best available time for young people. Public transport, if available in the first instance, was not always a practical solution. Frequency of services drops off after hours. Furthermore, there are issues concerning security of young people travelling alone in public after hours. This means that participants were often reliant upon their families to transport them in the family car. Often, as one worker put it, 'It's just too hard' (1.1). Often, family resources might not be robust enough to respond to this additional burden. As one worker at a rural site noted:

I know some parents don't even have cars, or access to any form of transport.

Occupying adults, who transported their children from remote locations for the 2-2.5 hour duration of the group, was identified as a further challenge. For participants living with one parent, the situation was even more critical, particularly if the sole parent was affected by mental illness. Some workers reported that despite achieving successful referral into the program, the difficulties associated with after hours access to the group venue was an insurmountable barrier for some families, and as a result the young person was unable to participate in a group.

3. Worker access to recruit families

Interviewing families where a parent is affected by mental illness is part of the process of converting referrals into participation by engaging family members in PATS. Often the best way to respond to this challenge was to conduct the initial PATS interview in the participant's home. Some PATS workers encountered difficulties securing transport to travel to family homes to achieve this, and one site lacked access to an agency vehicle:

One of the difficulties of this site is not having access to transport to do home visits. That would allow me to more easily engage families in PATS, that first step of getting kids into the program. I would like to focus on culturally and linguistically diverse families and visit them; going to them in their homes shows respect. They might then be (more) willing to bring the kids here.

Agency transport

The workers at sites in both of the regional centres decided to respond to the issue of participant access to the venue by using an agency vehicle and driving the participants to and from home. Over half of their participants were transported in this way. This imposed a considerable burden on the already restricted worker time available to perform PATS duties, and a considerable commitment by the worker, sometimes involving journeys that required several hours after the group session. There were, however, some benefits derived from participants, peer leaders and workers travelling together. They had considerable time to discuss matters relevant to PATS:

A lot can happen in the bus. You can talk about different stuff and find things out because you're concentrating on driving. It's a great time for just talk.

It should be noted that agency vehicle use is not free, but charged to individual projects. Furthermore, not all the sites had access to an agency vehicle, which restricted or prevented some PATS activities, and resulted in the application of considerable worker time and commitment seeking transport alternatives.

The group venue

A common response to minimise transport issues was to vary the location for the group session, holding it closer to the clients. The regional and metropolitan sites ran PATS away from their 'central' agency location, and went to identified nodes or concentrations of referred young people:

We would float (the venue) and respond to the referral base.

These nodes were often determined by the location of major referring agencies. An obvious advantage of this approach was its improved access to PATS for some families. It must be noted that none of the sites had the resources to conduct two group sessions concurrently. Referrals into the program assessed, as requiring urgent, that participants in a group simply had to be transported to the venue, regardless of distance, or be given priority on a waiting list for the next available group to be held in a more accessible location. This was not always a satisfactory solution.

A further complication was the requirements of the venue. It is important that participants perceive the venue chosen to host the groups adolescent friendly. Examples of acceptable venues were community houses, a fire station, and premises with established adolescent or family drop in zones. Finding an available venue that met these criteria was sometimes difficult, and required careful consideration before commitment to taking the venue to the participants. Venues that young people associated with medical treatment, mental health services, and oriented to other age groups, were generally undesirable.

Another issue that impacted on locating the venue near the referral source was stigma about mental illness, and the need for anonymity. In the case of one small rural town, for example, it was found to be inadvisable to attempt to locate the venue there despite a concentration of referrals:

Didn't work. It comes down to the different communities you are dealing with. Sometimes the kids don't want to be identified, because in the small communities, everyone knows everyone's business, or reckon they do, anyway, and what they don't they'll make up. If you set up something where certain people attend at a certain time each week, it raises curiosity. 'What are they doing' sort of thing. That was an issue we encountered. So we thought that if we hold the program in a regional centre it would be better.

It is important to note the PATS worker undertook a significant amount of travel time when venues were located remotely from the agency site.

Taxis

Sometimes, requests were made for the referring worker or agency to organise transport for their referred client. Responsibility for transporting participants to the PATS venue was sometimes shared between the referring agency and the PATS host agency. One worker managed to organise transport support from a group of service agencies in the form of taxi vouchers, Metcard tickets, and petrol vouchers for families. Another site transported participants almost exclusively by taxi during the evaluation period, a result of planning and partnership with an allied agency. This site is located on the urban fringe and anticipated referrals from a dispersed area involving round trips in excess of 100 kilometres in some cases. To achieve this, considerable funding was sought and secured from the partner agency during the establishment phase of PATS:

The funding for taxis is massive. If we didn't have that I don't know how well PATS would run because we are such a large area.

Co-ordinated trips occurred whenever possible, with several participants from the same area, or living en route, sharing the one taxi. The ability of the PATS worker to offer transport to families during the engagement phase after referral, was considered a contributor to the high rates of participation in the groups run at this site in 2004 – an average 7.5 out of the maximum 8 participants on the first night. This approach, however, was not always viable. It should be noted that having their children travelling unsupervised in taxis after hours was not always an acceptable solution for families:

It's been too difficult for the kids to get here ... there are the fears of parents and siblings around long public transport and taxi rides.

Taxi coverage is not universal:

The taxis just wouldn't turn up, so we had to move (the venue).

Dependence upon funding from another service agency exposes the sustainability of the program to the funding policies and direction of that external agency.

Agency resources

Workers responded to the need to travel to participants' homes by combining trips with visits for other aspects of their wider agency duties whenever possible. This approach was important in many aspects of running the PATS Program, especially promoting the

program and supporting the PATS participants and their families on an individual basis. This, however, was only a partial solution, and not an option for those workers solely employed to co-ordinate PATS groups and activities (see *Promotion* above).

2.3 Case Studies

A parent's perspective of PATS

The following is an extract from a parent's observations about her son's experiences with the PATS program. It is interesting to note the reported lack of options to provide sufficient and appropriate support for her son and the family before engagement with the PATS program, and the sustained benefit that is attributed to the young person's experience with the program. This perspective reports that PATS provided the young person with a positive experience of a professional service - one not previously encountered:

They had no answers and said that there was nothing out there for kids of parents with a mental illness and that my son will be fine. I went home to cope the best that I could, once again without any skills to do so. My son became angrier and more withdrawn. His unhealthy feelings and behaviours were becoming normal to both him and his family.

One year on I received a phone call from our Psychiatric Disability Rehabilitation and Support Service that they were going to hold a PATS program. I enrolled my son and he started the program with other kids in a similar situation. After the first meeting he smiled all the way home. And seemed happy. The next week he was telling me to hurry up because he didn't want to be late. The next week he wanted to iron his clothes and he brushed his hair and teeth! He never told me what they did in the meetings and although I was curious, I never asked, as I didn't want to break the magic spell that they must of put on him, as he was happy again. He was sad that the program had to end as he enjoyed it. I was grateful, that for a moment, my son remembered what it was like to laugh and have fun again. For a moment he forgot to take life seriously and acted his age.

8 months after the program, my son's life took a turn for the worse, his aggression and anger were turning into violence and he needed the specialised help of a psychologist. Because of his positive experience with PATS he was very receptive to seeing someone to sort out his problem. He knew that he needed to pay

attention to himself and find some solution to his problem. After his dad's illness and seeing so many people let him down during that time, from family to the mental health service, the PATS program was the start of something that he recalls as being a positive in his life. I know now that he struggles with liking himself and trusting other people because he now discusses how he feels with me. I know that the PATS program headed him in the right direction on this point. I know now that my son has the beginning of a skill/tool bag that would be the envy of any adult and we both credit PATS with helping to fill that bag.

My son now feels empowered to say that his dad has an illness and it is of a mental kind. He jokes about it with the family because PATS allowed him to feel OK about it and he saw his peers joking about it. He knows he is not alone in the world of mental illness that there are kids and adults out there that can help him and that maybe he can help them too.

A participant's perspective of PATS

This extract from Lyric's Story illustrates many of the key issues around engaging participants in the PATS program. Lyric's reaction to PATS range from initial reticence to participate at all, to whole-hearted engagement in the program, and progression to becoming an active advocate for PATS at the national level. Please note that Lyric has written her story in the third person:

Nothing was going right. It came to the point where her mother was hospitalised many times her mother never recognised she was ill (still doesn't) and finally when a worker had come for her mother she explained to Lyric what was going on. After 4 years off guessing and doing everything, she suggest that Lyric should go to a support group. Her mother was against the idea and so was her father she wasn't keen about it either. The first day she stepped into the building she can remember it like it was yesterday with her mother on her left and her mothers worker on her right. Walking upstairs into a room filled with chairs and painting on the wall. Sitting there waiting to be interviewed. She remembers when the PATS worker came in her mother complimented him told him that he looked like Dr. Carl on neighbours as the interview went on Lyric was answering his questions, her mothers foot on hers it was pressing against her foot when her mother thought she was saying to much. When it was done and she was walking her mother and her mothers worker out so she can start the group her mother was convincing her not to do it, it was wrong cause there was 'nothing' wrong with her mother. Lyric told her mother that

there is 'nothing to worry about after tonight I probably wont come back''. Waiting downstairs for the other participants to arrive she meet the Peer Leader she was extremely friendly, It was weird meeting someone in the same boat as u and actually understanding what u have been going through. The group went by quick they played a few games to get to know each other and introduction to PATS and what was in store for the next 7 weeks. Going home that night Lyric knew she wasn't going to go back she didn't belong there, well that's how she made herself feel. When going to school that week it was different sitting at lunch she knew that the people that she hang with or the teachers didn't understand her, yet the people in the PATS group did. She was struggling at school and PATS could help her through it as one off the weeks they were going to focus on school and teachers as the week went by she decided that she was going to go again. But it wasn't as easy as that her mother made it clear that she was not to go, yet surprisingly her father was all for it. He knew she needed help if only her mother could see the same thing. Unfortunately Lyric had to lie to her mother to go to the group. She didn't want to but she knew that it was best for her. She didn't want to be trapped she wanted to take her own breathe. So Lyric did go for the whole 7 weeks she learnt exactly about her mothers illness and it made her want to know more after the group she would go home and jump on the net to find out information about anything like her mothers illness or places where she can get support or other things. Things she never heard about, never knew about before. As she learnt new things she incorporated it in her life and Lyric now had a reason to smile. Her school was much more understanding, her father put less pressure on her and her duties at his place and he made peace with her mother which cause them to become friends and took a lot off load off Lyric well now she only had to cook once and they eat together. She knew what friends she could trust and those she cant. She knew the places to call if she needed help or if her mother had an episode even though it was still hard things felt like it had been lifted off her shoulders. Most importantly she stopped blaming herself and stopped getting so upset with her mother cause she knew her mothers illness was not her mothers fault and that she was not 'insane'. As Lyric grew she became more and more apart of PATS she did a couple more groups then she did a Peer Leading training and became a peer leader for PATS that was a totally different experience. She wasn't now there for herself she was there to share the information that she picked up to others, to also be a form of support and to be the stepping stone as her peer leader was to her when she did her first group. Lyric was a Peer Leader for many groups and still intends to be and then Lyric started being apart of the PATS reference group, she's

been speaking about her experience at conferences, in public, got to got to a Conference in Sydney to speak and also Queensland, she went to a couple of camps. She recorded a song she wrote about her mother and was asks to put on an Australian Hip Hop Album, she was in many theatre productions. She won a Youth leadership of the year award. Every little thing Lyric has done has been more than learning experience it has been a life changing experience, It has opened doors. She doesn't see life so negatively anymore nor does she complain as much. She knows now there is help and where to get it.

3 CONCLUSION

3.1 PATS Participants

Description of participants

The majority of PATS participants were from an Anglo-Australian background. Relative to the general population, PATS attracted a relatively high number of Indigenous participants and a representative number of Culturally And Linguistically Diverse (CALD) participants. While it is unclear whether either of these groups (Indigenous or CALD) would have greater need for such a program, it appears that the Program has been successful in attracting and engaging these young people.

The young people who participated in the PATS Program report extremely high levels of depressive symptoms and stressors, such as conflict at home, and feelings of isolation and stigma. They also report high levels of burden of care especially the emotional burden of caring for their parents and/or other family members. School suspension rates, especially for males, also indicate lower engagement and participation in school. The majority of PATS participants live in single parent families, and/or in families with lower than expected employment rates, indicating that many may also face economic disadvantages. This leads to the conclusion that this group of young people is in high need.

Young Carers

The measures for carer burden show that young people rated the emotional aspects of caring, such as worrying about their parent, higher than the tangible aspects of caring, that is, housework, paying bills and how demanding the responsibilities are. Whilst over the twelve months there was not a statistically significant drop in rate of carer burden, the figures are moving in a positive direction with carer burden dropping slightly.

What is important to draw from these figures is the significant emotional burden the young people report. This is important for service providers working with young people in this situation. Whilst there may not be practical tasks that these young people are undertaking to care for their parent, the emotional impact may be significant. These findings are consistent with the Commonwealth Young Carers Report. The question then to consider is whether there is a correlation between the high emotional aspects of caring with the high depressive symptomatology.

PATS takes a broad definition of caring. Whilst many young people may have primary or secondary caring roles, it is also important to recognise that within the population of young people who have a parent with a mental illness, not all young people fall into the Commonwealth's definition of Young Carer. Some young people within the PATS population have limited or no contact with their ill parent with 18.4% living in other arrangements. Separation and dislocation from parents occurs for young people who may be in foster care or living with other extended family. Whilst these young people may not have direct caring responsibilities for their parent, their needs are important to be considered and addressed.

3.2 Impact and outcomes of the PATS program

The following findings, and unprompted descriptions of how PATS has helped the participants, provide strong evidence that PATS is successfully meeting its program aims and objectives. The increased skills, understanding and attitudes the young people reported, help to explain the reduced levels of stigma; conflict at home (as assessed through the risk of homelessness measure); and depressive symptoms, and the increase in feelings of wellbeing. There are, therefore, promising indications from the longitudinal data that the PATS program has had a favourable effect on issues targeted by PATS, and encountered by young people with a parent with a mental illness. Below is a summary of the findings from this study's survey of PATS participants:

- 60% reported having depressive symptoms. This is significantly higher than young people in general (18%).
- Only 25% of PATS participants' parents lived together, compared with 70% from a statewide school-based representative survey.
- They are more likely to report high levels of risk of homelessness and suspension from school.
- A majority felt they were able to seek help from mental health services for themselves.
- They reported significant reductions in:
 - depressive symptoms (60% pre-intervention, 38% 12 months later)
 - risk of homelessness (44% pre-intervention, 17% 12 months later)
 - stigma (30% pre-intervention, 15% 12 months later) after their involvement in the program.

Participants also reported that PATS had helped them to:

- learn more about their parent's mental illness, thereby enabling them to recognise symptoms and not to be scared
- realise they were not alone - other young people were having similar experiences
- have increased confidence in seeking help
- understand better their parent's experience and to empathise
- not blame themselves
- cope better – through better communication, valuing self, staying calm
- accept and to deal with feelings
- have fun.

Implementation of the PATS programs

A range of advocacy approaches was undertaken by workers, and PATS participants, to raise awareness and understanding of the issues experienced by young people with a parent with a mental illness, and develop skills to better meet the needs of these young people. New relationships were formed and existing relationships with a range of youth services, mental health services, schools and family services were strengthened as a result of the implementation of the PATS programs.

Workers found they could not promote the issues concerning children of a parent with a mental illness and PATS to the degree they would have liked due to limited resources. Similarly, individual support for young people was not always as accessible as was required. Integrating PATS into organisations was seen as an effective way of 'sharing the load' within organisations, however this could require additional resources to achieve.

Being linked with a widely recognised and respected leading institution to coordinate the project was regarded as a benefit for the project. Being part of something larger than their local PATS program reduced the sense of isolation for both participants and workers.

Referral patterns differed between sites depending on the nature of their existing networks. Overall, referrals were most commonly received from mental health services, local government, schools and individual young people.

PATS reference or advisory groups were established in each of the sites to promote PATS and the needs of children who have a parent with a mental illness; to gain their input into the running of PATS groups; and to explore the support needs of these young people. These groups had varying success depending on the time and resources available to the

coordinators. Factors that affected the ongoing success of the reference groups were: competing priorities, worker turnover and distance to travel to meetings.

Whilst mental health services accounted for over a quarter of the referrals, it was perceived that there was great potential for many more referrals to be received. Reasons identified for the relative lack of referrals included: adult mental health service workers tending to be sceptical about non-clinical prevention programs; lack of time and expertise in exploring the needs of non-adult family members; and lack of regular promotion of PATS to these services.

Access was the most significant issue for most of the sites in terms of burden on the worker. Such issues included driving, picking up, and dropping off participants; costs, for example of taxis and young people's safety.

The personality and skill levels of the workers were regarded as significant factors in contributing to the success of the PATS program in each of the sites. Embedding the program within the host organisation, however, reduced the impact of workers leaving the position, so capacity within the organisation was maintained.

The content and structure of the eight-week group program was deliberately kept open to ensure participants were able to contribute to the content of the group - a key principle of youth participation. Some PATS coordinators, however, would have preferred to use a more structured approach.

The young people and family often needed considerable attention to achieve successful engagement and ongoing involvement in the PATS program. Parents often had misgivings about their children participating in PATS, including fear about what the child would say about them and after hours transport. Involving families as much as possible was the most effective strategy, including having an initial meeting with the parents and young person or going to the family home for the meeting. Important factors in encouraging young people to participate included: provision of transport; discussion; reminder calls and emphasising that the program was voluntary.

It is quite clear from this evaluation that young people who have a parent with a mental illness, and are referred to the PATS Program, are a disadvantaged group and at high risk of developing their own mental health and social problems. The PATS Program provides a form of early intervention in a model that engages these young people, provides emotional and practical support and equips participants with help-seeking knowledge and skills that build on their strengths. Consequently, issues experienced by individuals can be identified earlier, support offered sooner and concerns dealt with promptly. To date, this is the only known comprehensively evaluated, effective intervention for these young people. The investment of ongoing funding is necessary to ensure the needs of young people who have a parent with a mental illness are addressed. This will most certainly translate into financial benefits in the long term, by assisting young people who have a parent with a mental illness to decrease their isolation, increase their self-knowledge and develop healthy family and community connections.

4 Recommendations

Recommendation: Peer support programs such as PATS are recommended as an effective intervention in improving the health and wellbeing of adolescents who have a parent with a mental illness.

The outcome of the research indicates that peer support is an effective intervention in improving the health and wellbeing of adolescents who have a parent with a mental illness. To date, this is the only known strategy that results in improved outcomes for these young people. In the absence of any other effective interventions it is recommended that PATS programs continue and are expanded to each region to meet the needs of these young people.

Recommendation: Capacity building is recommended to raise awareness and develop the skills and knowledge of workers, organisations and communities in relation to young people who have a parent with a mental illness.

Capacity building to raise awareness and develop the skills and knowledge of workers, organisations and communities in relation to young people with a mental illness has also proved to be effective. It has been identified that more work needs to occur with adult mental health services in terms of building their capacity to better meet the needs of the adolescent children of their patients. Capacity building is a longer term strategy which would need continued evaluation to explore what aspects of capacity building are effective, where it is located, and so on.

Recommendation: Strong links need to be formed across community and mental health sectors to ensure the success and sustainability of peer support programs for adolescents who have a parent with a mental illness.

It is recommended that the PATS program be based in the community while the capacity building role is located in adult mental health services thereby ensuring strong networks and credibility across both community and mental health sectors, providing significant leverage across both sectors.

4.1 Peer Support

Recommendation: Adolescent peer support programs such as PATS are most appropriately located in community based environments, so as to provide a non-stigmatising setting that will attract young people.

In terms of the peer support group and ongoing social, education and recreational activities, the PATS Program is most appropriately located in a community-based environment that is:

- 'youth friendly'
- well networked with other local youth organisations
- has a preventive or early intervention approach, and is non-clinical
- is flexible to respond to local needs.

Basing the program in the community allows a range of families to access the program, including those linked into government and non-government agencies, and those who may not be receiving any service or agency assistance. A community-based program, by its very nature, is more accessible for young people with a parent with a mental illness in context of alleviating the stigma attached to mental illness.

Recommendation: It is recommended that adolescent peer support programs such as PATS be linked with other groups that benefit children, young people and families where a parent has a mental illness.

There are clear benefits in PATS and VicCHAMPS operating jointly to meet effectively the needs of children and young people with a parent with a mental illness. Advantages include cross referrals and enhanced capacity to undertake advocacy and workforce development. This was clearly evident in the Shire of Yarra Ranges where both the PATS Program and VicCHAMPS have been operating. The programs, however, need to retain clear foci in regard to the different developmental needs of these two age groups.

Recommendation: Although not as effective as peer support, alternative pathways need to be considered for young people who have a parent with a mental illness and cannot, or do not wish to, attend groups.

It has been recognised that transport and distance can be a significant barrier to young people accessing a PATS Program. Continuity of connection between the young people involved in PATS and being able to access PATS at different times, as their developmental needs change, is essential. Thus, although alternatives such as camps, workshops and chat rooms should be considered, they would not reproduce the benefits of the peer support element of the PATS Program.

A further viable alternative is that the PATS coordinator provided support to young people who cannot access a program such as: one-on-one meetings, resource provision or referring to other services. This is not ideal as it does not provide peer support, but ensures that the young person does receive support.

Recommendation: A peer support program for adolescents who have a parent with a mental illness needs to be integrated into the host service to ensure support and sustainability.

Management support and interest from the host organisation is a crucial element for long-term sustainability. It is recommended that the PATS Program be integrated into the function of the service, rather than be a stand-alone program. This would ensure that a range of workers become involved, thus enhancing the long-term sustainability of the program. Such integration, however, may only occur with additional funding, as with the Shire of Yarra Ranges.

4.2 Capacity Building

Recommendation: Mental health services need to build on family sensitive practices to identify, resource and refer young people who have a parent with a mental illness.

There is an urgent need to undertake further capacity building within adult mental health services to enhance their family sensitive practices to identify and consider the support needs of their client's adolescent offspring. For this reason, the capacity building element may best be located within adult mental health services. An important aspect of the capacity building role would need to include a policy to support workers in adult mental health services, taking into account the families of their clients. The capacity building role

would also be able to explore further funding options to expand the work undertaken around young people with a parent with a mental illness.

4.3 Coordinating Role

Recommendation: A statewide co-ordinating role is essential for the further development of supports for young people who have a parent with a mental illness.

There are a number of reasons why it is necessary to have a central co-ordinator to continue the support and development of interventions for young people who have a parent with a mental illness. The role is crucial in providing ongoing training, the development of resources and support to established sites. The position is also needed to maintain the integrity of the program and to resource and support the expansion of programs in areas that currently lack supports for young people in families where there is parental mental illness. At a broader level, the co-ordinating role can undertake advocacy and contribute to policy development in relation to state and federal developments concerning families in which there is a parent with a mental illness. There is also potential for further research into the benefits of youth participatory activities outside of the eight-week group and for alternative models of intervention.

5 References

1. AICAFMHA (Australian Infant, Child, Adolescent and Family Mental Health Association) 2001, *Children of parents affected by a mental illness scoping project report 2001*, Mental Health and Special Programs Branch, Department of Health and Aged Care, Stepney South Australia.
2. Angold, A, Costello, EJ, Messer, EC, Pickles, A, Silver, D, & Winder, F, 1995, 'Development of a short questionnaire for use in epidemiological studies of depression in children and adolescents', *International Journal of Methods in Psychiatric Research*, vol. 5, pp. 237-49.
3. Australian Bureau of Statistics 2001, *Labour Force Status of Families and Other Characteristics*, Catalogue No. 6203.0, ABS, Canberra
4. Australian Institute of Health and Welfare 2004, *Mental Health Services in Australia 2001-2002*, Australian Institute of Health and Welfare, Canberra.
5. Beardslee, WR, Keller, MB, Lavori, PW, Stanley, J & Sacks, N 1993, 'The impact of parental affective disorder on depression in offspring: A longitudinal follow-up in a non-referred sample' *Journal of American Academy of Child and Adolescent Psychiatry*, vol. 32, no. 4, pp. 723-730.
6. Beardslee, WR, Versage, EM & Gladstone, TRG 1998, 'Children of affectively ill parents: A review of the past 10 years', *Journal of the American Academy of Child and Adolescent Psychiatry*, vol. 37, no. 11, pp. 1134-1141.
7. beyondblue website, last updated 7 July 2004, www.beyondblue.org.au, viewed 10 June 2005.
8. Carers Australia, 2001, *Young carers research project, background papers*, Department of Family and Community Services, Melbourne.
9. Carers Australia, 2001, *Young carers research project, final report*, Department of Family and Community Services, Melbourne.

10. Chamberlain C, MacKenzie, D 1998, *Youth homelessness: Early intervention and prevention*, Australian Centre for Equity through Education, Sydney.
11. Chang, KD, Steiner, H & Ketter, TA 2000, 'Phenomenology of children and adolescent bipolar offspring' *Journal of the American Academy of Child and Adolescent Psychiatry*, vol. 39, no. 4, pp. 453-460.
12. Clarke, GN, Hornbrook, M, Lynch, F, Polen, M, Gale, J, Beardslee, W, O'Connor, E, Seeley, J 2001, 'A randomized trial of a group cognitive intervention for preventing depression in adolescent offspring of depressed parents', *Archive for General Psychiatry*, vol. 58, pp. 1127-1134.
13. Cowling, V, McGorry, P & Hay, DA 1995 'Children of parents with psychotic disorders - the invisible relatives of the seriously mentally-ill'. *Medical Journal of Australia*, 163, 119-120.
14. D'Zurilla, TJ, Nezu, AM, Maydeu-Olivares, A 2002, *Social Problem Solving Inventory – revised (SPSI-R)*, multi Health Systems Inc. New York.
15. Falkov, A 2004 'Talking with children whose parents experience mental illness', in: V Cowling (ed.), *Children of parents with mental illness 2: personal and clinical perspectives*, ACER Press, Camberwell, Victoria.
16. Handley, C, Farrell, GA, Josephs, A, Hanke, A & Hazelton, M 2001, 'The Tasmanian children's project': The needs of children with a parent/carer with a mental illness', *Australian and New Zealand Journal of Mental Health Nursing*, vol. 10, pp. 221-228.
17. Holdsworth, R October 2001, 'Youth participation', *Charting the Course Conference*, Australian Youth Research Centre, University of Melbourne, Victoria.
18. Hyde, J 2005, 'From home to street: Understanding young people's transitions into homelessness', *Journal of Adolescence*, vol. 28, pp. 171-183.
19. Jorm, AF 1997, 'Mental health literacy: A survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment', *Medical Journal of Australia*, vol. 166, pp. 182-186.

20. Jorm, AF, 2000, 'Mental health literacy: Public knowledge and beliefs about mental disorders', *British Journal of Psychiatry*, vol. 177, pp. 396-40.
21. Lieb, R, Isensee, B, Hofler, M, Pfister, H, Wittchen, HU 2002, 'Parental major depression and the risk of depression and other mental disorders in offspring: A Prospective-Longitudinal Study' *Archive of General Psychiatry*, vol. 59, pp. 365-374.
22. Mallett, S, Rosenthal, D & Keys, D 2005, 'Young people, drug use and family conflict: Pathways into homelessness' *Journal of Adolescence*, vol. 28, no. 2, pp. 185-199.
23. Mental Health Branch, Commonwealth Department of Health and Family Services 1997, *Summary of National Mental Health Strategy Projects*, Commonwealth Department of Health and Family Services, Canberra.
24. Montgomery RJV, EF Borgatta & ML Borgatta. 2000, 'Societal and Family Change in the Burden of Care' in *Who Should Care for the Elderly? An East-West Value Divide*, edited by WT Liu & H Kendig, The National University of Singapore Press, Singapore
25. National Mental Health Awareness Campaign, <http://www.nostigma.org/index.html>, viewed June 12 2005.
26. Olfson, M, Marcus, SC, Druss, B, Pincus, HA, & Weissman, MM 2003, 'Parental depression, child mental health problems, and health care utilization', *Medical Care*, vol. 41, no. 6, pp. 716-721.
27. Olsson, C, Boyce, M, Toumbourou, J & Sawyer, S 2005 'The role of peer support in facilitating psychosocial adjustment to chronic illness in adolescence', *Clinical Child Psychology and Psychiatry*, vol 10, pp. 78-87.
28. Ostman, M & Kjellin, L 2002, 'Stigma by association: Psychological factors in relatives of people with mental illness', *British Journal of Psychiatry*, vol. 181, pp. 494-498.
29. Pinfold, V, Toulmin, H, Thornicroft, G, Huxley, P, Farmer, P & Graham, T 2003, 'Reducing psychiatric stigma and discrimination: Evaluation of educational interventions in UK secondary schools', *British Journal of Psychiatry*, vol. 182, pp. 342-346.

30. Ramchandani, P & Stein, A 2003, 'The impact of parental psychiatric disorders on children: Avoiding stigma, improving care', *British Medical Journal*, vol. 327, pp. 242-243.
31. Shiner, M 1999 'Defining peer education', *Journal of Adolescence*, vol 22, 555-566
32. Wierenga, A, Wood, A, Trenbath, G, Kelly, J, Vidakovic, O 2003, *Sharing a new story: Young people in decision making*, Australian Research Centre, University of Melbourne, Victoria.
33. Youth Affairs Council of Victoria 2004, Taking young people seriously: Consulting young people about their ideas and opinions: A handbook for organizations working with young people, Office for Youth, Department for Victorian Communities, Victoria.
34. Zimet, GD, Dahlem, NW & Farley, GK 1988, 'The multidimensional scale of perceived social support', *Journal of personality assessment*, vol. 52, no. 1, pp. 30-41.

6 Appendices

5.1 PATS Participant Questionnaire

Brief

This questionnaire was developed for the PATS peer support program to record PATS participants' perceptions of themselves and their world. Young people across Victoria are doing this questionnaire.

- ◆ This is **NOT** a test. There are no right or wrong answers
- ◆ Please answer all the questions as truthfully as you can
- ◆ If there is a question you do not wish to answer you can skip it
- ◆ Your answers are confidential and will not be told to your family, friends or health workers
- ◆ Please do **NOT** put your name on this form

How to answer the questions:

- ❖ Please mark only one answer per question (unless it says "tick all that apply to you")
- ❖ Please attempt every question.
- ❖ Either tick a box or write in the space provided
- ❖ Answer each question in order unless there is an arrow next to your answer, then just follow the arrow to the next question
- ❖ If you are not sure of an answer, please give the best answer you can or choose the closest response
- ❖ If you make a mistake please put a cross through it and answer again
- ❖ If you have any questions, please ask your PATS coordinator

- ❖ The meaning of these two words will help you fill out questionnaire (elicit if you can):
conflict - arguments, fights, disagreements
manipulate - make you feel like you have to do things; make you feel guilty if you don't do things; make you do things in tricky or sneaky ways

Wave 1



PATS Participant Questionnaire

- ◆ This is **NOT** a test. There are no right or wrong answers
- ◆ Please attempt all the questions you can, as truthfully as you can
- ◆ If there is a question you do not wish to answer you can skip it
- ◆ Your answers are confidential and will not be shown to your family, friends or anyone
- ◆ Please do **NOT** put your name on this form

Thank you very much

YOU AND YOUR FAMILY...

1 How old are you?

- 12 or younger 13 14 15 16
 17 18 19 or older

2 Are you:

- Female Male

3 In which country were you born?

- Australia Other (which country?) _____

4 Are you Aboriginal or Torres Strait Islander?

- No Yes

5 What language do you speak at home?

- English
 English and another language (which language?) _____
 Another language (which language?) _____

6 Which of your parents (carers) is affected by mental illness? (tick all that apply to you)

- Mother Someone else
 Father (tell us) _____

7 Are your parents...

- Living together Have never lived together
 Separated or divorced Something else
 One or both of my parents have died (tell us) _____

8 Does your mother/stepmother/carers do paid work?

- Yes, full-time No, not working Not applicable
 Yes, part-time No, retired

9 Does your father/stepfather/carers do paid work?

- Yes, full-time No, not working Not applicable
 Yes, part-time No, retired

YOUR HOME...

Do you agree with the following statements?

- | | Disagree | Unsure | Agree |
|--|--------------------------|--------------------------|------------------------------|
| 10 I get into a lot of conflict with my parents/guardians/carers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11 I would like to move out of home soon | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12 I feel happy at home | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13 Do you feel safe at home? | | | |
| <input type="checkbox"/> No | | | <input type="checkbox"/> Yes |
| 14 Have you ever run away from home? | | | |
| <input type="checkbox"/> No, never | | | |
| <input type="checkbox"/> Yes, in the last 12 months | | | |
| <input type="checkbox"/> Yes, more than 12 months ago | | | |

WORK AND STUDY

This is about things that might have happened at work or school...

15 What best describes your current situation?

- Left school and unemployed
 - Left school and part-time employed
 - Left school and full-time employed
 - At school
 - At TAFE
 - At University
 - Apprenticeship

16 Overall, what have your marks been like?

- | | |
|------------------------------------|------------------------------------|
| <input type="checkbox"/> Very good | <input type="checkbox"/> Poor |
| <input type="checkbox"/> Good | <input type="checkbox"/> Very poor |
| <input type="checkbox"/> Average | |

17 How happy have you been with things at school or work recently?

- It is a very good part of my life
- Overall neither good nor bad
- It is causing me problems and worry

18 Did you miss a whole day (or more) at school or work, last school term?

- | | |
|------------------------------------|---|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes, 2 or 3 times |
| <input type="checkbox"/> Yes, once | <input type="checkbox"/> Yes, 4 or more times |

19 Which of these **best** describe your main reason(s) for not going to school or work?
(just tick the most important reason(s))

- | | |
|---|---|
| <input type="checkbox"/> Didn't miss any school or work | <input type="checkbox"/> Can't get work |
| <input type="checkbox"/> You were Sick | <input type="checkbox"/> Worried about people at home |
| <input type="checkbox"/> Parent affected by mental illness was sick | <input type="checkbox"/> Not happy at school or work |
| <input type="checkbox"/> Mum or dad asked you to stay home | <input type="checkbox"/> Just didn't want to go |
| <input type="checkbox"/> Chores to do at home | <input type="checkbox"/> Expelled, suspended or fired |
| <input type="checkbox"/> Other (tell us) | |
-

20 Have you ever been suspended from school?

- No Yes

21 Have you ever been expelled from school?

- No Yes

YOUR HEALTH

What you think about your health in the last six months...

22 In the last **6 months**, do you think you have had any physical health problems?

- No Yes

		No	Yes
23	During this time, did you tend to have more physical health issues than other people your age?	<input type="checkbox"/>	<input type="checkbox"/>
24	Do you think you needed professional help with these issues?	<input type="checkbox"/>	<input type="checkbox"/>
25	Did you receive the help you needed for these issues?	<input type="checkbox"/>	<input type="checkbox"/>

26 In the last **6 months**, do you think you have had any emotional issues?

- No Yes

		No	Yes
27	During this time, did you tend to have more emotional issues than other people your age?	<input type="checkbox"/>	<input type="checkbox"/>
28	Do you think you needed professional help with these issues?	<input type="checkbox"/>	<input type="checkbox"/>
29	Did you receive the help you needed for these issues?	<input type="checkbox"/>	<input type="checkbox"/>

Next page

ACTIVITIES

Were you involved in these kinds of activities **last term**?

30 Did you do 'organised' activities **at school** that are not subjects you study, during last term? (things like sport, music, drama, SRC, debating, clubs and associations)

No (tell us why not) _____

Yes

Not at school

31 Did you do 'organised' activities **outside school** last term? (things like sport, music, drama, youth group, scouts or guides, clubs and associations)

No (tell us why not) _____

Yes

32 Did you go out with friends to see a movie, go dancing or just to visit or have fun last term?

No (tell us why not) _____

Yes

SERVICES

Health, social and welfare services are trained people or organisations that provide help for individuals and families when they need it...

33 Do you use services for **yourself**? (eg youth worker, youth group, recreation program, doctor (GP), counsellor, mental health worker, school counsellor)

No

Yes

Which services do you use? _____

34 Do you know how to ask for help for **yourself** from some of these services if you need to? (or find out more about a service)

No

Yes

35 Does your family use any services? (eg psychiatrist, psychologist, hospital, doctor (GP), counsellor, mental health worker, family support worker, clinic, support groups, day programs, MIFV, Psychiatric Disability Support Service)

No Yes Don't know

36 Do you know how to ask for help for **your affected parent or family** from some of these services if you need to? (or find out more about a service)

No Yes

37 Do you have an emergency plan in place if your affected parent gets sick?

No Yes Not applicable

FAMILY AND FRIENDS...

How much do you agree or disagree with these statements about you?

	Very strongly disagree	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree	Very strongly agree
38 There is a special person who is around when I am in need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39 There is a special person with whom I can share my joys and sorrows.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40 My family really tries to help me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41 I get the emotional help and support I need from my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42 I have a special person who is a real source of comfort to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43 My friends really try to help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44 I can count on my friends when things go wrong.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45 I can talk about my problems with my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Very strongly disagree	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree	Very strongly agree
46 I have friends with whom I can share my joys and sorrows.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47 There is a special person in my life who cares about my feelings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48 My family is willing to help me make decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49 I can talk about my problems with my friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

YOUR UNWELL PARENT AND YOU...

Mental illness affects people in different ways. Like any illness, people have good days and bad days. In this section, the questions ask about how your parent's illness affects you.

50 Do you live with your parent or carer who is affected by mental illness?

- No Yes

51 Thinking about your parent's mental illness, overall how unwell would you say he or she has been?

- Very unwell Not at all unwell
 Somewhat unwell Don't know
 A little unwell Don't want to say

52 For how long has your parent been affected by mental illness?

- 3 months or less More than 2 years, less than 5 years
 More than 3 months, less than 6 months More than 5 years, less than 10 years
 More than 6 months, less than 1 year 10 years or more
 More than 1 year, less than 2 years Don't know

53 In your opinion, how has your parent's mental health been in the last three months?

- Not unwell at all Unwell most of the time
 Unwell a bit of the time Unwell all of the time
 Unwell some of the time

How much do you agree with these statements?

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
54 I worry what my friends think about my parent's illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55 I have no problem telling people about my parent's illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56 I feel uncomfortable when people ask me about my parent's illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57 Sometimes I feel embarrassed about having a parent who is affected by mental illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

58 What is the name of the illness that affects your parent?

(tell us) _____

Don't know

59 Do you ever worry that you might get a mental illness yourself?

No

Yes

60 How much do you worry that you might get a mental illness?

Not at all

Some

A little

A lot

61 Do you need more support when your parent is unwell?

No

Yes

What sort of support? (tell us) _____

62 Does your family need more support when your parent is unwell?

No

Yes



What sort of support? (tell us) _____

NEXT PAGE

Think about times when your mum or dad is well, compared with times when he or she is unwell. If your parent is always unwell, think about the times when your mum or dad is really unwell compared with times when he or she is not so unwell.

When your mum or dad is unwell (or really unwell), how much more of these things do you have?

(eg When my mum or dad is unwell, I have a little less time to myself)

 When my mum or dad is unwell, I have... 

...a lot more...	...a little more...	..the same...	...a little less...	...a lot less...
---------------------	---------------------------	------------------	---------------------------	---------------------

- | 63 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...time to myself. |
|----|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--|
| 64 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...stress in my relationship with my unwell parent. |
| 65 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...personal privacy. |
| 66 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...feelings that my unwell parent manipulates me. |
| 67 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...time to spend in recreational activities. |
| 68 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...unreasonable requests by my unwell parent. |
| 69 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...tension in my life. |
| 70 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...holiday activities and trips. |
| 71 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...feelings that my unwell parent is taking advantage of me. |
| 72 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...worries about my relationship with my unwell parent |
| 73 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...worries about things. |
| 74 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...time for friends. |
| 75 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ...time to do my work, study and jobs around the house. |

HANDLING PROBLEMS...

A problem is something important to you that bothers you a lot and that is difficult to make better.

How true are these statements about you?

	Not at all	Slightly	Moderately	Very	Extremely
76 I feel afraid when I have important problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
77 When making decisions, I do not carefully check all my options.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
78 When my first attempt to solve a problem fails, I believe that if I keep trying I will eventually succeed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
79 After I carry out a solution, I check to see how much the problem has got better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
80 I feel unsure of myself when making important decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
81 I try to see problems as challenges.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
82 When my first efforts to solve a problem fail, I get very frustrated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
83 When making decisions, I don't take the time to think about the good points and bad points of each option.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
84 I wait to see if a problem goes away before trying to solve it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
85 I believe that my problems can be solved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
86 I doubt that I can solve difficult problems no matter how hard I try.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
87 I go out of my way to avoid dealing with problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Slightly	Moderately	Very	Extremely
88 Difficult problems make me very upset.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
89 When making decisions, I try to predict the good points and the bad points of each option.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
90 I like to deal with problems as soon as possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
91 I spend more time avoiding my problems than solving them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
92 When solving problems, I go with the first good idea that comes to mind.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
93 I put off solving problems until it is too late to do anything about them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
94 When I have a problem, I get as many facts about it as possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
95 I put off solving problems for as long as possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
96 I believe I can solve difficult problems on my own if I try hard enough.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
97 Before trying to solve a problem, I set a goal so that I know exactly where I am going.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
98 When solving problems, I think of many different options.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
99 I am too quick to act when making decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
100 When making decisions, I go with my "gut feeling" without thinking about what will happen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

FEELINGS...

How you have been feeling about things **IN THE LAST MONTH?** Tick the answer that is closest to the way you have been feeling

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
101	How much of the time have you felt that the future looks hopeful and promising?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
102	How much of the time has your daily life been full of things that were interesting you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
103	How much of the time did you feel relaxed and free of tension?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
104	How much of the time have you generally enjoyed the things you do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
105	How much of the time have you felt loved and wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
106	How much of the time have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
107	How much of the time were you able to relax without difficulty?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
108	How much of the time has living been a wonderful adventure for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
109	How much of the time have you felt cheerful, light-hearted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
110	How much of the time were you a happy person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
111	How much of the time did you feel that your love relationships, loving and being loved, were full and complete?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

112 How often, during the past month, have you been waking up feeling fresh and rested?

- | | |
|--|---|
| <input type="checkbox"/> Always, every day | <input type="checkbox"/> Some days, but usually not |
| <input type="checkbox"/> Almost every day | <input type="checkbox"/> Hardly ever |
| <input type="checkbox"/> Most days | <input type="checkbox"/> Never wake up feeling rested |

113 When you got up in the morning, this past month, about how often did you expect to have an interesting day?

- | | |
|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Very often | <input type="checkbox"/> Almost never |
| <input type="checkbox"/> Fairly often | <input type="checkbox"/> Never |

114 How happy, satisfied or pleased have you been with your personal life?

- Extremely happy, could not have been more satisfied or pleased
- Very happy most of the time
- Generally satisfied, pleased
- Sometimes fairly satisfied, sometimes fairly unhappy
- Generally dissatisfied, unhappy
- Very dissatisfied, unhappy most of the time

115 How much does your parent's illness affect how you feel about yourself?

- | | |
|-------------------------------------|--------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> Some |
| <input type="checkbox"/> A little | <input type="checkbox"/> A lot |

116 How much does your parent's illness affect how you feel about your family?

- | | |
|-------------------------------------|--------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> Some |
| <input type="checkbox"/> A little | <input type="checkbox"/> A lot |

117 How much time do you spend thinking about your parent's mental illness?

- | | |
|---|---|
| <input type="checkbox"/> All of the time | <input type="checkbox"/> A little of the time |
| <input type="checkbox"/> Most of the time | <input type="checkbox"/> None at all |
| <input type="checkbox"/> Some of the time | |

In the past two weeks, how often have you felt like this?

	Not at all	Sometimes	Often
118 I felt miserable or unhappy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
119 I felt so tired I just sat around and did nothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
120 I was very restless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
121 I cried a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
122 I found it hard to think properly or concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
123 I hated myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
124 I was a bad person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
125 I felt lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
126 I thought I could never be as good as other kids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
127 I did everything wrong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
128 I felt I was no good any more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
129 I thought nobody really loved me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
130 I didn't enjoy anything at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SMOKING, DRINKING & DRUGS...

Most people come into contact with alcohol, tobacco, marijuana and other drugs.
Here are some questions about your experiences.

131 How often did you drink alcohol last term?

- | | |
|--|---|
| <input type="checkbox"/> I don't drink alcohol | <input type="checkbox"/> Less than once a month
<input type="checkbox"/> Once or twice a month
<input type="checkbox"/> Once or twice a week
<input type="checkbox"/> More than twice a week |
|--|---|

132 In the past month how many times have you had **5 or more** alcoholic drinks within a couple of hours?

- | | |
|---|--|
| <input type="checkbox"/> None
<input type="checkbox"/> 1-2 times | <input type="checkbox"/> 3-4 times
<input type="checkbox"/> 5 times or more |
|---|--|

133 In the past month, have you found yourself in situations you regret because of drinking too much? (Things like getting a really bad hangover, having a blackout, hitting or hurting someone, getting into trouble with the law, feeling unsafe, drink driving, having unsafe sex)

- | | |
|--|--|
| <input type="checkbox"/> I have never been in that situation
<input type="checkbox"/> 1-2 times | <input type="checkbox"/> 3 times or more |
|--|--|

134 Do you smoke cigarettes?

- | | |
|---|--|
| <input type="checkbox"/> I have never smoked cigarettes
<input type="checkbox"/> I have given up | <input type="checkbox"/> I smoke once or twice a month
<input type="checkbox"/> I smoke once or twice a week
<input type="checkbox"/> I smoke more than twice a week
<input type="checkbox"/> I smoke daily |
|---|--|

135 Have you smoked in the last 24 hours?

- | | |
|-----------------------------|------------------------------|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes |
|-----------------------------|------------------------------|

136 Do you use marijuana (yundi, pot, weed, dope, hash)?

- | | |
|--|---|
| <input type="checkbox"/> I have never used marijuana
<input type="checkbox"/> I have tried it once or twice | <input type="checkbox"/> Yes, once or twice a month
<input type="checkbox"/> Yes, once or twice a week
<input type="checkbox"/> Yes, more than twice a week |
|--|---|

137 Do you use other drugs (like pain killers, cocaine, solvents, ecstasy or heroin) for non medical purposes?

- | | |
|---|--|
| <input type="checkbox"/> I have never used other drugs
<input type="checkbox"/> I have tried other drugs once or twice | 112
<input type="checkbox"/> Yes, once or twice a month
<input type="checkbox"/> Yes, once or twice a week
<input type="checkbox"/> Yes, more than twice a week |
|---|--|

PATS

138 What other PATS activities have you done? (tick all that apply to you)

- I haven't done any other PATS activities, just this group
- I've been in another PATS peer support group
- I've been on PATS social outings and events (going to a film or surfing etc)
- I've spoken at PATS talks and presentations (public speaking)
- I've been on a PATS Reference Group
- I've contributed to the newsletter
- I've done Leadership training
- I've done media or other training organised by PATS
- I've been a Group Peer Leader

AND FINALLY...

139 On the whole, how accurately were you able to answer these questions?

- | | |
|--|--|
| <input type="checkbox"/> Very accurately | <input type="checkbox"/> Very inaccurately |
| <input type="checkbox"/> Mostly accurately | <input type="checkbox"/> Don't know |

140 Overall, how easy did you find the questionnaire to understand?

- | | |
|--|--------------------------------------|
| <input type="checkbox"/> Not at all easy | <input type="checkbox"/> Fairly easy |
| <input type="checkbox"/> Not very easy | <input type="checkbox"/> Very easy |

141 What about the length of the questionnaire, did you find it...

- | | |
|---|--|
| <input type="checkbox"/> Much too long | <input type="checkbox"/> A bit too short |
| <input type="checkbox"/> A bit too long | <input type="checkbox"/> Much too short |
| <input type="checkbox"/> About right | |

Thank you for completing our questionnaire

Please check you have answered all the questions (except those you don't want to)

Seal this booklet in the envelope provided to keep it confidential and give it to your PATS facilitator

5.2 Prompts and questions used in the two rounds of semi-structured interviews with PATS site coordinators.

Round 1 November – December 2003

- Worker background
- Setting up PATS:
 - history of PATS
 - Who expressed interest in program?
 - When were you (Co-ordinator) involved?
 - promoting PATS – agencies contacted – methods employed
 - issues around set-up
- Management group:
 - make-up of group; agencies represented
 - how often met; important decisions and process etc.
- Setting:
 - What are the issues facing young people with pami?
 - Is PATS meeting the needs of young people in the region?
 - Are there any gaps in services needed for people with pami?
 - service agency issues
- Running PATS
 - summary of experiences so far
 - sources of referrals
 - feedback from participants
 - levels of participation of young people (reference group, peer leader role, participant input in setting group agenda)
 - support both from within host agency and from partner agencies; current status and what needed
 - support from CAH; current status and what needed
 - main issues arisen and what being done to tackle them
 - transport/access
 - density of referrals
 - stigma, anonymity and local communities
- The future direction
 - What is being done well?
 - What could be being done better?
 - obstacles/enhancers to success of program
 - What needed to sustain program?

Round 2 November - December 2004

- How have things been going over the last 12 months?
 - what's gone well (successes)?
 - what challenges have you faced?
 - changes – staff, organisational structure, etc
 - is program meeting needs
- Referral patterns – accessed and untapped sources
- Youth participation
 - working or not; why not; how overcoming challenges
 - examples of youth participation (e.g. mural)
- Is the 8 week model working?
 - alternatives
 - would a different model attract different group?
- How have you found the role of CAH?
 - gaps and improvements
 - support from other agencies
- Is program located in optimum location?
 - geographic and agency
- Evaluation
 - has this impacted on your work – positively or negatively?
 - how could the evaluation have been improved?
- The future
 - funding – what's going to happen when the current funding period ends?
 - is there support for the program – agency and partnerships?
 - is the program sustainable?