International Young Carer Programs

The Many Paths We Take
© Artist Pauline Miles
Dedicated to all who have for many reasons been involved with
Children who have a parent with a Mental Illness and their Parent

“If we value our children, we must cherish their parents.”

John Bowlby, MD

When I was asked to write the forward for this Directory I felt humble and felt that this was an
honour and wanted to give it my best. I am especially thankful to my mother whom without
her I would not be writing this. I would also like to acknowledge many people who have
travelled with me on this journey in raising awareness about the issues of COPMI children in
Australia.

It was back in the nineties that I first broached the subject of children of who have parents
with a mental illness (and to find there was almost nothing going for them), when I became
a mental health Consumer Advocate. It was through Debbie Waddingham who was the
consumer project officer for the HCC (Health Consumer Council). Debbie was setting up
Consumer Advocacy Groups at mental health clinics in WA. This started me on my crusade
to evoke the mental health system, Government, and community to become conscious of
this vulnerable group of children and their parents.

There were a lot of reasons why I wanted to raise this issue and put it on the agenda in the
mental health services. Living with a mental illness as a parent with two young children I
knew what this was like for them as I too was born to a mother with mental illness and
nothing had changed in the system to help children or help parents to care for their children
whilst they were parenting with mental illness. I was born in the 1940’s and my own children
were experiencing the same lack of support and services that my mother did in the 1940’s
and this was now the 1980’s and my children were experiencing the same as I had done
when I was a child.

Another of those people is Vicky Cowling whom I met at my very first TheMHS Mental
Health Services Conference held in Sydney in the 1990’s. It was at this conference that I
saw that in the conference program Vicky was presenting about the COPMI (Children of
Parents with a Mental Illness.) I could not believe it, my luck had come, and someone was
talking about this important issue. Although I had been speaking up in Western Australia it
was after a lunch time chat with Vicky who had been presenting this issue for many years
and had a lot of wisdom and knowledge in the field I felt more confident and this galvanized
me into more action in WA.

However due to this I was determined due to my experience in the system and the
opportunity that had been presented to me by Debbie Waddingham to take up Consumer
Advocacy I would take a look at this issue that is now called COPMI (children of parents with
a Mental Illness) and since then a lot has taken place but more still needs to be done which
leads me to talk about the new directory that has put together by Joanne Pollard from the
WAAMH (Western Australian Association Mental Health).

“Nothing truly valuable arises from ambition or from a mere sense of duty; it stems
rather from love and devotion towards men and towards objective things.”

—Albert Einstein
This new well researched recourse directory by Joanne that presents current worldwide programs that provides much needed support for children who have parents with mental illness has been a mammoth undertaking and shows what can be achieved by people who when passion and dedication come together how one can achieve the best one can do. We can all take heart that together we can achieve more and by sharing recourses and knowledge that’s contained in this directory we can draw on this to excite us all too develop new programs for COPMI (Children of Parents with Mental Illness)

I would like to thank all those I have had the good fortune to meet whilst I have been involved in COPMI here in WA, interstate and internationally. So I say thank you to all who have contributed to support for children and families from the bottom of my heart, children and families need your support and without this their mountain top would be that much harder to reach. Thank you so much from all of us children, parents, grandparent’s friends, brothers, sisters, and families.

"Let it be said by our children’s children
that when we were tested we refused to let this journey end, that we did not turn back
nor did we falter; and with eyes fixed on the horizon and God's grace upon us,
we carried forth that great gift of freedom and delivered it safely to future generations."

President Barack Obama - Inaugural Address

Margaret Cook
Convenor
COPMI WA Children of Mentally Ill Consumers

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Comics
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Education
• Dundee Young Carers - Young carers Resource Pack for schools - Contact details in the Directory.
• Cardiff Young Carers - Issues Affecting Young Carers on Transition from Primary to Secondary School – Lesley Noaks & John Noaks – Contact details in the Directory.
• The Children’s Society – A variety of resources, including an exemplar job description for a school lead and a schools notice-board pack. Contact and web details available in the Directory.
• The Princess Royal Trust – A variety of resources including how to identify a young carer and schools resource pack, teachers action list and school action list. Contact details in Directory.
• Young Carers Australia Resources developed for both primary and secondary school teachers are available from the Young Carers website www.youngcarers.net.au.

GP’s and Hospitals
• The Princess Royal Trust for Carers – A variety of resources, including GP Information Pack, Carer Friendly Practices, Working with Young People and many more. Health - http://www.carers.org/professionals/young-carers/health,3065,PP.html

Handbooks for Children and Youth
• Kids in Control, Canada - When Things Get Really Weird! – For children who have a parent with schizophrenia – Contact details in the Directory.
• Kids in Control, Canada - When Moods Go UP and Down – For Children who have a parent with Bipolar Disorder - Contact details in the Directory.
• Kids in Control, Canada - When Things are Sad and Gloomy – For Children who have a parent with depression - Contact details in the Directory.
• Cardiff Young Carers – The Way It Is – Contact details in the Directory.
• Barnardo’s Message in a Bottle – Me When I Cheer My Mummy Up by dancing – Contact details in the Directory.
• Smiles Program - ‘Handle with Care’ – a Workbook about Mental Illness for 8–12 year olds - Contact details in the Directory.

• Smiles Program - A Booklet for Young People about Mental Illness'; Moonbeam – a Book of Meditations for Children’ or similar titles – Contact details in the Directory.

• Carers Australia - Young Carers Kit

Identification of Young Carers

• The Princess Royal Trust for Carers – A variety of resources, including identifying carers through pharmacies. Available from http://www.carers.org/professionals/health/articles/identifying-carers-through-pharmacies,860,PR.html

Professional

• The Children’s Society, UK – A variety of resources for professions including teachers and school staff, health professionals and Children's and Adults’ Services – Contact details in the Directory.

• Cardiff Young Carers - Available from Young Carers Cardiff. Contact details available in Directory.

• Cardiff Young Carers - Cardiff Joint Young Carers Strategy – Cardiff Children and Young People’s Partnership – Contact details available in Directory.

• SUS Denmark – What Is The Matter by Tytti Solantaus – Contact details available by contacting SUS in Denmark.

• SUS Denmark – Rosa’s Mother is in a Psychiatric Hospital – Book for children from 3 years of age. Contact details in the Directory.

• SUS Denmark – The Sea in the Head- Contact details available in Directory.

• Joanne Nicholson, Ph D., Professor – A range of resources, including Parenting Well When You’re Depressed: A Complete Resource for Maintaining a Healthy Family. Available from Joanne Nicholson at the Centre for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School,55 Lake Avenue North, Worcester, MA 01655, phone: 508-856-8712. Email: Joanne.Nicholson@Umassmed.edu. www.parentingwell.info; www.umassmed.edu/cmhsr/faculty/Nicholson.cfm

• Bring it! 2008 Young Carers Forum Report (2009)

Program Downloads

- KIDZ CLUB KIT (Program Kit) Mater Children’s Hospital, Queensland KidzClub Available from Mater CYMHS, Raymond Terrace South Brisbane, Queensland 4101 or http://kidsinmind.org.au/deliver/content.asp?pid=6953.

Refugee


Resource Packs

- Barnardo’s - Barnardo’s Keeping the family in mind – Barnardo’s Action with Young Carers, Liverpool, UK 2003 - Available from Barnardo's Message in a Bottle – Contact details in Directory.
- Supporting Our Family COMIC (Children Of Mentally Ill Consumers) Paola Mason and Nerrelle Goad - Co-convenors 2000. Email comic.admin@bigpond.com; http://www.howstat.com/comic.

Toolkits

- The Children’s Society - The Whole Family Pathway – Contact and web details available in the Directory.

Ulysses Agreement

- Ulysses Agreement – http://www.parentalmentalillness.org under Resources or Dr Robert Lees, details in the Directory.

Workforce Resources

- COPMI - Keeping Families and Children in Mind: COPMI Mental Health Worker Education Resource - workforce development training resource available from Kylie Eddy on 8367 0888 ext 25, or email: eddyk@aicafmha.net.au.
• Partners in Care (UK)  2005
  A checklist for professionals coming into contact with the children of parents with
  mental health problems. Available from
  http://www.rcpsych.ac.uk/campaigns/pinc.

• PATS (Paying Attention to Self) PACK Danielle Forer, Available via Email -
  forerd@cryptic.rch.unimelb.edu.au.

• Care Plan COMIC (Children Of Mentally Ill Consumers) Paola Mason and
  Nerrelle Goad - Co-convenors 2000. Available from
  comic.admin@bigpond.com; http://www.howstat.com/comic.

• Family Support Plan The Koping Forum, Child & Youth Mental Health Service,
  Royal Children’s Hospital and Children’s Health Services District  2006. Available from
  koping@health.qld.gov.au; +61 07 3266 3100.

• Young Carers’ Assessment questionnaire produced by North Yorkshire County
  Council in association with Carers’ Resource (Harrogate, Craven and Airedale).
  Download the questionnaire (625 KB).

Useful Websites
• COPMI National Australian resource centre – www.copmi.net.au
• Barnardo’s - http://www.barnardos.org.uk/
• The Princess Royal Trust for Carers
  http://www.carers.org/professionals/young-carers/
• Children of Mentally Ill Consumers (COMIC) www.comicwa.org
• Australian Infant, Child, Adolescent, Family Mental Health Association
  www.aicafmha.net.au
• The Princess Royal Trust for Carers
  www.carers.org/professionals/health/primary-care.805.PP.html
• The Princess Royal Trust for Carers
  www.carers.org/professionals/health/hospitals.806.PP.html
• The Princess Royal Trust for Carers www.carers.org/professionals/young-carers/
• Carers Australia - www.youngcarers.net.au
Introduction

The purpose of this document is to create a practical, easy to follow directory of young carer programs internationally. It aims to be a resource for individuals and organisations looking for innovative ways to support young carers who have a parent with a mental illness and to facilitate the collaboration between agencies state wide, nationally and internationally.

It became apparent that some countries have a minimal to nonexistent services for young carers, and this resource may be able to assist them with knowledge of what is possible and contacts of people who are working in this area on any specific program.

This research was initiated while undertaking a project titled ‘Partners in Respite’, which was funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). During the project it was identified by the Western Australian Association for Mental Health (WAAMH) that there is a gap of support for this group of children and young adults. As a result of this WAAMH undertook research into programs that exist around the world.

This resource is by no means exhaustive. Countries that have been contacted include Austria, Australia, England, United States of America, Estonia, Israel, Spain, Netherlands, Denmark, Iceland, Argentina, Swaziland, Poland, Cyprus, Czech Republic, Ireland, Latvia, Luxembourg, Morocco, New Zealand, Scotland, Slovakia, Switzerland, Denmark, Northern Ireland, Slovenia, Japan and Wales. Some countries were contacted but due to language barriers it proved difficult to obtain the required information.

If we receive enquiries asking for a program to be included in this resource, another edition may be able to be produced.

I would like to acknowledge all the participants in this project for their contributions to the research and report. With their kindness, enthusiasm and willingness to share, they have made the sharing of knowledge possible.

Further, I would like to acknowledge Margaret Cook, who for many years has been an advocate and driving force in the efforts to close the gap that young carers experience. Margaret’s sister Pauline Miles has also worked with Margaret, and has very kindly produced artwork for this report.

The organisations conduct evaluations, but due to the size of the document, and time constraints, we were not able to include these. We recommend that anyone seeking information on how effective a service is should contact the identified service directly.

Joanne Pollard
Western Australian Association for Mental Health
September 2009
Reception@waamh.org.au
www.waamh.org.au

Funded by the Australian Government under the Mental Health Respite Program
The program supports young carers who are at risk of not completing secondary education or vocational equivalent due to the demands of their caring role.

The program enables young carers to access respite services and age appropriate support including educational, social and recreational activities, for example time off to study for exams, tutoring, skills development, young carer camps and activities in the school holidays.

The program also provides a range of information, advice and referral services, including referral to counselling, to support young carers in managing the challenges they face as part of their caring role.

The Australian Government will provide over $7.7 million in funding for 2009-10 to continue providing services to help young carers.

**How the program is implemented**

1. **Respite services**
   Young carer respite services are delivered through the Commonwealth Respite and Carelink Centres located across Australia. The program provides respite services and access to age appropriate support to undertake activities including studying for exams, attending recreation or activities such as cooking or budgeting lessons, tutoring or someone to talk to.

   Examples of respite services include:
   - Young Carer Camps
   - Domestic assistance
   - In-home respite care
   - Tutoring
   - Transport to social or support activities

2. **Information, advice and referral services**
   Information, advice and referral services are delivered by Carers Australia and its network of Carers Associations.

   - Interactive website
   - Referral to counselling
   - Information about available support
   - Regional networks
   - Community awareness and education

*Thank you to Judy Phillips and Gaye Greed for their advice*
About Carers Australia

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Through its members, the state and territory Carers Associations (the Network) there is a unique infrastructure Australia wide. The Network delivers specialist information, advisory and counselling services to carers in 60 sites around Australia.

Carers Australia is informed about carer issues through its member Carers Associations and its participation in national and international forums.

Carers Australia believes all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education. Unfortunately, research clearly indicates that many carers are disadvantaged socially, physically and economically.

About Young Carers

Young carers are a group of young Australians under 26 years of age who provide unpaid care in families where someone has an illness, a disability, a mental health issue or who has an alcohol or other drug problem. They are required to perform the same caring tasks as older carers including providing emotional support and assisting with mobility, the provision of medications, housework and intimate care tasks. The time spent caring can be as much as 30 hours per week which is almost equivalent to full time employment in Australia. Young carers have to juggle their caring responsibilities and their schooling.

Naturally, young carers see themselves as daughters or sons, brothers or sisters who are part of a family rather than a “young carer”. A general lack of awareness and focus on the needs of young carers, within schools and among other professionals, means their needs can go unnoticed.
We do know that it is very difficult to accurately estimate the numbers of young carers across Australia due to the numbers who are ‘hidden’ in our community. However, current figures suggest that there are:

- 348,700 under the age of 26, and of these 170,600 are young carers under the age of 18
- 132,000 are primary carers – that is they provide the most care
- Approximately 105,500 carers are under the age of 15
- One-third to one-half of young carers live in rural and remote areas of Australia where services that support families are, in general, not adequate.

Characteristics of young carers

Young carers are a diverse group with different needs and levels of vulnerability. In Australia it has been found that:

- Young carers have been identified by services as being as young as 6 years of age
- Females are only slightly more likely to become young carers than males
- Young carers are generally representative of the general population in their cultural background
- Young carers spend most of their time providing care or thinking about the person they support
- Over half of young primary carers are caring for a parent who is more likely to be a mother and the family is also likely to be a sole-parent household
- Approximately one quarter of young carers provide care for a person with a mental illness.

Impact of Caring on Young People

The caring role has the potential for significant negative effects on young carers, including reduced life choices and limited opportunities.

Young carers are a diverse group and all these children and young people have different needs and levels of disadvantage and vulnerability. However, the literature and data has overwhelmingly demonstrated that as a direct consequence of their caring role, the majority of Young Carers are at risk across a number of social and economic areas.

Health and Wellbeing of Young Carers

Young carers’ health is at risk from stress, limited sleep and the multiple physical and emotional demands on them.

Many young carers report constant feelings of sadness, guilt, fear and worry which can contribute to impaired psychological development.

Young Carers are at risk of, or do experience, social isolation and loneliness due to the physical and emotional demands of their caring role. As a direct result of their caring role, young carers don’t get to participate in normal child / young person activities such as going to the movies, catching up with friends outside of school, playing games or going shopping.
National Young Carers Information, Advice and Referral Services

These services are nationally funded as part of a broader program dedicated to the support of young carers. This service is funded through the Australian Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)

Our objectives under this funding is to support young carers in their caring role by:

- Providing them with a clearly identifiable and accessible point of contact for information, referral and advice services
- Identifying each young carer’s needs and arrange appropriate support services, including referral to age specific counselling services
- Increasing awareness of young carers and their issues within the community including but not limited to: service providers, government departments, schools and health professionals
- Undertaking activities that increase the rate of identification of young carers seeking assistance and support.

The National Young Carers Information, Advice and Referral Services program is managed by Carers Australia and delivered through the state and territory Carers Associations.

Thank you to Dee Penna for her advice
Youth Service
The youth service at Arafmi provides a free service for young people between the ages of 8-18 who care for someone with a mental illness with:

- One on one counselling;
- Information;
- Psycho-social education workshops;
- As well as recreational activities.

Anyone can refer a young person to Arafmi. Referrals can come from health services, youth services, and families themselves. To be eligible for the service, the young person must be living in the North and East metropolitan regions of Perth.

Counselling
The counseling service aims to help young people manage some of the feelings that they are having in relation to their loved one who has a mental illness, and to acknowledge that these feelings are OK.

It also aims to help the young person:
- Build coping skills and resilience,
- Looks at developing care plans appropriate to each individual and
- Also aims at providing age appropriate education around mental illness.

Currently the youth service is run from Arafmi offices in Perth, Whitfords and Midland servicing young people from the North and East Metro regions of Perth. Due to issues around transport, particularly for those parents who have the mental illness themselves, Arafmi is looking at developing partnerships with schools in order to facilitate counseling during school hours to suit the young person, their family and the school.

Holiday Program
The service also includes a Youth Holiday Program which involves social activities such as:

- Bowling;
- Paintballing;
- Cinemas;
- Water parks;
- Some education on mental illness.

The activities run over several days during the school holidays, are divided between primary and secondary school age and the activities change with each school holiday. The program aims to reduce the risk of isolation for the young person, provide peer support, offer respite and also incorporates some education around mental illness.
Resources
- Arafmi has also produced a therapeutic resource for young people aged between 8 and 12 called Handle with Care;
- A Workbook about Mental Illness for 8-16 Year Olds.

These workbooks provide age-appropriate information to young people about mental illness, specific conditions, as well as ways of coping with the practical and emotional issues that may be experienced as a result of having a loved one with a mental illness.

School Education Program:
Arafmi provides services for young people through School Education and Youth Services programs. The aims of the program are to:
- To improve understanding of mental illness among young people;
- To dispel myths and stigma surrounding mental illness;
- To provide information about mental illness;
- To advise of available information and support;
- To encourage early intervention;
- To promote good mental health.

The Arafmi School Education Program started in 1987 in Sydney. An Arafmi member, whose daughter was experiencing difficulties at school because of her sister’s mental illness, proposed going into the classrooms in Sydney’s Inner West. She developed a resource package to assist both herself and a volunteer to undertake some interesting and informative classroom discussion. It was not fully appreciated that these classroom presentations would attract state, national and international interest.

The School Education Program in Perth covers the Perth metropolitan area as well as extending out as far as Bunbury, Meriden and Narrogin. The program is aimed at secondary school young people. Arafmi’s main aim is to address the stigma of mental illness however some schools have certain issues they face and we often cater for those needs and present on specific issues like depression and eating disorders.

The school education program has proven to be extremely effective through evaluation processes from the young people, the school staff and the volunteers that make the program immensely powerful.

Our vision for young Australians is that through this program they will gain a more positive attitude towards and understanding of people with mental illness and their carers. They will develop an awareness of their own mental health; that those students who may now, or in the future, live with mental illness themselves, or in a friend or relative, will be less isolated and afraid and be more empowered to seek help and support.

To date, the overall outcome of this program has opened a door in the hearts and minds of the students, staff and the general community who have witnessed classroom presentations. It has provided information and presented real life experiences on a subject which was once regarded as a social taboo. Students recognise and openly state that without this program they would still be ignorant of the facts; the effects on family and friends living with mental illness; the perspective of the person with a mental illness and the help and support now available within the community.

This program is about the health of the communities and working within the school community is about advancing the mental health of that community.

Thank you to Laura Green, Anna Albrecht and Liza McCormick for their advice
Champs (Children and Mentally Ill Parents) programs were first developed in 1995 as part of a two-year Commonwealth funded project called the C.H.A.M.P. project. From 1997 the programs were intermittently funded primarily under the auspice of Eastern Health Adult Mental Health Program in metropolitan Melbourne. In 2003 Eastern Health received from VicHealth, BeyondBlue and the Department of Human Services Victoria for a three year project to evaluate a model of best practice for children aged eight to twelve who have a parent with a mental illness. VicChamps as it was called, ran a range of programs including school holiday and after school programs. At the completion of this funding the Department of Human Services, Division of Mental Health and Drugs developed a Service Development strategy for Families where a Parent has a Mental Illness (FaPMI). The strategy is available online www.health.vic.gov.au/mentalhealth/families/index.htm.

The overall aim of the Strategy is to develop ‘family focussed’ services working together to support children of all ages and their families where a parent has a mental illness. “Champs” continues to be the name associated with programs for children of primary school age.

The aim of the VicChamps project was to increase resilience and social connectedness of children with a parent with a mental illness and their families through enhancing community capacity and partnerships between sectors and services, and providing peer support programs.

Eastern Health has continued to provide Champs programs and also has one of the eleven FaPMI Coordinator positions in Victoria. Funding for the program is primarily through philanthropic or community funding.

Champs Programs include:

- **After school program** – This is an 8 or 9 week program which is a peer support program that provides information about mental illness and a range of other activities to promote resilience. It includes a family pizza night where parents can spend separate time with a facilitator hearing about what has been discussed as well as a chance for particular issues to be raised.

- **School Holiday program** – run over 3 or 4 days with children and /or families. In addition, a peer support program for parents is offered in the region as well as a facilitated playgroup.

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The website http://www.easternhealth.org.au/champs/champs.shtml has a range of information for children and parents including a section for 5-8 year olds and for 9-12 year olds and information sheets on a range of mental illnesses. The website has resources available for the development of the program, including session plans, Crisis Action Plan – with instructions on how to develop a plan for children, a sample letter to families and a consent form.

Thank you to Rebecca Allchin and Rose Cuff for their advice
COMIC WA brings people together from various organizations providing a forum to speak about the issues of children and parenting with a mental illness and also providing service providers with opportunities to engage with each other and learn about other organizations. COMIC WA is run by people with a lived experience.

They have

- Developed a Facilitators Manual and Participants manual for TELL (Training Education Learning and Listening);
- Launched a series of booklets for families that were developed by consumers and carers in partnership between COMIC WA and Ruah Inreach WA;
- Developed a set of booklets Understanding Mental Illness in Your Family for children;
- Input into research of COPMI issues and family friendly service development, both state and national;
- Representation on various committee such as drug and alcohol and rehabilitation and recovery;
- Advocate to Government on the issues facing families where a child is living with a parent with a mental illness;
- Workshops which provide education and training with a whole of family emphasis to Government and Non-Government agencies groups, universities and international colleges;
- Art projects for children of parents with a mental illness.

Aims of Comic WA:

- Advocate for services to be made available to all families where a family member has a mental illness;
- Be guided by the experiences of children and adult children who have a parent with a mental illness;
- Lobby Government to provide funding for services where mental illness is present in families;
- Map any existing programs that deliver services to children who have a family member with a mental illness;
- Provide education to families, government and Non-Government agencies about the needs of children who have a parent with a mental illness

Thank you to Margaret Cook for her advice
The Joondalup Health Campus Mental Health Unit in Joondalup, Western Australian has created a 'whole of family' concept in order to include and support the children of its patients.

Based on experience, the unit has found that many of its patients’ families are not aware of the assistance that is available to them but is working to overcome this issue. Upon admission to the unit, the patient is asked about their family members so they can provide them with information regarding:

- Support services accessible to the children and other family members
- Alternative care arrangements for children while the parent is in hospital
- Parental assistance services.

Should a parent have any concerns during their stay in the unit, they have access to:

- A Family Therapist, who can provide counselling for the parent and the family together
- Social Workers, who can assist in accessing services, negotiating and advocating and assisting with concerns regarding the children or family as a whole.

**Weekly Parenting with Mental Illness Groups**
The unit also holds weekly ‘Parenting with a Mental Illness’ groups to discuss how patients with children are coping during their stay in the unit. They will be given appropriate information and assistance to help resolve any issues or concerns.

**Private Family Space**
The unit has a family friendly meeting area attached to the secure ward and a children’s game room, allowing families to spend time together.

There is also an outside area for picnics, ball games or just to sit, chat and spend time with the children.

_Thank you to Dani Barnes and Annette Pinnell for their advice_
Koping is a comprehensive service delivery program offered by CYMHS in the CHSD to support children, young people and their families where there is a parent, caregiver or sibling with a mental illness. Koping offers a group-based intervention program to young people from the ages of 12-18 years with aims to increase peer support, resilience building and awareness raising of mental health issues. The program also offers resources, consultation liaison and support for service providers working with families affected by mental illness and/or drug and alcohol concerns.

Once known as the KOPING Project, it was commenced in the year 1999 from a collaborative initiative and support of members of the KOPING Forum. Now 10 years on, the KOPING Program has been firmly established with recognition, awards and credibility towards its advocacy and support for the children and young people of this target population. With the ongoing support of the KOPING Program under CYMHS of the RCH & CHSD, KOPING will continue to evolve and develop with an expectation of raising awareness and supporting the establishment of similar programs in areas beyond this Health Service.

Services that KOPING provide include:

- **The KOPING Adolescent Peer Group Program** - a group program for young people (12-18 years) with a parent with a mental health problem. It provides the opportunity for young people to access peer support and information, and to develop helpful coping strategies. The 3 day peer support program is run over four weeks and is held at The Salvation Army, Stafford every term. Participation is free, fun and completely confidential.

- **The Koping Consultation and Liaison Service** was developed in 2007. The service consists of a part time Consultant Psychiatrist and The Koping Program Coordinator. The service aims to increase collaborative work between adult and child mental health services and assist service providers in supporting children and families in which a parent/s or carer have a mental illness. The services offered include advice, information and resources, joint assessment and recommendations regarding care planning and appropriate services.

- **The Family Support Plan** is aimed at minimizing disruption that occurs when a parent is hospitalised. The Family Support Plan is aimed at working with a parent/s when they are well, helping them to plan for any future care arrangements that may be required in a crisis situation. The plan specifies important information such as emergency respite options, custodial restrictions, medical requirements/medications etc, school/daycare contacts, children’s routines and needs etc.

- The Future Families Program also utilises a Baby Safety Plan for younger children.
• The **Queensland State-wide Network** provides an avenue for information sharing across the State via an electronic newsletter. This newsletter is produced quarterly. Please contact the KOPING Program Coordinator if you would like to receive this newsletter.

• The **KOPING Forum** is an interagency network made up of representatives from Government services, private providers, community agencies and community members. The KOPING Forum was established in the Children's Health Services District in December 2000, recognising the need to develop improved responses to supporting children and young people, and their families, where a parent is living with a mental health problem.

• The **COPMI Learning Circle** is a collaborative of agencies currently working with or planning to work with COPMI and/or their families. The Learning Circle provides an environment in which workers can share their experiences in working with COPMI and their families, gain/provide advice, reflect on best practice and strengthen current and future program development.

**Koping Resources**

• **Koping Kids Kall Out CD**
  The CD “KOPING Kids Kall Out” was developed as part of a project involving graduates of the KOPING Adolescent Group Program. The CD contains three original songs, performed by a core group of seven young people ranging in age from 12-16 years. The songs were written to express the young people’s experiences of having a parent with a mental illness. Copies available free of charge by contacting the KOPING Project Coordinator.

• **KOPING DVD**
  The KOPING DVD and accompanying CD ROM resource has been developed to support children, young people and their families whose parent/s are living with a mental illness or dual diagnosis by providing information about other young people’s experiences, ways of coping and how to get help. The DVD can be used to stimulate discussion with young people, as part of professional development, or for families to view together to enhance their understanding from the young person's perspective. The DVD is available for borrowing from the KOPING Library held at Nundah Specialist Teams CYMHS, or can be purchased for $50.00. Included in this package:

  **Koping DVD**
  - “Their Stories”- a 22 minute movie for young people aged 12-18 living with a parent with mental illness or dual diagnosis
  - A 5 minute animation for primary school aged children living with a parent with mental illness or dual diagnosis
  - 5 minute overview of both animation and “their stories”

  **CD ROM**
  - DVD facilitators Manual
  - Resources for working with families that have a parent or carer affected by mental illness or dual diagnosis, including information brochures, tip sheets, referral forms, program brochures etc.

• **KOPING Adolescent Program Facilitators Manual Package (includes the Koping DVD and CD ROM)**
The Koping Adolescent Program (KAP) is a 3 day psycho education, peer-support based program developed for young people between the ages of 12 and 18 that have a parent or carer affected by mental illness or dual diagnosis. Along with the appropriate KAP Facilitator Training, this manual and accompanying DVD give you a step by step guide to running a Koping Adolescent Program. The manual provides important background information regarding the issues that children, young people and their families who have a parent or care giver affected by mental illness or dual diagnosis face. It provides information on program set up, implementation, training requirements, organisation from pre-referral to post group stages, outcome measures, supervision and risk assessment/behavior management. The manual contains copies of activity sheets, certificates, referral forms, suggested service agreements, case note proforma’s, safety plans and copyright guidelines.

Included in the package:

- Koping Adolescent Program Facilitators Manual
- Koping DVD
- CD ROM

The Koping Adolescent Program Facilitators Manual Package can be purchased for $90.00.

Through the KOPING Program, the Child and Youth Mental Health Service (CYMHS) in the RCH CHSD is working to develop ways to support the complex needs of families in which a parent has a mental illness. A number of service supports and resources are currently available including:

- The KOPING Kit is a referral kit to assist adults, children and service providers to access appropriate services. Copies are available from the KOPING Program Coordinator or can be downloaded from this website.

- The KOPING Library is a dedicated library that stocks resources relevant to the area of parental mental illness. It is aimed at improving access to information and resources for both service providers and families. The KOPING Library has been developed as both a local and state-wide resource, and supports out of area borrowers through a free postage service. The library contains books, group programs, videos, cassette tapes, fact sheets and other resources.

Thank you to Nikki de Bondt for her advice
The Family Support Program provides services to families where there is mental illness. The FSP team works in the North Metro Health area of Perth and provides assessment and support to all members of a family: the consumer, other adults and the children, all of whom are affected when a family member has a mental illness.

The children are supported in a number of ways:

- Having a Support Worker in the home provides the children with someone to talk to and can create a safer psychological environment when a child has been experiencing a chaotic home life;

- The Worker can provide a different perspective to the adults in the home on the ways the children are coping or not coping;

- The Worker can advocate for the child at school or if they need psychological/counseling assistance;

- The worker can suggest parenting courses or in-home assistance to the parents with their parenting style, if that is appropriate.

The FSP Worker can also provide a very useful role by supporting the parents and advocating for the child if the child has a mental illness or disorder and is engaged with other services such as Child Protection agencies, Disability Services or Mental Health clinics or hospitals. The Family Support Program places the safety and security of the children as their foremost priority and, in so doing, works to assist the functioning and health of the parents, and sometimes grandparents, so that the family stays together as a healthy, caring unit.

Thank you to Merrill Stokes for her advice
ON FIRE! are a group of volunteers who share a common purpose to promote the mental health and well-being of children and young people living in Sydney, whose parents or siblings have mental health issues.

ON FIRE! is a not for profit community group that is volunteer led and driven. These volunteers have a range of professional, business, and life experiences. A significant number of these volunteers work in mental health. All volunteers receive training and support and all leaders complete mandatory child protection documentation.

ON FIRE! provides a range of peer support, life skills development, and leisure activities. Activities include:

- Camps;
- Fun Day Outings and sleepovers;
- Peer Support Groups;
- Creative Expression Groups;
- Skills 4 Life Groups;
- Mental Health Learning Groups;
- Personal Coaching Program.

Young people play a key role in choosing activities, making sure they are fun, interesting and relevant.

ON FIRE! works in partnership with the Schizophrenia Fellowship of NSW which provides the auspices and other much needed support for ON FIRE! activities.

Thank you to Nickolas Yu for his advice
OurSpace Queensland

Program Coordinator: Adam Lo (Early Intervention Officer/Occupational Therapist)
Email: adam.lo@health.qld.gov.au
Telephone: (07) 3290 0500, Fax (07) 3208 0242

The ‘OurSpace’ COPMI initiative was launched in 2007 and changes have continually been made to best cater for the unique needs of the COPMI population in the Metro South Health Service District region.

The aim of the OurSpace Initiative is to bring together children in similar circumstances to:

- Address feelings of isolation;
- Increase mental health knowledge, awareness and understanding;
- Build peer support network;
- Develop interpersonal and social skills to enhance their coping mechanisms and resilience;
- Enable the children to have a better understanding and insight of what their parents, siblings or relatives are experiencing;
- To develop help-seeking skills and awareness of relevant support services.

OurSpace embraces the whole of community approach in service delivery. To ensure the program reaches all the children in need in the area, the steering committee includes representatives from various sectors of the community.

The OurSpace initiative is made up of three programs:

1. **OurSpace Koping 4 Youth (OK4Y)**
   - OK4Y Junior program for 10 – 13 year olds;
   - OK4Y Senior program for 14 - 18 year olds.
   This is a three-day intensive psycho education and peer support program.

2. **Chill-Out**
   This is an ongoing drop in support group.

3. **OurSpace JustTalk Telephone Support Program**
   The telephone support program consists of a short phone call from the OurSpace coordinator to the participants about every 4 weeks. Its aim is to provide ongoing support to maintain connectedness to the program.

   Thank you to Adam Lo for his advice
PATS
Paying Attention to Self
Victoria

Web:  www.smha.org.au;
      http://www.rch.org.au/pats/contact.cfm?doc_id=7091l
Telephone: +61 3 9385 5118

PATS is a group peer support program for young people (12 – 18 years of age) who
have a parent who has a mental illness. It was developed in 1996 and has been
implemented in several parts of Victoria. PATS is an early intervention program aiming
to prevent the development of mental health difficulties in young people who have
been identified as being at increased risk. It comprises an 8 week group program with
additional social activities and opportunities to develop leadership skills. The group
program is facilitated by a health professional and a peer leader who undertakes a
peer leadership training course. The PATS program covers a range of topics including
education about mental illness, coping strategies, feelings about mental illness, and
dealing with stigma.

Historically the program has been auspiced by a number of organisations including the
Centre for Adolescent Health, Shire of Yarra Ranges and Inner South Community
health.

Once the program is finished, there are further opportunities for the participants to
continue to be involved, such as participating in Community Forums and Reference
Groups, and presenting at workshops or seminars. PATS participants have contributed
for example to Mental Health Week activities and community murals. During school
holidays, activities such as surfing, horse riding, city excursions have been offered to
past participants and those young people attending the next term’s program.

PATS provides young people with important opportunities to develop their leadership
skills both by co-facilitating the program and in some cases assisting with the
programs for younger children – CHAMPS programs.

Following involvement in the PATS program, young people reported significant
reductions in depressive symptoms, risk of homelessness and stigma.

There is no cost to attend the program, and in some circumstances assistance with
transport can be provided if required.

Thank you to Rose Cuff for her advice
Most clients of the Poppy Play Group have been referred to the service by the Mental Health Team after an initial assessment. Others have been referred by other services or Mental Health practitioners. Occasionally a client self refers. A criterion to attend is to have been diagnosed with mental ill-health. Clients are offered playgroups for as long as they like to attend or are transitioned into a parent run playgroup as they gain more confidence.

Prior to the commencement of the playgroups the Mental Health worker may be consulted, and the Family Welfare Worker and Early Childhood Teacher meet to plan activities specific to the attending clients needs. Information about the clients is shared and a plan completed.

Social networks are encouraged as an ongoing strategy.

Weekly sessions and information (including guest speakers) have included:

- Stress management
- Nutrition information
- Speech Therapy
- Early Literacy
- Child safety
- Mental Health issues
- Managing stress
- Toilet training
- Family budgeting
- Quit smoking
- Meditation
- Importance of play
- Child development and behavior management

Some ongoing topics during discussion, for example, include education on weaning children off bottles, sleeping with bottles and the relationship to dental health.

A program of discussions on relevant topics is incorporated into the session planning and opportunities for spontaneous discussion are taken up. Topics discussed include - toilet training, morning time management, discipline, child development, nutrition, literacy, child safety in the home, etc.
Guest speakers have included:
- Pediatric registrar
- Speech pathologist
- Librarian
- As well as informal discussion on a variety of subject initiated by parents
- A previous guest speaker presented a session on Nutrition

A program is developed each term to stimulate the development and learning of the children attending. Activities include early literacy experiences and two sessions on *The Importance of Play* presented by the Early Childhood Teacher.

A program of activities is planned each week for children such as:
- Play dough
- Painting
- Construction toys
- Books and stories
- Some physical activities

Workers set up activities and model play techniques with young children, offering encouragement and gentle direction to parents. Modeling includes age appropriate redirection of children’s behavior demonstrating to parents how to manage children in a positive way. Age appropriate behaviors are explained. Children are given positive feedback and encouragement as another technique to encourage positive interactions, redirection and bonding between parents and children.

**Planning**
The first week of each session involves brainstorming ideas for group rules of the playgroup. In this session activities are programmed to facilitate familiarity between participants and workers.

Other activities used to promote social networks and improve self esteem have been pamper days, Christmas lunch, meditation and relaxation sessions, and the Poppy reunion picnic.

The development and/or maintenance of relationships outside of the playgroup are often the subject of discussion with the Family and Mental Health workers and include topics such as conflict over parenting, contact with other parents, support outside of playgroups, grandparents, friends, and so on.

A visual record (photos and text) of progressive weeks is created from the playgroups and is also used to engage parents in conversation about their child, their child’s strengths, interests and emerging skills.

**Lunches**
Parents and children are encouraged to participate in the planning of lunch. Lunch includes nutritious sandwiches and fruit. On occasions a parent brings a home baked cake or biscuits to share with the group.

**Transport**
Transport is supplied weekly for those families who need it.
Referrals to other services
Referrals for other services have also been made including Volunteer Home Visiting (Barnardo’s), child-care, mental health services, other playgroups, parenting support (eg. NIFSS), Anglicare, Illawarra Child Development Centre, Child and Family Health, Illawarra Mental Health, Northern Illawarra Family Support, Bulli Community Centre, Noogaleek Pre-School, Illawarra Family Support Service, and Berkeley Neighbourhood Centre. Child referrals have been made to the Speech Pathologist, Child and Family Health, Pediatrician and other early childhood settings.

Thank you to Lynda Sinnott for her advice
The Raw Energy program is an initiative of Carer Support that supports young carers between the ages of 5 and 25 who reside in the South and East Metro areas of Adelaide.

Raw Energy aims to educate young carers to care for themselves; to foster an understanding within families that the caring role is only one aspect of who young carers are; to support young carers to build resilience and self-confidence; and to promote connectedness to their local communities and support services.

We provide personal and educational support specifically for young carers, such as social/recreational activities, tutoring, family/one-on-one support, respite, skills development and workshops.

Over the last ten years, the program has developed into an innovative and successful model of carer-driven service delivery. Our service is tailored to individual needs to empower young people to make their own life choices, overcome isolation and build resilience. We work in partnership with young carers, their families, communities, other agencies, and volunteers to achieve this.

Raw Energy provides:

- Information and advocacy
- Group work
- Social / recreation activities
- Family support
- 1:1 support
- School support
- Skills development and workshops
- Young carer respite
- Camps
- Quarterly newsletters
- Support to regional young carers networks
- Community Awareness, training, education
- Resources for principals and school counsellors

Thank you to Deb Miller for her advice
Siblings Australia is a unique national organisation committed to providing support for brothers and sisters of people with special needs; including disability, chronic illness and mental health issues.

They provide workshops, print and web-based resources and networking opportunities for families and providers across Australia and overseas.

These children can grow up in a situation of considerable stress, often in single parent households and, possibly, a depressed parent. They also have to deal with often challenging behaviors of a brother or sister and the fact that the needs of this other child seem to have much greater importance. Not only can siblings be overlooked within their families but their needs are largely overlooked by government and community services. Without outlets for the expression of their difficult feelings these children can feel very isolated which further increases the risks of mental health problems like anxiety and depression. However, if siblings are acknowledged, and connected to sources of support, they are likely to become more resilient.

One group of concern is siblings of people with mental illness in particular. Again these young people or adults can be overlooked when a brother or sister’s needs take priority. They need support to deal with the many difficulties that might arise.

The work of Siblings Australia focuses on preventing health problems arising by working with siblings directly and with parents and providers so they are more able to support these children.

The focus of Siblings Australia in on strengthening families, hence the aim is to increase the availability of information and support services for siblings of people with special needs, through increasing awareness, understanding, skills and capabilities at three levels:

- Direct support to siblings;
- Enabling parents to support their children;
- Working with services providers who, in turn, offer support to families.

**Programs**

Programs that Siblings Australia offers include:

- 6 week peer support program for children aged 8 – 12, SibworkS;
- Development of a manual for people wanting to run these groups;
- Internet Forums – Not all situations are best face to face, therefore Siblings Australia has developed 3 internet forum allowing siblings to connect with each other and share experiences and strategies for coping. These are:
  - SibChat4Kids
  - TeenSibChat
  - SibChat (for adult siblings);
- Parent workshops/education;
• Workforce development for service providers and undergraduate students. There is potential to provide training, including e-learning options, to a range of sectors;
• Website with extensive resources;
• Involvement in research.

Thank you to Kate Strohm, Executive Director, for her advice
References from
‘Guest Editorial, Too important to ignore: Siblings of children with special needs’ by Kate Strohm’ Australian e-Journal for the Advancement of Mental Health (AeJAMH), Volume 7, Issue 2, 2008

© Artist Pauline Miles
SKIPS is a unique program that deals directly and honestly with the issue of mental illness in families and how primary schools support the children in those families. The program helps primary schools understand and support children and their families when a parent has a mental illness. SKIPS has had consumer and carer involvement throughout the planning stage.

SKIPS has developed a selective preventative strategy to address needs of children of parents with a mental illness through current support services for children within primary schools.

Schools that have had the SKIPS program implemented into their school have reported that SKIPS not only impacts the grades 5 and 6 classrooms and the staff but makes an impact on the whole school community affecting child / parent relationships, child / child relationships, staff / child relationships and staff / parent relationships.

The SKIPS program has also facilitated parents disclosing their own mental health issues to the school for the first time.

The program has two main objectives:

- Addressing the roles of schools and teachers in supporting children and families affected by the mental illness of a parent;
- Reducing stigma through classroom education about mental illness.

The program consists of two workshops for the whole school staff and three classroom sessions for grade 5 and 6 children run by a team of two presenters, a consumer and a speaker who talks of their own experience.

The teacher workshops give teachers:
- An understanding of the impact that mental illness in the family has on children;
- Confidence in supporting those families and children;
- Practical strategies;
- Information on signs that can be observed in children and parents, how teachers can support children, and strategies for engaging parents.

The classroom sessions give children:
- An understanding of mental health and illness;
- Appropriate language for talking about mental illness;
- Each session lasts one hour and includes interactive activities, games, worksheets and lots of discussion.

Parent Information Evenings:
- If requested SKIPS presenters will also run an information evening for parents.

Thank you to Liz Wrigley for her advice
SMILES is the abbreviation for Simplifying Mental Illness plus Life Enhancement Skills. Created in 1997 by Erica Pitman and internationally recognised as best practice by the American Journal of Orthopsychiatry in 2004. The program has been delivered extensively throughout NSW Australia and in Canada.

SMILES is a program especially designed for children aged 8-12 years or young people aged 13-16 years whose mum, dad, brother or sister has a mental health problem such as schizophrenia, bipolar disorder, depression or anxiety.

The program has proved to be very effective, and the incorporated activities can be used in individual counselling sessions, may be adapted for use with other populations and have been used successfully with adults as well as children. The program is downloadable from the web-site www.COPMI.net.au under programs and services or the SMILES Program. The free program download includes the structure, suggested program format, requirements, budgets, guidelines, resources, suggested daily plan, background music, singing and activities.

The program runs over 3 days and is generally delivered during school holidays with a minimum of 8 and maximum of 10 participants. Each program is facilitated by trained professionals such as counsellors, psychologists, social workers or teachers.

The aim of the program is to provide age appropriate education about mental illness and life skills. This is achieved through learning strategies to improve capacity to cope more effectively and increase resilience; participating in activities to improve self expression, creativity and self-esteem within a safe environment; reducing feelings of isolation by meeting other young people in the same situation.

The program consists of a combination of:

- Education about mental illness
- Communication exercises
- Problem solving
- Art work and music
- Interactive exercises
- Relaxation exercises
- Peer support

Resources used within the program include: ‘Handle with Care’ – a Workbook about Mental Illness for 8–12 year olds; A Booklet for Young People about Mental Illness'; Moonbeam – a Book of Meditations for Children’ or similar titles.
Activities include the following, and instructions for all of these are included in the free download for the SMILES Program.

- Ice Breaker
- Family Drawing
- Mental Illness Education
- Anxiety Education
- The Innerview
- Pie Chart
- “It’s Good To Be Me” Game
- Meditation
- Favorite Pet/Object/Person
- Friends Drawing
- Problem Solving
- Children on a Tree
- Create a Card
- Outdoors
- Photograph
- Feelings Story
- Compliments

_Thank you to Erica Pitman for her advice_

© Artist Pauline Miles
Wanslea offer a service whereby a qualified and experienced child counsellor attends the child’s home and works at the child’s pace.

Wanslea’s COPMI programs works in the southern metropolitan area of Perth, Western Australia.

Wanslea’s COPMI program:

- Helps a child understand their parent’s mental illness by providing information and talking through any questions the child might have;
- Helps a child develop skills for coping with challenges;
- Helps a child with crisis planning and developing a safety plan;
- Helps a child identify and develop support systems and who can help them when the parents have to go to hospital.
- If it is appropriate, they provide group work for children on a regular basis
- Assistance is provided for the parents, if they are experiencing difficulties with their parenting.
- Peer support programs for children and young people are run in the school holidays.

To see the child, the counsellor can attend the child’s home or elsewhere if preferred. Parents can be included in the discussions if the child wishes.

Thank you to Jenny Terry for her advice
Austria
Structure

No overall framework, strategy or master-plan exists for the support of family members of people with a mental illness in Austria. Support is subject to considerable regional variation, both with regard to funding and also with regard to the intentions i.e. ideas of the initiatives. Regional projects for children of parents with a mental illness are, to a large extent, based on or driven by individual commitment and usually dispose over a small budget (mix of public and private funding).

The table below presents a range of examples of services and initiatives for children of people with a mental illness taking place in Austria. Some of these are for vulnerable children in general (not only for the before mentioned target group). Thereafter selected initiatives/services are described in more detail.

To date no comprehensive national assessment of services for this group of children has been undertaken. The topic has only started to receive increasing attention during the recent years.

<table>
<thead>
<tr>
<th>Region</th>
<th>Service/ Initiative</th>
<th>Website, contact person, further information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cross-national</td>
<td>Child welfare/protection services</td>
<td>Austrian working group for child welfare/protection services <a href="http://www.jugendwohlfahrt.at/">http://www.jugendwohlfahrt.at/</a> Regional offices in the 9 Austrian regions Others such as Jugend am Wek, Kinderfreunde, etc.</td>
</tr>
<tr>
<td>Cross-national</td>
<td>Legal representatives for children/young people</td>
<td><a href="http://www.kija.at/">http://www.kija.at/</a></td>
</tr>
<tr>
<td>Districts / Communities / Regions</td>
<td>Departments for family, children and youth on the level of the districts/communities/regions (district/community or regional authorities)</td>
<td>Various websites and contact persons of/in the different districts/communities/regions</td>
</tr>
<tr>
<td>Community and regional level</td>
<td>Ambulatory psycho-social services (e.g. day clinics/centres, day intervention centres, etc.)</td>
<td>Run by hospitals or partially also by NGOs</td>
</tr>
</tbody>
</table>
| National Regional | Telephone hotlines/crisis lines for children/young people but also for the general population:  
- Rat&Hilfe Forum  
- Rat auf Draht (telephone and online counselling)  
- Telefonseelsorge (telephone and also online counselling in several regions: Burgenland, Lower Austria, Styria, Vorarlberg, Vienna)  
http://rataufdraht.orf.at/  
www.telefonseelsorge.at  
http://foren.wienxtra.at/forum/soziales-&-gesundheit (Vienna) | http://rataufdraht.orf.at/  
www.telefonseelsorge.at  
http://foren.wienxtra.at/forum/soziales-&-gesundheit (Vienna) |
| Cross national, implemented on the national level and in the regions of Tyrol, Styria, Carinthia and Lower Austria | A National Alliance against Depression was established in Austria in 2006. It is based on a European project (European Alliance against Depression, EAAD) which was initiated in 2004 and has, in 2009, changed its status from being an EU-project to becoming an association. Various Austrian regions (Tyrol, Styria, Vienna, Carinthia and Lower Austria) have joined the European Alliance as regional partners.  
The initiative involves: information events, contact information for people with a mental illness and their families, literature and links, information for family members (also containing a small section for children of people with a mental illness). | Austrian Alliance against Depression,  
http://www.buendnis-depression.at/  
European Alliance against Depression (EAAD):  
http://www.eaad.net/ |
| Cross-national | Austrian League for Child- and Adolescent Health: Cross-professional organisation of individuals, institutions and medical societies in the field of child- and adolescent health: The aim is to promote the health of children in the field of mental health. | Contact person: Prim. Dr. Klaus Vawrik |

Subsequently selected Austrian initiatives for children, young people and adults with a parent with a mental illness are presented in more detail.

*Thank you to Joy Ladurner for her advice*
HPE is a national organisation with offices in all Austrian regions.

HPE’s central focus of work in the field of children/young people is placed on the process-orientated support (accompanying) of individual children and adolescents, whose mother respectively father suffer from a psychiatric illness. Simultaneous communication with the parents – predominantly the healthy parent – is initiated, the underlying intention being to promote the creation of a supporting network for the child/the adolescent. HPE will moreover, if deemed necessary, initiate communication with authorities or schools.

Any activities always consider the cognitive, emotional, social and moral stage of development of the child as well as its role within the given context.

Similar to adults, the priority of the work of HPE for children and young people is placed on the provision of information, the management and handling of guilt, loss, shame and overburdening. Another crucial aspect is the targeted strengthening and building of resources. This is very important because the individuals belonging to this group have still not completed their personal development and bear a higher risk of falling ill themselves.

The overall aim is to create a relationship based on trust. This is facilitated by establishing a creative experience space (games, conversation, nature and outdoor-activities) in which the child/adolescent has the opportunity of developing according to his or her abilities. Their attitude in this process is characterised by empathy and acceptance: they observe, listen and commiserate. They also become tangible individuals for the children. To a certain degree they get involved in order to promote an actual dialogue. This gives them the opportunity to, if required, leave the classical therapeutic space and, depending on personal needs, undertake specific excursions to for instance the Christmas market or the cinema.

In case the situation makes it necessary and all parties involved express the explicit wish, the process can also involve (mobile) home visits to patients.

The duration of the guidance i.e. support depends on the needs of the child and should, as far as this is possible, not be limited to a defined number of hours. This would, on the one hand, be a contradiction of the fundamental ideas of the services they offer (“relationships require differing time spans to be established). On the other hand children need the feeling of time and space in order to build trust.

In general the number of contacts varies between seven and fourteen days.

When planning and implementing activities for children of mentally ill patients, HPE is strongly interested in continuously involving directly concerned individuals in the process.

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3 Based on Baubin (2008)
• Age-specific management of illnesses and their related consequences is crucial;
• Establishing a creative experience space (through games, conversation, nature and outdoor-activities);

H.P.E. offers the following services for children:
• Counselling (personal and online counselling),
• Information for families (on illnesses, on organisational/administrative issues, on what to do in certain situations, general support, etc.)
• A range of peer-groups which meet regularly (for a variety of illnesses and target groups): Amongst these also one for adult children of parents with a mental illness (since October 2005), and one for siblings of a person with a mental illness (since September 2009) are offered at the HPE office in Vienna
• A brochure for children of parents with a mental illness (for younger children/school children) was published recently (2009)
• The HPE Office in Vienna has recently adapted a room which is used solely for counselling sessions with children (child-friendly, toys, craft supplies, etc.)
• The regional office of HPE in the region of Tyrol offers a mixed group for adult children and siblings.
• The branch of HPE in Salzburg, which is called AhA (Angehörige helfen Angehörigen) offers a range of special services for children (e.g. the JOJO project, which is also presented in this report).
• The regional office in Upper Austria has published a children’s book for children of mentally ill parents several years ago. It is about a little elf explaining to a boy why his mother acts so “strangely”. The office also supports pregnant women with a mental illness and their families during pregnancy and after giving birth
• Counselling services for children offered by HPE in Vienna are partially also utilised by individuals from Lower Austria.

In addition to the above listed services offered to children and young people, HPE also provides many more services to family members in general and to specific groups of family members (e.g. counselling, self-help (peer) groups, seminars, awareness raising, information, destigmatisation, health policy work, publication of a monthly magazine, organisation of lectures and events, etc.).

Thank you to Joy Ladurner for her advice
“JOJO – childhood in the shadow” is a project for children of parents, suffering from mental illnesses – ideally in a state before they show noticeable behaviour. Their premise is to react quickly, non-bureaucratically and flexibly, depending on the special needs of the children and their parents. Last year JOJO was awarded with the “1st Salzburg children rights-award”

They offer:

- They support the children in a warm and trust-building one-to-one-session. Their confidant is a young female psychologist and kindergarten worker. They meet one day a week or when needed for a period of six months. Main topics are the parental illness and how they can cope with that situation, in a suitable way.

- They are also planning to conduct group-sessions for four to six children the same age: about ten sessions are planned in the afternoon every second week. In this setting they are motivated to train and develop their soft skills. With this intervention JOJO is transferring knowledge about parental mental illnesses in a playful and creative way. The main benefit of being together with other children is their experience of not being alone with their challenging life-situation. The main intention is to strengthen the children and to empower them.

- Additionally they offer a parent-directed program, which will strengthen their education-competence. They also have the possibility to exchange experiences with other parents.

- They focus on networking with other welfare services and youth-organisations, among them also schools. In this area they want to intensify their endeavours.

- Workshops for professionals in the psycho social field were very successful.

- They combat stigmatisation and taboos. For parents, the barrier to give support to their children still exists. Often they are afraid that other people could get to know about their illness and that the children could be taken out of the family. In public relation work we have to re-emphasise that those programs for children with mentally ill parents encourage empowerment on both sides – that of the children and the parents. For the benefit of the family there has to be found coping-strategies and a deep understanding for the others’ situation.

Thank you to Ulrike Rausch-Götzinger for her advice

The two puppets are always accompanying the therapist Petra Rebhandl when she works with children.
SINN is carried out in team work, consisting of a psychiatrist, developmental psychologist, as well as networking contacts with all relevant helpers in the particular family system.

They exam what the child needs to cope with the overall situation in a stronger/more resilient way to be able to deal better with this living situation in terms of prevention.

Their designed evidence-based method of a ‘resource / burden analysis” includes:

• A detailed diagnostics of the child / children in terms of a developmental, attachment and interaction diagnosis;

• An extensive examination regarding resources and/or burden of important adults;

• The integration of relevant supporting systems (grandparents, kindergarten, etc.);

• They make detailed support plans which are conveyed to the parents and the child and youth welfare service, including:
  o What (in their view) the child/the children need in terms of supporting activities;
  o What the vulnerable parents needs;
  o What the whole family system needs.

• After approximately 6 months, they contact the person in the child welfare center who is responsible for the family, to check the efficacy of the suggested interventions.

Thank you to Aleksandra Dimova for her advice
Canada
This 237 manual provides all that a local planning group might need to set them on the process of planning a one day "community education and development" forum on the topic “Supporting Families with Parental Mental Illness”.

It was developed in British Columbia through a consultative process with hundreds of service providers and consumers concerned about this issue.

The manual contains specifics of how to organize a local planning group, who to invite as well as sample educational components of a community forum. This includes considerable content that any person with some confidence speaking in groups could adapt. The flow of the workshop includes:

1. An introduction to mental health;
2. The impacts of parental mental illness on children and parents and

A community “best practice” check list allows local communities to assess their own readiness to “support families with parental mental illness”. The premise of the manual is that parents and families with parental mental illness can do better when they are supported by understanding communities.

The workshops are intended to bring together educators, child welfare, adult mental health, child and youth mental health, first responders, consumers and other community members to increase mental health literacy and to develop a platform for further community planning.

Research on the implementation of this manualized approach to community development and education has shown:

- Participants indicate a significant increase in their awareness of the issues;
- Changed attitudes towards seeing that parents with mental illness can parent if given the proper supports;
- Changed attitudes towards cooperative care for families with parental mental illness;
- In most communities the one day workshop became the focus for a smaller ongoing planning committee.

The manual is free for download at:
http://www.mcf.gov.bc.ca/mental_health/publications.htm
Or at www.parentalmentalillness.org

Thank you to Dr Robert Lees, R.Psych for his advice
Kids in Control

Web: www.kidsincontrol.bcss.org
Email: bcssprov@telus.net
Telephone: +1 604 270 7841 or +1 888 888 0029

Resources: Kids in Control have excellent handbooks for children, written especially so that they can be understood easily:

*When Things Get Really Weird!*
For children who have a parent with schizophrenia

*When Moods Go Up and Down*
For children who have a parent with Bipolar Disorder

*When Things are Sad and Gloomy*
For Children who have a parent with depression

Kids in Control is a support group for children who have a parent with a mental illness, based in British Columbia. It is designed for children 8 – 13 years of age whose parent has a mental illness and is run by the BC Schizophrenia Society. They usually have a waiting list, and they are currently piloting a teen version of this program.

The name Kids in Control was chosen by the first group of children who ever attended the program. They chose the name because the program helped them to have a sense of control in their lives that was missing before.

Kids in Control provide knowledge about mental illness in a safe, accepting environment where kids can connect with others who have similar experience.

Once a week, for 8 consecutive weeks, the children meet for about 1 ½ hours. During the sessions, children are given information about mental illness plus an opportunity to develop and practice health coping strategies for dealing with the difficulties they may be facing.

Using crafts, games and interactive learning activities, children have the opportunity to join together in developing health attitudes and coping skills. The course content consists of:

- **Session 1:** Group Building and Story Telling
- **Session 2:** Group Building and Learning to Identify Feelings
- **Session 3:** Learning How to Communicate Feelings
- **Session 4:** Learning about Mental Illness
- **Session 5:** Learning About Treatment for Mental Illness
- **Session 6:** Resilience
- **Session 7:** Societal Attitudes
- **Session 8:** Self-Care and Self-Esteem
- **Reunion:** The group is called together a month later for support and reinforcement of learning from the program.
When they have completed the program, children are invited to attend reunion meetings for ongoing support.

Feedback from children who have taken the program reveals several helpful aspects. Learning about mental illness helps them identify resources, increase resiliency, and to allay fears so that “now it doesn’t seem as bad”.

**Children learn the importance of “The 3 C’s:”**

- I can’t Cause it
- I can’t Cure it
- I can take Care of myself

Learning how to deal with stigma and to resist messages of self-blame are other important topics.

The program was researched for two master theses:

- Gordon Richter, (2006) Trinity Western University did a quantitative study (with Daryl Maybery as external examiner), and it had promising findings - “Fostering Resilience; Evaluating the Effectiveness of Kids in Control”.

*Thank you to Jane Duval of BC Schizophrenia Society and Dr Robert Lees Founder of Kids in Control for their advice*
Powerhouse Project

Web: www.powerhouseproject.ca
Email: aarsenio@powerhouseproject.ca
Telephone: +1 905 834 3629 (Niagara Office)
          +1 905 768 4488 (Haldimand-Norfolk Office)

Powerhouse is a not for profit agency with a mission to promote the well being of young carers, the families and their community partners.

Powerhouse Project is an inter agency strategy developed to establish two centres in Canada to meet the needs of young carers and their families. A holistic approach to assess the needs of the entire family is used to support young carers in both the Niagara and Haldimand-Norfolk Region. These two centres are represented separately in this report as 1a and 1b.

The program is for all young carers, but several families are involved due to mental illness, including anxiety conditions and depression. Many of the young carers are caring for multiple family members.

The Powerhouse Project offers a variety of services and activities to empower young carers, and give them time where “kids can be kids”. The social, leisure, educational and skill development opportunities offered at the Drop In Centre and during “on the road” programs will include:

- Workshops to develop practical skills
- Crafts
- Homework help
- Video Games
- Computer Access
- Movie Nights

In addition, the Powerhouse Project provides presentations in the community free of charge….chatting about young carers and their services.

Staff developed different programs for each region, based on the different needs of Niagara and Haldimand-Norfolk.

Due to the geographic spread it is necessary to develop partnerships with other agencies in both regions. In addition a well trained and enthusiastic base of volunteers has become increasingly necessary.

Identification of young carers
To identify young carers, the Powerhouse team talk with agencies serving at-risk populations (housing assistance, soup kitchens, etc), people with illness (Alzheimer Society, AIDS service organisations, MS Society, etc) and those serving children (Boys and Girls Club, YMCA, school board). This covers all the agencies that may feasibly serve young carers and not know it, because it is still a new concept in Canada. By providing information about young carers, they can work with agencies to uncover families that may need their services.
Working Holistically
Powerhouse work by looking at the family as a whole. When one person is ill within a family unit, all the members are affected and typically help out in different ways. They work to serve the young carers in particular, but the needs of the family are considered in the construction of programs and events and when referrals are provided.

On the Road Program
The Powerhouse Project has many ‘on the road’ programs they deliver at other locations. Some examples are Acting Up!, Cooking with Care, The Power of You and Balance. All the programs are creative ways to teach children practical skills in a way that is both fun and educational. These programs can be offered at the same time as support groups, allowing parents and children to access services that will serve to benefit the entire family.

This part of the program requires organization, effective partnerships and wonderful staff. The partnering agencies give space free of charge, which allows them to offer far more programs that they could otherwise. A number of local organisations provide services at reduced rates.

The On the Road Program enables them to offer, in a typical week, programs / special events in at least three cities / towns for each region.

Thank you to Angela Arsenio for her advice
The following programs are offered at the Niagara branch of the Powerhouse Project in Ontario:

**Acting UP!**
An 8 week drama program targeted for children 5 -12 years old. The programs are designed to get kids inspired in theatre…and through concentration techniques, voice projection and improve and creative writing.

Children are introduced to drama techniques, while improving their confidence and having fun.

**Balance**
A program designed to help children learn to chill out and have fun with an 8 week session of programs, for example, yoga, meditation, singing at karaoke, drumming circle, craft, exercise.

Balance is designed to teach children practical, age appropriate ways to cope with stress and anxiety.

**Cooking with Care**
A program designed for children and youth who are interested in cooking and often find themselves preparing meals for their families. This is a 6 week cooking circle, where a new meal is created each week.

They also learn safety, cost effectiveness, purchasing groceries.

**The Power of You**
A program designed to provide an opportunity to reflect and establish themselves as individuals. Young carers will take a ‘walk through the power of self awareness, through group activities such as adventure-based challenges, personality profiles and the development of a personal coat of arms and self-portraits.

*Thank you to Angela Arsenio for her advice*

© Artist Pauline Miles
As a rural region, Haldimand-Norfolk has a few unique populations, such as aboriginal populations on reserves and the low-German speaking Mennonite population in Houghton. They require the recognition of cultural differences, and the respect of particular practices accepted in these communities. A formal request to the Six Nations Councils has been acknowledged, and they are addressing each step in order to deliver programs to young carers on the reserve. They are also working with the school board, REACH, and the Community Help Centre in Houghton as a way to establish a drop in centre for young carers.

The following programs are offered at the Haldimand-Norfolk branch of the Powerhouse Project in Ontario.

**Cuisine and the Tree of Life**
This 6 week cooking circle is designed for young carers who are interested in cooking.

Each week, children learn how to cook a traditional Haldenosaunee dish as well as some cultural history behind the tree of life food guide, the three sisters, the harvesting values for hunting and fishing.

They also learn kitchen safety, measurements and the importance of well balanced nutritional meal planning. The program is designed for on-reserve and off-reserve.

**What is a young carer**
A 3 day session designed to introduce the concept of a 'young carer' to children and youth accessing the Powerhouse Project. The program identifies the difference between health and unhealthy relationships, and promotes a better understanding of the roles of family members and young carers through role play, games, and an examination of case studies.

**Sports and Fitness Blender**
A 4 week program where participants learn different sporting activities together. They also learn about the importance of good sportsmanship and teamwork. Nutritious snacks are provided.

**Outdoor Adventures**
Designed for youth between the ages of 12 to 16 who are interested in “burning some steam” through adventure based outdoor adventures. They will learn new skills such as hiking trail etiquette and safety, while discovering how to be ‘green’.

*Thank you to Angela Arsenio for her advice*
Powerhouse is conducting an aggressive awareness campaign across the LHIN to bring the needs of young carers to the forefront of public attention. Before the campaign began, several steps were required:

• Logo and branding;
• The development and dissemination of educational material.

Methods of promoting young carers include:

• In order to re-invigorate the young carers Network of community agencies, information packages were distributed in early January across both regions. The information packages were designed to increase understanding of the issues for young carers, as well as to create a seamless referral system between the Powerhouse Project and the community agencies serving other caregivers, people with illness or disability or children / youth groups;

• Over 25 presentations were given in the community to nonprofit agencies and service organisations, as a way to provide education about care giving families, and uncover the hidden and silent population of young carers;

• They continue to request partners and other agencies to make modifications to their existing intake process in order to ask their clients about children living in the home, the ways the children are providing family support, and if they are affected by the illness of the family member;

• Media coverage has been another way to raise awareness in the general public. The Powerhouse Project has been featured on two radio spots, and in several local papers;

• The project has been a presence at several health fairs and events geared for families, as yet another way to promote the project in both regions.

_Thank you to Angela Arsenio for her advice_
Background
Fraser is a government of British Columbia, Canada, administrative region that encompasses most of the cities that surround Vancouver and the area known as the Fraser Valley. The population is about 1.3 million living in cities and rural communities spread over a corridor of about 80 miles or 120 kilometers. The region is ethnically and racially diverse with large clusters of people of Asian origin.

Ulysses Agreements (UA)
Ulysses is a term of convenience attached to collaborative advance planning for a person with a disability. In this case it is used for persons with a broad range of psychiatric disabilities or mental health challenges. It can be a discharge planning document or a component of an ongoing plan of care. It can be used for parents with mental illness and include a section of planning on how to care for children should the parent become unwell or it can be used for children and youth discharged from mental health care.

It differs from a “representation agreement” in that a Ulysses Agreement is a non binding agreement meant to improve communication and care activity. In some cases the person with a psychiatric disability, as a function of their illness, may reject plans within an agreement but the collaboration among professionals and concerned parties prepares the network for improved functioning in crisis.

Typical components of UA’s would be a description of the person’s early warning signs of illness, appropriate actions to take including whom to contact. Plans often have a strength focus, articulating signs of wellness. A central element is the collaborative and inclusive process that is the platform for writing a Ulysses Agreement.

Fraser Region, Ministry for Children and Family Development Program
Since 2006 the government of BC has funded the BC Schizophrenia Society to provide a professional gifted in collaborative practice, to be available to any community based teams that wish assistance in developing UA’s. Many of the referrals come from child welfare professionals who want to provide safety for children while honoring the capacity of people with psychiatric disabilities, to parent. Evidence from a program review indicated the ability of UA’s to empower parents and families and to improve communication between professionals and families.

Thank you to Dr Robert Lees, R.Psych for his advice
Denmark
**Structure**

In Denmark there has been a rising awareness on children with parents who are mentally ill since the middle of the 1990’s.

Many municipalities and counties have developed activities to support parents who are mentally ill and their children.

So far the activities have mainly been financed through the Danish Ministry of Social Affairs and from the Danish Ministry of Health.

Currently the development trends show that more and more municipalities and regions finance the activities themselves.

The activities can briefly be categorized in the following way:

- Qualifying ordinary staff in day facilities, municipalities, treatment psychiatry, social psychiatry, etc.;

- Establishment of groups for children and young persons. Now there is about 60 groups for children in Denmark (population: 5,1 mill);

- Training of key staff/experts;

- Development of politics and routines for e.g. co-operation;

- Development and implementation of a child perspective in adult psychiatry;

- Treatment and support services for pregnant women and families with infants and small children;

- Investigation of the extent and nature of the problems and the current services.

*Thank you to Bjarne Moller for his advice*
SUS is a non-profit organization; working at improving conditions for socially marginalized people. Currently they are working on approximately 60 different projects/topics – including the topic 'children of parents who are mentally ill'. SUS has been working with this topic since 1994, and the primary activities are:

- **Sharing knowledge**
  - Production of folders, guidelines and books for staff. Production of material for children and parents;

- **Education**
  - Training staff to start and run groups for children. Training staff to carry out communication with families.

- **Network**
  - Establishment (1995) and operation of network for staff working specifically with children whose parents are mentally ill;
  - Two annual network meetings (March and September). Up to 100 participants from all over the country.;
  - Planning and carrying out study trips to The Netherlands and Sweden.

- **Research**
  - Researching available services for children and parents in adult psychiatry in Denmark.

- **Consultancy, support and guidance**
  - For staff, municipalities, projects, Ministries. And for parents and children.

**Project ‘Better Interdisciplinary Initiative’** www.tvaerfaglig-indsats.dk (in Danish)
In collaboration with MUUSMANN Research & Consulting, Social Development Centre SUS has carried out the Project ‘Better Interdisciplinary Initiative’.

The aim of this project is to develop a collaboration-model that will ensure the necessary support and help for children of parents who are mentally ill and/or are substance abusers.

This model will contribute to:
- An early detection of these children;
- Developing support and help services that will cater for the children’s special needs;
- Make it easier for children of parents, who are mentally ill and/or are drug abusers, to know where to turn when in need of help and support and what kind of help is available.
Development of the collaboration-model is partly based on knowledge acquired from previous research and already initiated projects. This knowledge is collected in the project's first phase and constitutes the starting point for further work. The report can be downloaded from www.tvaerfaglig-indsats.dk

In the project's second phase during the spring of 2007, a LEAN-inspired workshop was carried out in four selected municipalities. Herby, existing practices, relevant players and routines in the area among others, have been revealed.

After this, working groups was put together across the four Municipalities. The working groups described necessary/relevant players, structures and processes to enable the viability of the project’s goals. The working groups meet three times in the spring of 2007 with a consultant, who will contribute to the working process.

At the start of the project's third phase in August 2007, the hitherto results was presented and it was, decided which elements of the collaboration-model that should be tested in the selected municipalities.

The testing phase was started off with a conference attended by representatives from the region and the four municipalities who have taken part in the project. In the spring of 2008 the project’s collected results was disseminated at a series of conferences in Denmark.

The activities were carried out in the period of September 2006 to April 2008 for The National Board of Specialist Consultancy and Social Service in Denmark.

2009: 19 municipalities have received funding to implement the collaboration-model.

**Small shoulders Big burden** A film about children with mentally ill parents
Produced by Social Development Centre

“I think my mom is a schizophrenic, but nobody has ever told me. I figured it out by reading about it.”

“My mother is an Infant Jesus that has been swapped. That’s what she says. And that’s all right by me! As long as I don’t have to be her disciple. When she loses it completely she gets hospitalized, and I then move down to the Jensen family on the 2nd floor. They are my relief family but I call them uncle and auntie and Monse. Monse is our cat.”

Combining documentary and fiction this film focuses on what it means to grow up with a mentally ill parent. The film also gives advice to the best ways of offering support to these children.

The film is for everybody, but it is primarily directed at people currently and in training for working in the social- and health sector.

This film is produced with funds from the Danish Ministry of Social Affairs.

The film is available with English, Norwegian, Finnish and Swedish subtitles.
Publications for children and youth of parents who are mentally ill
SUS has produced several publications for professionals - and for children and youth - about the theme,

- ‘What is the matter’?
  This publication is translated into Danish and adapted from Finnish and the author is Tytti Solantaus, with illustrations by Antonia Ringbom.

- ‘Rosa’s mother is in a psychiatric hospital’
  In 2007 SUS published ‘Rosa’s mother is in a psychiatric hospital’. This publication is aimed at children from 3 years of age. This publication has also been sent out to all the adult psychiatric wards and outpatient psychiatric centres, as well as to the different counties’ and municipalities’ counselling and support services for children and families.

- Latest publications is called ‘The sea in the head’

Thank you to Bjarne Moller for his advice
The Network of Health Promoting Hospitals in Denmark has 50 hospitals as members.

The Network of Health Promoting Hospitals in Denmark was established in March 1999 with the aim of strengthening and maintaining the activities and responsibilities of the hospitals with regard to disease prevention and health promotion – covering patients, staff, and the local community.

The Network of Health Promoting Hospitals in Denmark is part of the WHO Network Health Promoting Hospitals which consists of 25 National and Regional networks and more than 700 hospitals.

One of the prioritized areas in Denmark is children of parents who are mentally ill. The purpose is – via network groups and through accumulation and exchange of knowledge and experiences – to strengthen hospitals work with regard to health prevention and health promotion.

This work is completed in 2007 with a publication/s of good working methods, recommendations etc.

Thank you to Bjarne Moller for his advice
Family talking’s with children as relatives in the adult psychiatry in the Region of Zealand

The Adult Psychiatry in The Region of Sjælland have taking the responsibility to ensure that the children as relatives to a father or a mother with an mentally illness get a possibility to have one or more talks with professionals’ in psychiatry about their father or mother’s mentally illness. They are talking with the children about, how they understand the mentally illness, how it affects the child in his or her daily life and how the child and the parent can manage, so that the illness does not or at least does as little harm to the children as possible.

The Region of Zealand covers at part of the eastern Denmark as you can see on the map below, The Region of Zealand is the blue part. It contains about 800,000 people. Until end of 2006 it was departed in to 3 counties with various experiences working with children of mentally ill persons. From 2007 these 3 counties have become one unit, The Region of Zealand

They offer all patients who are also a parent one or more talking’s about being a parent with a mentally illness. Then we invite the parent to at family-talking with his or her children and together with the other parent. We want the father and the mother to be together with their children, when we talk about the mentally illness. We first of all want to help the family to build at bridge between the gap of communication, that often occurs, when a parent get a mentally illness for at shorter or longer time.

The children who are 7 years or more and up to 18 years old also get an offer to join a group for children / youngsters, where they are together with the children in different ways are working to strengthen their understanding of the mentally illness combined with an effort to strengthen their way of manageability and feeling of meaningfulness in their lives.

They are working to get a Children’s consultant in each of the 6 district in the region to ensure:

- That a children’s perspective is implemented and maintained as a natural part of the treatment of patients;
- That the key staff members are updated on the newest knowledge about children with mentally ill parents;
- To offer ongoing support groups for children;
• To assist the key staff members in their family talking’s and
• To evaluate the effort;
• To cooperate with local authorities about children in concern.

**They are working on have key staff members in every psychiatric unit to**
• Contribute to staff members’ knowledge of and focus on children whose parents have a mental illness;
• Be sparring partner for colleagues in relation to the efforts towards patients who have children;
• Help their colleges to remember filling in the information sheet about the children;
• Inform parents about family conversations and support groups;
• Assist in referring children with special needs to local authorities;
• Offering family conversations with the whole family.

They are also working on **qualifications of staff members** to deal with the challenges they meet by:
• Basic qualifications of all staff members who have contact with patients: one day introductory course about children of mentally ill persons;
• Education and training of Key staff members for 12 days;
• Central educational unit in the region are organising the education and courses;
• Courses for key staff members are paid with a central fund in the region.

**Their Policy and procedures concerning children with a mentally ill parent are**
• Discovery and registration of children in the patient’s medical record: information sheet;
• Talking with the parents about the children and supporting patients in their parenthood;
• Supporting children in understanding and coping with the illness by giving them information in cooperation with their parents -> offering family conversations and children’s support groups.

**They have an overall policy and procedures concerning children with a mentally ill parent**
• Enabling children to visit parents while they are hospitalized – child friendly visitor conditions at the psychiatric units;
• Assist to discover vulnerable children and contact the local authorities when special support is needed;
• Developing standardized booklets for staff members and families.

**They also want to have a continuous evaluation of the efforts:**
• To ensure the efforts are implemented;
• To document the quality of the efforts and, if needed, carry out initiatives to improve the quality of the efforts.

We have being working on these gains through the last 5 or 6 years and we can see we are going forward, although it is very hard to change the culture and the way of which the psychiatry used to think about children, when a parent is in psychiatric treatment.

*Thank you to Ingelise Nordenhof for her advice*
Nordic Forum provides 2-3 day meeting each year. The events are organized by and takes place alternately in the Nordic countries.

The 5th Nordic Forum took place in Gilleleje, Denmark - from the 25th till 27th of May 2009. It was arranged by Social Development Centre.

The Nordic Forum 2009 had participants from Denmark, Sweden, Finland, Iceland, Norway and The Faroe Islands.

The theme of this year’s meeting was ‘The voices of the children with mentally ill parents’.

Among the focused items were:
- Tools and methods in children’s groups
- Tools and methods in family conversations
- Tools and methods in conversations with parents
- Strategies for development and implementation
- Alternative ways of supporting children, youth and their families
- Documentation, research and evaluation.

The forum was a mix of presentations at the plenum, in workshops, during a 'marketplace' etc.

In 2010 Nordic Forum will take place in Lappvik, Finland - in June.

Information (abstracts, program, dias/slides and documents), can be seen at the website above.

Thank you to Bjarne Moller for his advice.
The bus is a roving classroom, a mini-library and an exhibition place, focusing especially on schools, high schools and continuation schools.

There is a place in the bus for 25 pupils at a time, which allows for the possibility that the students can visit the bus in classes.

Three staff members are available for training which takes a starting point in a dialog between the trainer and students. Through troupe work, discussions and the film sequences the students get a glimpse of what it is to have a mental illness and what it means for a child of a parent who has a mental illness.

The training also focuses on mental health and on the possibilities available to young persons and children who have mental problems.

Thank you to Bjarne Moller for his advice
Estonia
Young Carers – Estonia

Web:  www.hot.ee/epityhendus  (Estonian Association for Supporters of people with mental disorders)
Email:  galinapod@hotmail.com
Telephone:  +372 527 1920

Galina Podberjoznaja works in the Tartu Mental Health Care Centre as psychologist-family psychotherapist and has contact with the clients. They also have families and children who are in risk groups.

Young carers, Estonia, work with family members suffering schizophrenia, and have programs for children whose parents are ill. Galina’s program works with people in South Estonia, but there are groups for children in the whole of Estonia.

For children age of 10 – 12 they do playing-training groups, where they talk about positive and negative emotions, plus group work about schizophrenia, depression and suicide.

The program involves:

For children

- Play and talk groups for a maximum of 10 children with eleven meetings held once a week.
- Home visits in case of crisis or regular registration of the parent.
- Educational – training group for children aged 16 – 18 for a maximum of 10 children, with 24 meetings, held twice a week.

The themes are:
- Getting to know each other
- Feelings – which feelings exist
- Feelings – how to express the feelings
- The influence of the problems of the parents on the kids their life and feeling
- What roles they are playing in their life
- Information about sickness and heredity
- Coping with teasing and bullying
- Coping with the problems of the parent
- What to do if they do not feel very well
- The importance of a social network

The program uses art therapy, music therapy and psychodrama. They use role games and video training.

For parents

Educational support course

For intermediary – Teachers, GP’s, Foster Carers, Local Youth Care

Eductional meetings
Training consisting of 3 sessions
Consultation

Thank you to Galina Podberjoznaja for her advice
England
National Lead Policy Maker
Department of Health – National Government

Regional Strategic Health Authorities
Have a role in determining strategic delivery of national priorities and keeping the overview of locally commissioned services

Locally
Mental Health Trusts, Primary Care Trusts and local authorities through social service departments. They provide services directly to carers, through assessments, information and advice, some through support groups, etc. Some of these organisations also contract out support to the voluntary sector.

Each area has strategic duties for commissioning and delivering services in its own area.

The voluntary sector provides a lot of support to carers which are very diverse. They are national organisations with local branches and local organisations.

Thank you to Emily Holzhausen for her advice
24/7 Young Carers Project, support young carers, by giving them some time out from their caring role. This is done by:

Holding regular activity sessions, workshops, group-work, one-to-one work, advice and support.

8 – 12 years
13 – 15 years
*The groups are held on a fortnightly basis in a youth club setting.*

16 – 19 years
*This age group currently meets once a month.*

The Project has been able to offer support to young carers by:

- Giving young carers a positive experience;
- Providing them with support and guidance where appropriate;
- Bringing young carers together with others who share similar experiences;
- Providing time away from their caring role;
- Forming Positive peer relationships;
- Forming friendships with other young people;
- Providing fun activities;
- Providing residential weekends away;
- Getting involved in film making, drama groups;
- Getting involved in community groups/events.

24/7 Young Carers Project also offers support in the following areas:

- One to one support;
- Counselling;
- General advice and guidance;
- A listening ear;
- Help with family issues;
- Signposting to appropriate services across Manchester.

**Funding**

24/7 Young Carers Project is mainly funded through a Carers Grant from Manchester City Council. The project also sources separate additional funding for specific pieces of work from local funding bodies.

*Thank you to Brenda Norford for her advice*
121 Young Carers and 121 Befriending Services are projects under the organisation VAWK (Voluntary Action Within Kent). Areas of specialism developed, Young Carers, Sherwood Project, Music Mentoring, Zero Tolerance. It offers the befriending and support service to vulnerable young people aged 6 to 16 years of age living in West Kent.

121 Befriending Services matches volunteers to young children who need a positive influence in their lives. They offer friendship, experience, mentoring and the chance to have some fun. Volunteers are aged between 24 and 25 and volunteer for 2 hours a week. 121 Befriending Services also provides free training.

121 Befriending Services act as role models and give young people the chance to trust an adult outside the family. One to one meetings take place once a week and they also meet other 121 children for group activities, giving them a chance to socialize and feel part of the community.

121 Befriending Services offers support to young carers by:

- Fun respite activities (camping, bowling, theatre, outdoor activities, horse riding, teambuilding, attending the annual Young Carers Festival);
- Regular youth clubs, providing a space to socialize, eat healthily and play games, do arts and crafts etc;
- Information and advocacy;
- School awareness (assemblies and classes) and school lunch-time drop-ins;
- Ad-hoc activities / projects / programs.

They run a program of 6 weeks each, on a Friday evening in winter called Talkshows 4 U. The first meeting is a consultation with the young carers to decide how to run it, and what topics they want to cover. They pick topics such as bullying, socializing, relationships and deprivation. Each week a topic is discussed, with a young carer taking turns to act as the presenter, another to be the case study and they have their resident expert a psychotherapist to help manage emotions and answer difficult questions, keeping it safe.

Thank you to Kelly Chambers for her advice
Barnardos is one of the UK’s largest children’s charities working with over 110,000 children through 400 projects across the UK.

In 2008/2009, Barnardo’s provided support to 3500 young carers aged (0 – 21 years).

CareFree Young Carers’ Services
CareFree Young Carers’ Services started in June 1996 to support children and young people under 18 years of age whose lives are affected by caring for a family member who is ill, disabled, has mental health related difficulties, learning disabilities or alcohol/drug dependency. They provide services across Leicester and Leicestershire and estimate that they have supported over 1,300 young carers since their inception.

CareFree provides a range of services including:
• Information
• Advocacy
• Service coordination
• Group work including free transport and activities
• One to one support work
• Inclusion work
• Grant applications
• Access to holidays
• Consultancy and training regarding young carers’ issues.

Some examples of interventions with young carers:
• CareFree undertakes assessments with both the young carer and their disabled parent and agrees a support plan for the whole family. The needs highlighted on the support plan are scaled with family on a 1-5 ratio and then reviewed after six months and re-scored in order to determine the progress made. Assessments include consideration of the type of care role the young carer has and the impact that role has upon their health and development.

• One of the greatest risks to a young carer’s physical health can be undertaking inappropriate lifting and moving of their parent. In such instances, CareFree would make a referral to Adult Social Care and Health Services for a Community Care and Occupational Therapy assessment. This would enable the disabled parent to be as independent as possible and alleviate care responsibilities and risks to the young carer.

• Carefree is firmly committed to young carers being active partners in the design, delivery and evaluation of their individual support plans. For example, young carers will agree and sign their support plans and contracts for one to one work and be offered the option of writing their own contact
sheets for this work. They were also involved in writing their own annual report for the year. They are always actively involved in the six month review of their services.

- CareFree supports young carers to access activities that will aid a healthy lifestyle such as learning to ride a bicycle; horse riding; dancing lessons; joining a rugby or football club or gym. This type of inclusion work also underpins CareFree’s commitment to resilience building by enabling young carers to have the chance to feel good about themselves, develop a hobby or interest and have access to role models and universal support systems in their community.

- The emotional support needs of young carers are met in a variety of ways including one to one work for anger management, self-esteem building, confidence building, understanding feelings and emotions, understanding parental ill health, especially mental health conditions and how these impact on family life. If specialist therapeutic services are required, the relevant referrals are made.

- CareFree also run four respite activity groups for under 12’s and one for 6 and 7 year olds. They support an additional 10 young carers’ groups for over 12’s which they have developed with partner agencies. Typical activities include swimming, arts and crafts, cinema, theatre, sports, bowling and going out for dinner. They also help to ease emotional as well as social isolation by enabling young carers to be with others who understand their situation and share many of the same experiences.

- CareFree works with young carers who are subject to a child protection plan. Their specialist assessments can help the local authority decide appropriate plans to safeguard the welfare of the child. CareFree will also help young carers to have their views and wishes expressed either directly or indirectly at Case Conference and Core Group. Service coordination for parents is also often a contributing factor in enabling young carers to be safe. For example, a referral for a Community Care and/or Occupations Therapist can assist with the cooking.

- School advocacy is also an important support role which many young carers require. CareFree will liaise with schools to address bullying and discrimination issues and ensure that robust support systems are in place for the young carer. Their approach aims to be an empowering one in as much as they will support the young carer to self-advocate to a degree which they find acceptable. They have found that usually schools are unaware of a child or young person’s caring status.

Barnardo’s Projects:

Barnardo’s runs over 15 projects throughout the UK that support young carers and help keep their families together. They provide various services that make it possible for a child to just be a child:

- Advice and emotional support through counselling and drop-in sessions;
- Making sure that parents get all the help they are entitled to so they can get on with being parents;
• Liaising with schools so teachers can support their students better;
• Opportunities for recreational and social activities;
• Chance to meet other young people and share experiences;
• Support to a child over any concerns or difficulties they may have;
• Time out for fun!

In England Barnardo’s projects include:

• Action with Young Carers, Bolton;
• Action with Young Carers, Liverpool;
• CareFree, Leicester;
• Willow Project, Leeds.

*Thank you to Nikki Thompson and Jane Glover for their advice*
The local view is taken that if providing a high level of care for an adult can be harmful to a young person’s health, well being and development, then services should be working to reduce that and not support them as carers. The service does not provide respite activities as the local view is that young carers should be entitled to access mainstream opportunities with their non-caring peers, and that an activity based response can create an “investment” for young people in remaining in the same situation. Barnardo’s in Bolton use Family Group Conferencing as the means of delivery for the service because of the evidence base that it is effective in highly complex situations as a way of empowering families to solve their own difficulties. Bringing extended family to the table has proved really effective and the team are also able in this way to ensure that a review of adults’ care plans by Adult Services occurs at the same time as a discussion around the child’s needs.

This model also aims to take on board the criticisms of young carers services from organisations around their rights and the ways in which working with the child in isolation can problematise and disempower parents. This also links with central government initiatives around “Think Family” where services are being challenged to consider the needs of each family member as part of a holistic unit.

Family Conferencing for young carers

- Family Group Conferencing enables engagement with the wider family as part of the plan for the young person, which can ensure that plans are more sustainable.

- Young carers are always part of their meeting and are always offered an advocate to ensure their views are represented fully.

- The family chooses the venue, what food they want, who they want to invite, and any other requirements they need in order for the meeting to be appropriate to their individual needs.

- An agenda is prepared with the family in advance of the meeting which sets down clearly the decisions which the family are being asked to make, what support is available (so agencies can attend on the day with clear information for the family as to what they may be able to provide), and what any “bottom line” may be if things do not change. Agencies are asked to be clear as to what the family could access, so that families can make effective decisions about services they wish to access as part of their plan.

- Once information has been shared, the family is left alone to write their own plan which is structured in the way they feel is best for them as a family.
As part of this plan, families are asked to decide what help and support they wish to access, and young people choose from the range of support which has been offered, so that choice, control and empowerment are at the heart of the process. This promotes the sustainability of the plan and the resourcefulness of the family. The family chooses the review timescale for their plan and the aim of the plan is to move the young person to Level 1 of the Framework for Action so that specialist services are no longer needed and mainstream services can meet the family’s day to day support needs.

Young Adult Carers
In Bolton, Barnardo’s receive funding from Comic Relief to work with young carers up to 21 to support them as they become young adults with caring responsibilities. The focus is on helping them to access services as they move from Children’s Services to Adult Services. They support young adult carers in accessing training, further education or employment as a key priority for this age group.

Transitions Work (16-21 year olds)
- Individual support for young carers to access further education, training or employment;
- Life skills work, focused participation work in their Young Carers Youth Council;
- Work to help adult services meet the needs of young carers aged 16 – 21, with particular links with Connexions and Bolton Carers Support.

Other services they also offer
- Advice and information;
- Individual support for young carers on a one to one basis;
- Assessment of needs of young carers and their family;
- Opportunities for young people to meet other young carers;
- Opportunities for young people to join in with mainstream groups and activities;
- Family support to help access appropriate services for the cared for adult;
- Provide information regarding the illness or disability;
- Advocacy work;
- Training and awareness sessions (with professionals and young people);
- Group work sessions with other agencies and professionals.

Resources
- “Young carers Specific Guidance Information Needed for CAF Form’ which gives explanations of required information.
- The resource also includes a check list for professionals to identify possible young carers.

Evidence
They can also provide loads of evidence as to the outcomes of the service as they are finding that empowering families in this way makes a real difference around the impact of caring and the young person’s resilience as one would expect. They have also made a 21% improvement in young people’s attendance so far in 2009.
Thank you to Rob Harrison for his advice

Charity Nos. 216250 and SC037605
Worker attends service planning meeting and offers short term intervention for up to 12 weeks around any required work to reduce the impact of caring or around accessing breaks. Worker reviews progress after the agreed period and closes.

If CP issues are identified at any point the process, we will hand over the lead role to Children’s Social Care.

Structure

CONTACT MADE WITH YOUNG CARER SERVICE

ALLOCATED WORKER CHECKS YOUNG PERSON MEETS CRITERIA AND IF ANY OTHER AGENCIES ARE INVOLVED AND IF THERE IS A CAF IN PLACE

SOCIAL CARE INVOLVED

CAF ALREADY STARTED

LEVEL 1 ‘POTENTIAL CARERS’ RE-DIRECTED

NO CAF

Worker meets lead professional to determine if this service can add to their plan or take on the lead if necessary.

Worker begins CAF and plans Team around the Child, including Adult Services where possible.

Worker adds caring issues to existing CAF and supports Child Action Meeting.

CLOSE

CAM OCCURS

Service provides:
- Advocacy and signposting support for families in accessing appropriate services
- Family are referred to specialist services if required e.g. CAMHS/Social Care
- Considering how extended family can be involved in the plan
- Advocacy for the child to express their views
- Access to sustainable support resources for the child
- Monitoring of accountable service delivery to ensure the plan happens

Review Meeting – progress assessed

Family access universal provision including activities

CLOSE

Lead Professional identified from services with continued involvement.
The service in Liverpool grew out of the Liverpool Action with young carers and the Barnardo’s, Keeping the Family in Mind (KFIM) service working very closely together. When the service was first set up in 2001, they jointly conducted research with parents, young people, service providers and commissioners to develop a service which would complement the direct service delivered by the young carer’s service. Initially the parents voiced their concerns about the impact on their children’s emotional and education development, their struggle to maintain an adequate parenting role while ill, their grief at being separated from their children if they were admitted to hospital and the lack of support and acknowledgment from mental health services that they even had children.

At the heart of the project’s work are children and young people themselves and KFIM is committed to ensuring that any changes which come about are informed by the voices and experiences of children and young people.

The team works at a strategic level, together with young carers, young people and their parents who have mental health problems, working to improve systems.

Louise Wardale has produced a DVD, ‘Telling it like it is’ with young carers on their experience as a young carer which she uses in training and workshops.

**What the KFIM team do:**
- The KFIM team runs awareness raising sessions using the KFIM pack (see details below) on specific topics such as:
  - Setting up a family room in a mental health inpatient unit
  - Mental health awareness
  - Children’s participation;
- Provides training and education;
- Run consultations with young people;
- Influence the development and implementation of local and national policies;
- Developed services;
- Contributed to research and evaluation;
- Helped set up professional networks to share learning;
- For Children’s Sake post-card and poster anti-stigma campaign;
- Family care planning tool – ‘Message in a Bottle’ (see details below);
- Young carers’ assessment pathway (including assessment tools);
- Improved the visibility of affected children within the common assessment framework;
• Improved the visibility of affected parents and children with the care program approach;
• Active working relationships across children’s services and adult mental health systems;
• Increased staff awareness of families’ needs and a more confident workforce;
• Improved identification of young carers leading to services and support.

Keeping the Family in Mind Pack
The purpose of the Keeping the Family in Mind pack is to:
• Raise awareness of the issues faced by children and young people, whose parent has mental health difficulties;
• Educate professionals and agencies that may come into contact with parents with mental health difficulties and/or their children, hopefully inspiring professionals and agencies to change the way they work.

The pack does not prescribe a specific approach to working with families affected by parental mental ill health.

The pack includes:
• Posters;
• Reports;
• Advice sheets;
• ‘Telling it like it is’ film. This film tells Sue’s story, of what it is like to care for a mother with schizophrenia suffering from depression, mood swings and delusions. The film explores how parental mental health can affect the whole family and includes 10 key messages to professionals, written by young carers, drawing on their own experiences. The ‘Telling it like it is’ film was produced and stars young carers aged 6 to 18 from Liverpool. A film company helped them turn their plans into reality;
• 10 Key messages drawn from advice of children and young people who have a parent with mental illness. The 10 key messages are used in everyday practice.

Message in a Bottle
The Message in a Bottle resource was designed by and for children and young people, in language they can understand and was developed from meaningful participation by young carers.

The Message in a Bottle pack includes a booklet about mental health, written for children and young people.
Contents of the pack include:

- Booklet about mental health written with young carers for other children and young people;
- A list of further resources, including books about mental illness for young people;
- A prompt list of questions a child might want to ask about their parents and their care treatment;
- A list for the child to complete giving the names and telephone contact details of people who are available to help when the parent becomes unwell;
- Contacts in the trust if the child is concerned about their parent’s mental health;
- The contact list can be stored in a plastic pot that can be kept in the fridge, so that the child knows where it is and the mental health and emergency services can find it if they are called to the child’s home in a crisis.

Children informed Louise Wardale that sometimes when in crisis, they don’t know their own name; let alone what medication their parent is taking.

The Message in a Bottle was developed as a means to overcome and support these children through this.

Thank you to Louise Wardale for her advice

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Charity Nos. 216250 and SC037605
Willow Program

Willow is a support service for young carers aged 5 - 17 years old living in Leeds. It is a partnership between Barnardo’s and Leeds City Council, and was established February 1994. They support children and young people who are caring for, or affected by, a family member with a serious physical illness, disability or mental health issue.

The young carer works closely with the worker developing their own action plan who will then help them to achieve their goals.

A highlight last year was the production of a ‘Young Carer in Education CD-ROM’, which was commissioned and funded by Leeds City Council. Young carers produced the CD-ROM and the CD Rom is being used as a resource tool to all primary and secondary schools in Leeds.

The service is currently commissioned to support 250 young carers, however statistics extrapolated from the UK 2001 Household Survey identified 2046 young carers under the age of 18 living in Leeds.

Services

Services that Willow provides include:

- Holidays;
- Activity days and residential breaks;
- Financial support for buying food during Christmas, domestic appliances, moving house etc;
- Assisting families to apply for benefits and grants;
- Funding to secure out of school activities which promote healthier lifestyles;
- Speaking to other agencies and professionals to plan support;
- Performing Arts - Young carers wrote and performed a series of short plays about the lives of young carers, and performed in a number of schools in Leeds, reaching over 1000 students;
- Workshops, including media, music, cooking, IT, English, maths and presentation skills;
- Group work and 1-1 work;
- Awareness raising in schools. The staff team are allocated clusters of schools to engage with;
- The young people aged 15-17 will be referred to Connexions to ensure they have a plan following on from school;
- A register of young carers to track where they are when their intervention ceases;
- Support around education, training and employment;
- Transport to and from the group will be organised for the young person either by taxi or by the worker.
**Education**  
Willow staff work to raise awareness in schools and support young carers in schools. They attend assemblies to raise awareness amongst students and work with teachers.

In one case a young carer experiencing difficulties at school asked them to attend a whole school assembly and work within her own class. Using the CD-ROM that the young carers had produced they were able to raise awareness and empathy within the school community, enabling this particular young person to benefit from a more supportive and inclusive experience at school.

Another student at a school in Leeds was supported by the worker meeting with the school and the young person together, with the outcome of the school asking how they could help. The school in turn arranged for free school meals for the student.

**After school**  
Willow partner with Connexions West Yorkshire where young carers are supported in a range of tasks designed to help them establish either college or work placements.

**Future Initiatives**  
Next year they would like to host a young carers conference together with education, health, social care and the voluntary and community faith sectors. Young carers will be key to the development and delivery of this initiative.

*Thank you to Brent Lumley for his advice*
Barnet Young Carers and Siblings is part of Barnet Carers Centre, and supports young carers and siblings aged 5 – 17. They have been in operation since 2001.

They provide the following services for young carers and siblings:
- 4 Fortnightly clubs involving physical games, basic cookery and art activities;
- Minibus transport to clubs;
- Monthly outings for the over 9’s;
- Quarterly teen time outings;
- Joint activity initiatives, e.g. Big Knit, Glass Workshop and Arts Depot;
- Counselling;
- One to one counselling;
- Monthly newsletter;
- The opportunity to meet and talk to other young carers/siblings;
- Advice and support;
- Advocacy;
- Home Visits;
- Assemblies and PSHE lessons in school;
- Awareness and support within schools;
- Support groups in school;
- Discussion Board;
- Specialist support for young people affected by a family member misusing drugs or alcohol;
- Telephone helpline;
- Time 4 Us Program (a 2 year funded project which began in 2007 working with 5 – 17 year olds affected by substance misuse by a family member) provides one to one support and access to mainstream activities;
- Training for professionals.

Future services include Family Days, Dance Club, Sports Club, Cookery Club, Art Club, Homework Club, Training, Assertiveness Workshop, Confidence/Self Esteem, Bullying Workshop, Dealing with anger, moving and handling of a parent, role as young carer.

The Barnet Young Carers also incorporates activities for the whole families of the children, and these future initiatives are planned:
- Family Day;
- Residential Trip;
- Sports Club;
- Cookery Club;
- Art Club;
- Homework Club;
- Confidence/Self Esteem;
- Bullying Workshop;
- Dealing with anger;
- Moving and Handling;
- Role as Young Carer.
During evaluation the following statistics of the benefits of the service was established:

Young Carer Members:
- Made Friends 76%
- Socialise 65%
- Feel More Confident 59%
- Have Fun 94%
- Is something to look forward to 82%
- Discuss Individual Concerns 18%
- Meet others 65%
- Get out and about 82%

Parents have given the following feedback:
- Helped them to make friends;
- Given their child the chance of independence;
- Given confidence;
- Have fun;
- Helped with self esteem;
- Made them feel they are not alone;
- Been an outlet for them;
- Break for them;
- Been able to go on trips that they wouldn’t have been able to take their child;
- Experience something different.

Identifying young carers
Identifying young carers predominantly took place through:
- Social/health services;
- Schools – Some schools are engaged in raising awareness of young carers, but some schools are difficult to engage;
- Barnet Carers Centre;
- Voluntary organisations;
- Parents/self referrals.

School Work
Barnet Young Carers has a dedicated Schools Liaison Officer (SLO) to work within schools to raise awareness to enable schools to recognize and identify young carers. The SLO works with teachers to enable them to identify issues with young carers and how to support them; Change the culture of the school relating to young carers.
Members of a Working Party were advised that

- Having a link person within a school for this work was vital, particularly for longer term planning;
- It was important to start with Year 7 and develop this through Years 8 – 11;
- It was important to empower young people where they would be able to carry out self-referrals and deliver inset days;
- There was a support group within the school which helped young carers, which was made up of a small number of girls that did not/could not join the Barnet young carers due to family pressures and cultural differences;
- Young carers do not want preferential treatment.

Thank you to Sangita Patel for her advice
A small team of people provide a radio program for carers. They hope to provide live programs for all sectors of Carers in the international community and are currently setting this up. They hope that this will give them the opportunity to provide a wide range of programs for adult carers, young carers and others.

There is not a specific young carers program at the moment, however, their next program in July 2009 features a young carer event in London which launched a new DVD. They are currently working with a young carer’s organization to provide programs produced and presented by young carers to air in June 2010 as part of the UK Carers Week.

They developed a training course for the young carers in Surrey and then produced a series of four, two hour programs which the young carers produced and presented. This group included young carers looking after parents whom had mental health problems.

The program is broadcast from the UK to help connect carers to information, support and the human side of the issues faced.

Thank you to Ron Critcher for his advice.
Crossroads Care is a network of independent charities operating throughout England and Wales. They provide various support services for carers, including young carers who have a parent with a mental illness. This support is delivered in a variety of ways, according to local needs and availability of funding.

Crossroads Care work with over 35,000 individuals and their families, helping carers to make a life outside of caring. They are an umbrella organisation that has 106 member schemes throughout England and Wales.

They provide a range of support, including:

- Homework clubs
- Social outings
- Counseling services
- Domestic training – healthy cooking
- Advocacy
- Family Work

**Rurality**

Norfolk is largely rural area with few urban centres which are quite spread out. It is difficult, particularly outside school holidays to see young carers as often as we would like to because of the high number of active cases we are working with.

Each project officer works a specific area in order to efficiently manage time and transport costs.

**Supporting Education**

59 young carers have been supported over a variety of school issues:

- Improving school attendance
- Preventing exclusions
- Bullying
- Homework
- Communication with the person cared for and school
- Improving school support to the young carer
- Friendships

A number of young carers have some difficulties with school attendance which can be very poor and sometimes non existent. Most common reasons are around bullying because they are young carers. Some do not want to leave their parent alone at home.

*Thank you to Annalise Cooke for her advice*
Dazu has been running programs for over 19 years and currently have a membership of approximately 540 local families and 270 young carers and their families. Their activities are for children aged between 2 and 18 years.

Dazu runs three main areas of provision:

1) A Young Carers Project, which supports children and young people who care for a relative with a mental health problem, physical illness or disability;
2) Recreational and inclusive leisure activities for children and young people, which extra support for children who are disabled or have additional needs;
3) A counselling service for children and young people.

Referrals can be made by phone, email or post. They can be self referrals or referrals from other voluntary agencies, statutory bodies or schools.

They also offer a Siblings Group for those children and young people who are Sibling Carers. Some activities for this group have included Circus Skills sessions, trips to see The Lion King, and meals out.

Services for young carers include:

- A free counselling service
- Trips to various venues
- Free access to Dazu’s recreational activities
- A quarterly newsletter written by a young Carer
- Leisure vouchers twice a year
- Advocacy
- Information and support

Activities include
The leisure activities as listed on the website are free to young carers. Classes aim to build confidence and self esteem while developing new skills in a fun, safe, stimulating environment.

For children aged 4-11
They hold a Saturday Arts Club Dance, Drama and Theatre Crafts. Children will participate in a range of activities including dance and drama, mask and costume design, pottery and tennis coaching. Professionals from a wide range of backgrounds in dance and movement from different cultures and countries, and with a wide experience in Art, offer workshops. The workshops also include tuition on percussion, making musical instruments and many other activities.

Dazu also offers holiday play schemes for children aged 5-11 years.
For children 11 plus
There is street theatre, where they are introduced to theatre skills and video skills and is an opportunity to develop performances for special events and look at costume and prop design.

For youth aged 11 – 17 - 1JBz Youth Club
They hold activities such as sports, pool, art and crafts, pottery, bowling, video evenings, computer games, disco etc.

Thank you to Lisa Poole for her advice

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Family Action is England’s leading family charity, supporting over 45,000 families every year. It supports parents with mental health problems and other complex needs to be effective parents to their children, enabling families to stay together. Family Action operates a number of mental health family support services across England, working with the whole family to ensure all get the support they need.

Family Action Building Bridges services work with the whole family unit, usually on an outreach basis, and seek to meet the individual needs of each family member, supporting the need of the adult in their role as a parent or carer and responding to the related but separate needs of the children at all stages. The key characteristics of the service include:

- Tailor-made to meet individual families’ needs
- Support with practical issues alongside emotional support
- Manage risk and assess safeguarding issues
- Available at times when other services often are not, e.g. early morning, evening, weekends, bank holidays
- Work with parents and their children in their own homes
- Promote positive attachments by identifying support resources and encouraging sustainable community links e.g. children’s centres, groups,
- Increase children’s understanding of their parent’s illness
- Improve family relationships by enabling parents and children to have a better understanding of each other’s needs
- Use international clinically validated clinical tools to measure the effects of intervention
- Work in partnership with other agencies
- Provide culturally sensitive services

Family Action’s Newpin model is centre-based, working with parents and their children under five where there is a significant difficulty in the parent–child relationship and/or an identified mental health problem. This is a long-term intensive service providing successful interventions for some of the most troubled families that come into contact with statutory services.

Family Action Young Carers’ services provide support by:

- Developing a plan with the Young Carer based on their individual needs
- Helping to access other services in the community e.g. Connexions
- Providing advocacy on behalf of the young carer and their family to other agencies
- Giving information e.g. about mental illness
- Supporting with any issues at school
- Providing a listening ear and arranging counselling if needed
• Offering group work, regular clubs and/or individual work according to individual need, e.g. chill out groups, theatre groups
• Providing activities with other Young Carers or children and young people in the community to give them a break and have fun,
• Offering opportunities to have new experiences, learn new skills and be involved in how the services is run
• Activities with parents and children together, e.g. after school cooking clubs
• Counselling sessions or lunchtime discussions groups within schools;

Thank you to Rose de Paeztron for her advice

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Charity No. 264713
The Young Carers Project supports children and young people aged 5 – 18 years old, who are caring for someone in the family who is ill, disabled, elderly or with drug/alcohol problems. Caring tasks can range from general household chores to full personal care.

Furness Young Carers offers:

- Someone to talk to who will listen and believe them;
- Recognition of their role as a carer;
- Information about their relatives illness/condition i.e. books and videos in simple language about different illnesses and disabilities;
- Time for themselves to be children and have fun;
- The opportunity to participate in 'out of school' activities;
- Provide support/activities/holidays for young carers on an individual and group basis;
- Provide an escort service for scouts, swimming club etc;
- Provide after school clubs
  The after school club for primary age children offers a variety of activities including:
  - Games
  - Activities in the local community e.g. golf
  - Visits to the park
  - Sessions on topical issues e.g. bullying, healthy eating
  The club for secondary school children offers:
  - Visits to local activities e.g. sports centre, meals out, golf
  - OCN certificate in Motivation for Life
  - Somewhere to chill out with other young carers
  - The opportunity to plan activities according to the young carers own wants and needs;

- Public transport information is provided and taxis can be provided to enable the children to attend the clubs;
- Respite activities in school holidays, for example, visiting Grizedale Forest, Ducky’s Park Farm, Barrow Fire Station, Climbing Wall, Chill Factor, Blackpool Pleasure Beach, Go Karting, swimming, bowling, cafes and restaurants.

Awareness Raising in Schools
They have held awareness raising sessions in both primary and secondary schools in Furness and the surrounding area. The number of children self-referring children has risen due to the increased awareness of the project’s work in schools.

Thank you to Susan Jones and Laura McCormick for their advice
Gateshead Crossroads Caring for Carers

Web: www.gatesheadcrossroads.org.uk
Email: enquiries@gatesheadcrossroads.org.uk
Telephone: +44 1207 549 780

Gateshead Crossroads Caring for Carers provides support to carers living within the Borough of Gateshead. Below is a guide to the services they provide for young carers.

They currently have a case load of 340 young carers.

The service is staffed by:

Team Manager
Assessment Worker
Administration Worker
4 Family Support Workers
Activity Co0Ordinator
5 part time works for social activities
Occasional volunteers

This service provides support for young people under the age of 18. The young carers Service offers:

- Time out activities;
- Social activities for young carers between the ages of 8 to 18;
- Overnight stays, weekend trips;
- Transport is provided where possible if it is needed in a mini bus, or if not available, they arrange for a taxi;
- One to one support;
- Youth clubs;
- Help with homework;
- Film making;
- Drama;
- Photography;
- Information;
- Help to access services.

They have an area at school where the young carers can go for chill out space, talk to counsellors and to mix with other young carers.

They offer social activities between the ages of 8 – 18.

The service enables young carers to have time to make friends, have a break, visit new places, talk to someone about the problems they face, receive training and information to help them in their caring role: e.g. first aid, anger management.

Thank you to Anthony Lea for his advice

Charity Number 1059917
The service is for young carers who are aged between 8 and 18 years and live in the London Borough of Hammersmith and Fulham.

Hammersmith and Fulham Young Carers’ Service enables young carers to have a break from their caring role, peer support from other young people in similar circumstances and an opportunity to learn new skills. As a result they set up their own web-site, www.bubblycrew.org.uk. The web-site gives young carers who are unable to attend the activities at the centre the opportunity to be linked to the project.

The web-site was the inspirational work of the young carers, and was nominated for an award in the Cable and Wireless Childnet International Awards. To receive the Award they went to Paris for a week to attend the ceremony.

More information on the web-site follows.

The service they offer is holistic and offers the following at a Carer’s Centre:

- Young carer’s assessment, takes place in the home with the young carer and the person they care for, and may include other members of the family. The purpose of the assessment is to ensure that the needs of the young person are fully understood and to help identify which parts of the service would be most beneficial to the young carer.

- After School Club
  The after school club provides activities designed to support the young carer in their educational achievements and also provides a venue and support where they can catch up on their school work. This can be done through giving assistance with school homework and through participation in a range of educational activities; many of which are art-based and creative projects. The activities undertaken in the homework club lead now to an accredited qualification.

- Advice, information and referral
  Advice, information and referral are an integral part of the service to young carers and their families. For example, advice has been given to parents on appeals for school admissions. Under appropriate circumstances advocacy for the young carer or their family can take place.

- One to one emotional support is now available for all young carers who attend the after school club.

- Art and Drama Therapy both in group session and on a one to one basis.

- A Parents Forum has now been established and meets quarterly.

- Respite breaks for young carers are available twice a year.
• A school activity program runs during most of the major school breaks, activities ranging from cookery courses, theatre work, dance and jewelry making through to days out and theatre trips.

• They give assistance with the transition into adulthood.

• Support and education on healthy eating and nutritional education.

• Support and advocacy in the case of any bullying.

• Support through emotional difficulties which occur when becoming a teenager.

• Financial advice.

• Workshops on:
  Alcohol awareness
  First Aid
  Drama
  Art
  Media

• Sports opportunities.

  Thank you to Harbhajan Purewal for her advice

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Charity Number 1084267
This is an excellent web-site designed by young carers for young carers.

The web-site was developed in accordance with the wishes of the young carers, as they found it difficult to get away from the home and was an avenue where they could make contact with others in similar roles.

The site is divided into the following sections, and can be translated into English, French, Italian, Dutch, Spanish languages.

The web-site the young carers received the Childnet International website award.

Profiles
Gives information about each young carer who developed the site.

Their experiences
Gives information about what it is like being a young carer from their own experiences.

Your Views
They post their feelings and view on the lives of young carers, and want information from others throughout the world.

Movies
Short cartoon movies, which they have made themselves about themselves.

Interviews of young carers
Here you can hear the answers to questions we asked key people within and around a young carer’s world.

**Insert from Website**

“Hello there, we are the Bubblycrew, we are a group of young carers that live in Hammersmith and Fulham. Each of us cares for a family member suffering from a disability or a long-term illness. This website was designed and produced by us, with some help of course! We felt our voices were unheard by the adult population so we had the ingenious idea of creating a website to show people that we are here. We also wanted to be able to have a centre point of communication between carers all around the world. This is the finished product. You can learn about us, what we go through in an average day of our lives and all about the carers centre and how it helps us. You can also let us know what you think and feel about young carers and issues surrounding them.”

*Thank you to Harbhajan Purewal for her advice*
The Young Carers Project in Hounslow was established in August 2002, and is now run by Hounslow Council, in the Integrated Youth Support Service. It is the only project in Hounslow Borough that supports young people aged between 5 and 18 who have a significant caring role at home.

The Hounslow Footprints Project supports young carers in the following ways. The project is for all young carers, including those carers of a parent or other person with a mental illness.

- Holistic Assessments to identify the needs of the young person concerned as well other family members;
- Advocacy – they assist with liaising with agencies to support families to gain the services that are needed;
- After school drop in activities;
- One to one support – To address specific needs and support to make positive changes;
- Working within the Borough to raise awareness and identify and support young carers in Schools – A PSHE pack was developed, aimed at year 7, but elements can be adapted and used with older and younger groups;
- Offers opportunities to meet others in similar situations - support if needed
- Regular mail outs;
- Access to drop in at the young carer’s centre;
- Referrals to other agencies to support the family;
- Being a link person between school and any issues around being a young carer;
- Fun activities;
- Linking young carers into the broader positive activities programs and generic youth work activities (as appropriate);
- Time away from home doing new, fun things;
- A friendly listening ear;
- Computer and newsletter groups;
- A regular exciting newsletter with competitions and prizes;
- Time to be yourself;
- A handbook for young carers, designed with the input from young carers.

Thank you to Emma Yates and Elizabeth Hassock for their advice
The YC may be providing:

- Personal care – assisting with toileting, bathing, dressing, etc;
- Practical care – helping with housework, preparation of meals, caring for siblings, etc;
- Emotional care – listening to/talking through issues and difficulties with the cared for person.

**Referrals** are accepted from all sources, including self-referral.

All YCP services are available to all databased YC’s.

Each new referral receives a home visit where a qualified worker meets with the YC(s) and their family.

Appropriate services (both YCP and other agencies) are discussed with the family and services/referrals activated as agreed at this time.

**There** is no cost to the family for any of the YCP services.

There are 6 main services offered by the YCP:

1. **Activity & Residential Scheme**
   - Day trips in all school holidays – eg. seaside, theme parks, zoo, historic places of interest, bowling, ice-skating, theatre, cinema, etc;
   - 3-5 short holidays each year – eg. Outdoor sports weekend, seaside holiday, sightseeing holidays anywhere in the UK, etc.

   This provides:
   - Opportunities for children/young people to go out and make friends with other young people who are in a similar situation.
   - Opportunities to go places/participate in the ‘usual’ childhood development activities that their peers take for granted;
   - The chance for a child to be a child.

2. **3 x Homework Clubs** – twice weekly in term-time in 3 x ‘local areas’ of Lambeth.

   Each club operates a pick up from school/take home service where appropriate.

   Each club provides educational support, helping to ‘fill the gaps’ in basic education which arise from poor attendance at school due to the YC being needed in the family home. Also they provide time/space and support to complete homework/coursework which may not be available in the home.
3. 3 x Monthly Youth Clubs – in the same 3 ‘local’ areas – provides:
   - A social environment where YC’s can meet, form ‘local’ friendship groups, thereby gain peer support outside of Project time.

   [Both homework and youth clubs are operated in partnership with local area, mainstream youth provisions. This enables YC’s to ‘get to know’ their local youth clubs/youth workers. Over time this enables YC’s to access mainstream youth groups/activities through these clubs]


   Provides:
   - A qualified worker for YC’s and parents to talk to outside of office hours/someone outside of the family situation to discuss problems/issues that may have arisen throughout the day;
   - Seek emergency advice/assistance if/when required.

5. 1-1/Family work

   Provides:
   - Support for YC’s and parents around relationship difficulties;
   - Advice and advocacy when dealing with statutory agencies/accessing care packages, etc;
   - Support within Child Protection procedures, Core Group meetings and Care Plans.


   Provides:
   - Support for YC’s within their school (YCP and /or partnership school based staff);
   - A peer support group within the school;
   - Enables YC issues, which may impact upon education/attendance/etc, to be addressed ‘at source’.

   Thank you to Debbie McDonald for her advice

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Charity Number 1066799
Kim Penketh Children and Young Peoples Participation Consultant The Mental Health Foundation

The Mental Health Foundation and The Princess Royal Trust for Carers conducted research into the mental health of children and young people aged 10 - 21 who care for a parent with a severe and enduring mental illness in England, Wales and Scotland.

Information was gathered from surveys, interviews and focus groups with professionals and young carers.

Research was carried out due to the 2001 census identifying that 17,000 young carers were caring for a parent with severe and enduring mental illness. Research suggested that between 25 - 50% of these children and young people will experience mental health problems during their childhood or adulthood.

The final report is to be published at the end of 2009 and will provide a comprehensive evidence base from which a range of policy recommendations will be drawn, with the aim of:

- Promoting the mental health of this group of young carers;
- Improving services’ awareness of, and responses to, their specific mental health needs.

The research explored:
- Cultural differences;
- Resilience;
- Long term coping strategies;
- Perceptions and experiences of professionals working across the statutory and voluntary sector including; Education; Child and Adolescent mental health services; Adult mental health services and young carers services;
- Young people’s perceptions and experiences of being a young carer

Main themes that emerged from the study were:
- Issues with identifying young carers;
- Not making assumptions about the needs of young carers;
- The need for more funding for services;
- The need for individualised support.

From the research:
- Gaps were identified, what is needed and what has worked;
- A resource is being developed for school and professionals.

*Thank you to Kim Penketh and Dan Robotham for their advice*
Surrey Young Carers support many young people caring for someone with moderate to severe Mental Health illnesses.

Many young carers have attended generic young carer groups which are issue based. During sessions they have a chance to deal with worries and concerns have time out from their responsibilities build confidence and mix with their peer group.

The team at Surrey Young Carers identified early on that because of the nature of mental illness children would benefit from a focused Workshop. Many of these young people have trouble talking about the conditions because unlike a lot of disability it is not so visible or obvious and the bulk of the caring is emotional based. Bringing young people together with others with a similar caring responsibility made them more comfortable to discuss their issues and more open to preventative work.

Initially the team had challenges in encouraging the children to attend, but have now developed the program to make it informative, fun and non-threatening, for example they have had an activity of Go-Karting.

They have also included a presentation by a child and adult psychiatric nurse from the Child and Mental Health Service. For this particular session the children are encouraged to ask questions by writing their questions anonymously about mental illness on a piece of paper and putting them into a bucket. The Psychiatric Nurse then draws out one at a time and is able to answer each question.

They try where possible to work alongside other agencies and previous workshops have included running them with the help of www.rethink.org, who supplied someone living with a Mental Health illness to talk through effects with the young people and have question and answer time.

They now have a mental health pack which can be handed out on initial visits. The mental health pack consists of ‘frequently asked questions’ put together from the questions that the children asked on the day and ones that the psychiatric nurse is asked for. Where possible they try to supply recourses such as Minds Myths and Me (downloadable from www.glosyoungcarers.org.uk/mindmythsandme.html and The White Mouse for younger age groups, www.youngminds.org.uk/children/the-wise-mouse/). Feedback on these resources has been very positive and enables the adult with a mental health condition to explore their illness with their child and start dialogue with them.

Thank you to Geoff Parks and Lisa Roberts for their advice

Charity Number 1116714
The Children’s Society Include Project

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The Children’s Society Include Project works with young carers projects and other organizations and consults with young carers and their families in order to develop good quality support and information for young carers, their families and those who work to support them across the United Kingdom.

The Include Project has set up the first National Young Carers Forum, which informs delivery of a national training program assisting local authorities in ensuring that young carers get a more responsive, whole family and needs-led service. The members of the forum created a DVD called “Listening to young carers” in which the young people talk about common issues they face and the solutions that will help improve their lives.

The Include Project is home to four strands of work:

- **The National Young Carers Initiative**, which works nationally to promote good practice for young carers and their families. This involves working with policy makers in Local Authorities to put into place guidance to support young carers and their parents, providing training to statutory services and resources to agencies and individuals supporting those working with young carers;

- **The Hampshire Young Carers Initiative** which works within Hampshire to promote good practice and works to support professionals working with young carers and their families with substance misuse issues, mental ill health problems and disabilities. They also help shape policy and have recently been involved in the creation of a new pan-Hampshire protocol for Substance Misuse and Mental Ill Health;

- **The Leading Edge Initiative** improves access to education for young refugees aged 11-18. A range of effective study support services is available to improve achievement, integration and inclusion including young refugees with caring responsibilities;

- **The Family Inclusion Project** works to support young carer who are refugee and asylum seekers focusing on inclusion in health services to prevent them providing inappropriate support such as translating for medical appointments.

The Include Project has a comprehensive website (www.youngcarer.com) with a directory of local and national services and a range of resources including:

- A practice guide – Making it Work: Good Practice with young carers and their Families (published by The Children’s Society in partnership with The Princess Royal Trust for Carers);

- A schools notice-board pack;

- **GP’s Information Pack** which contains a ‘quick checklist for supporting and signposting young carers’, a poster for the GP’s waiting room, a poster for the
staff room and a Supporting young carers– Information for health professionals leaflet.

The Whole Family Pathway is a free online resource for all practitioners working across all sectors including Adult’s and Children’s statutory services, Health and Education to ensure that whoever or however the family (parent or child) in need of support first makes contact with an agency the same processes or pathway will be followed. Using the Whole Family Pathway will help practitioners achieve the Key Principles of Practice and promote Whole Family Working.

The Refugee Toolkit (www.refugeetoolkit.org.uk)
This is an online toolkit which has information and practice resource for all practitioners, including those from Adult’s and Children’s services, Health, Education and the Voluntary Sector to ensure both asylum seeking and refugee people with children under 18 have access to appropriate health services, and that their children do not have to undertake inappropriate care.

These key principles of practice are an invaluable tool for policy makers and practitioners. As a statement of the essential values and common understanding that should underpin all support for young carers and their families, they give clarity, direction and purpose to professional practice.

Taking Care of Ourselves: The Young Carers Recipe Book.
Contains healthy eating tips, recipes from young carers and food safety tips

Supporting children who have a parent with Mental illness - Information for Professionals

The Children’s Society Include Project produces a range of other leaflets and packs for professionals working with young carers, available on their website.
The Children’s Society Hampshire Young Carers Initiative is working with Hampshire County Council to develop School Leads for young carers in all schools. The aims of the program are:

- To raise awareness and inform practice so that young carers will have the same access to education and career choices as their peers.
- To promote, train and support Designated School Leads for young carers in all schools in Hampshire.
- To ensure the inclusion of the needs of young carers and their family within all school policies across Hampshire.
- To enable Hampshire schools to identify external partners, when needed, to support pupils who have caring responsibilities.
- To begin to monitor the impact of the service delivered and plan its future focus by developing a process that quantifies the impact that being a young carer might have in terms of attendance, exam results and overall achievements.

A School Lead does not need to be a teacher, as schools are staffed and supported by a range of professionals playing different roles, but needs to be someone who can relate well to children and young people and have sufficient influence in the school to make things happen.

Experience has shown that it is important for a school to develop a team of people who can “be there” for young carers. This can include the nurse, welfare officer, school administration officer, learning mentor etc. The children should drive the choice of School Lead, as they will know the sort of person they can relate to and trust. It should also be someone who has enough influence in the school to make things happen.

Key responsibilities for School Leads include:

- To be a point of contact for young carers and their families.
- To raise the awareness of the school, and the children and young people, to the range of resources and support that exists for young carers and their families.
- To develop effective links with those who can provide support for the young carers and their families out of school.

The Children’s Society has an Education Development worker who is able to support schools with this role. Some of this work includes looking at how the curriculum offers opportunities for schools to develop a climate within which children and young people can explore the impact of being a young carer. See the website (above) for details of other work in Hampshire.

The Children’s Society Include project in partnership with The Princess Royal Trust for Carers have developed an exemplar for a job description for school lead for young carers and their families, available on the Include training pages of www.youngcarer.com.
The Hub
Young Adult Carers in Bedfordshire
16-24

Web: http://www.carersinbeds.co.uk
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Telephone: (+44) 1234 214 914

The Hub for Young Adult Carers 16 – 24 run by Carers in Bedfordshire

They are a not for profit registered charity and a member of The Princess Royal Trust for Carers. All their services are free.

Their purpose is to identify, engage and support all unpaid young adult carers and past carers throughout Bedfordshire.

They offer practical and emotional support, advocacy, information, advice, training, social group, rights, events and outings along with help in any other areas which they think are important to them.

The Hub strives to ensure the needs of individual young adult carers are met so that they are able to be motivated to engage in education, employment, training, a healthy lifestyle and to make a successful transition to adult life. Together through The Hub they can have fun, gain mutual support and think about ways to improve their lives.

They continue to be a platform for the young adult carers’ voice, work together with statutory and non statutory services to raise awareness, participate in research projects and inform and support school, colleges, universities and places of employment.

Thank you to Robert Cunningham for his advice

Charity Number 1106364
The Princess Royal Trust for Carers is the largest provider of comprehensive services to carers in the UK. Through its unique network of 144 independently managed UK-wide carers’ centres, The Trust provides quality information, advice and emotional support.

The Trust has developed web-based communities on carers.org and youngcarers.net, enabling carers to gain support and access information on-line. This is especially helpful if the carer is not able to leave their home because of their caring role.

In 2008, they were awarded the contract to deliver a new initiative for carers; that of training. The training consists of a number of modules to help with increasing confidence, as well as specific units developed to meet the needs of special areas.

This year, The Princess Royal Trust for Carers has been awarded funds for the development of services to support young carers, with which they will be able to support 12 – 15 not-for-profit organisations.

Nationally The Trust provides:

- Specialist support through trained advisors with experience of running voluntary sector young carers’ services, who help services to build the capacity, quality and sustainability of young carers’ services.

- Resources and toolkits. To date, The Trust has produced over 50 specific pieces of Trust Guidance, Pro-formas and Policy Templates which young carers support workers can download from the website and implement for their own service.

- Training, conferences and regional networking events. Their northern and southern training conferences for young carers’ workers give young carers workers a range of different practical training experiences to develop their skills in particular areas of their work. These are also available to young carers’ workers from other organisations.

- Funding and grants to young carers and young carers’ services.

- A link to policies and practices across England, Wales, Scotland and Northern Ireland. The Trust is working very closely with English, Scottish and Welsh governments on key policies such as the National Carers Strategy review. In Scotland, The Trust is supporting the Executive to develop a national young carer’s festival as a vehicle for getting young carers’ voices heard by politicians.

- A national research and evidence base. The Trust initiates national pieces of research and demonstrating projects in order to provide models of best
practice and the evidence needed to influence policy for the benefit of carers. Currently, they are working with Nottingham University to undertake two major pieces of research; the first is looking at the needs of young adult carers, aged 16 – 24 and the second is researching the outcomes that carers centers achieve from both adult and young carers. These pieces of research are being led by Professor Saul Becker, recognised as the world leader in young carer’s research. The Trust has provided briefings, presentations, information and support to the young carers agenda in the US, Australia and Germany.

- Website support to young carers through YCNet (www.youngcarers.net). The Trust manages the UK’s first interactive website specifically for young carers which provides information, support and dedicated trained professionals to help and mentor young carers.

Currently, Carers’ Centres in The Princess Royal Trust for Carers’ network offer the following services to support carers:

- Finding hidden carers via outreach in GP surgeries, hospital wards and other locations;
- Finding the correct information for carers;
- Advocating for Carers’ rights;
- Supporting Carers emotionally;
- Help find other sources of support for the parent;
- Run clubs, activities and holidays;
- One to one support and mentoring in schools;
- Train teachers, doctors, youth works and others to recognize the signs of a hidden caring role and offer support with young people’s health, well being and education.

Most centres are in a place of prominence and provide outreach to cover rural areas.

Resources can be found at:

www.carers.org/professionals/health/primary-care.805.PP.html
www.carers.org/professionals/health/hospitals.806.PP.html
www.carers.org/professionals/young-carers/

Thank you to Paul Chance for his advice
Approximately a third of the young carers seeking assistance from the York Young Carers are for young carers who have a parent with a mental illness.

To support the children, they offer:

- Trips events and activities – include things such as: theme parks, Go Karting, bowling, outward bound e.g. climbing, or even just a picnic in the park & a game of rounders;
- Residential breaks – we try to offer one per year for each age group, activity based for younger age group & young carers festival (chance to meet a wider group of other young carers) for middle age group & caravan park or similar for older group or depending on funding a trip to London or similar;
- One to one support – this allows for them to be allocated a key worker who will work with them on issues which can vary hugely depending on their individual situation, ensures they have all the services they are entitled to as a family & give them opportunity to talk and off load. Through this part of the service we support young carers if their parent goes into hospital, advocate on their behalf and can work with people over a prolonged period of time;
- LAFFS groups, (laughs, Advice, Fun, Friendship, Support), offering a youth club for young carers and the chance to do arts and crafts, sport or just chat with friends.

**Schools Project**
They have a schools project, aimed at raising awareness and ensuring schools are set up to support young carers.

**Forum**
A Young Carer’s forum is in its early stages of development, but already the young people are wanting to put on a conference to raise awareness of the issues they face.

**Aims**
The service also aims to:
- Raise awareness of young carers' needs and issues;
- Identify where increased services are needed;
- Offer training for schools and any agencies who work with young people;
- Can provide lessons for schools or help with lesson plans.

*Thank you to Sharron Smith for her advice*
Young and Unique works with young carers aged 8-18 Yrs who care for a family member with a physical condition, Mental Health, Drug or Alcohol Problem.

They are based in Manchester.

Young and Unique carry out young carers Assessments with young carers at the referral stage and look at the caring role the young carer is undertaking and the support necessary to safely continue this role.

After Assessment Young and Unique offers:

- Referral for counselling if needed;
- Referral to Connexions who work with young people aged 13-25 yrs to help them with career options such as employment/training options;
- If safeguarding issues have been highlighted within the assessment stage then they make a referral to Manchester Contact Centre (Social Care) who will allocate the case to Social Services to investigate;
- Receive regular information through the post regarding activity sessions they can attend;
- Information on ongoing projects including the young carers Representative Group where young carers discuss the issues that matter to them. Their views are the feedback at the young carers Steering Group;
- The young carers Book Group meets every month to discuss a selected book. They are focusing on books that have been made into films so once we have had the discussion group, the following month they watch the film;
- They also have a monthly radio show which is hosted by one of our young carers. The radio show airs on a community station and is based in Manchester. The young carer hosts the show on the last Friday of every month and she has taken part in radio skills training which has enabled her to develop skills in presenting. She often invites guests to speak about a variety of topics and selects a variety of music she has called her show 'The Hour of Girl Power'.

The aim of Young and Unique is to give young carers a break from their caring role, a chance to meet other young carers who have similar experiences and help them to have a voice!

Thank you to Rochelle Jones for her advice

Charity Number 1103535
Finland
Structure

In Finland when someone becomes mentally ill, the first place to contact is a health center.

If necessary, they send the patient to special health care. The patient is cared for in an open ward if possible, but there are also mental hospitals, if that kind of care is needed. However, in recent years, hospitals have been put down, and care for outpatients is still not developed as well as it was meant to be.

The care for mental patients is thus much on the shoulders of families, who try to cope with patients as well as they can. There are peer support groups for patients as well as for family members. Also there are associations for patients and family members. These care for the rights of their members, and also arrange events and occasions to get information and support.

Children whose (both) parents have mental problems, are cared for by social welfare, and if parents are not able to care for them, they can be placed in foster families.

Thank you to Outi Stahlberg for his advice
Prevention and promotion in child mental health in psychiatric services for adults: The Effective Child & Family Programme in the Finnish National Health Service

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Tytty Solantaus, Marianne Sipilä, Mika Niemelä, Juulia Paavonen
National Institute for Health and Social Welfare

The Effective Child and Family Programme was launched in 2001 to develop, study and implement methods for the promotion of child development and mental health and prevention of disorders in families with parental mental health problems. The initial focus was to induce a change in psychiatric services for adult patients to attend also the needs of the patients’ children. The Programme has then expanded to community health and social services, to substance abuse service and somatic health services for patients with severe somatic conditions (e.g. cancer clinics).

The Programme has developed a Method Family. All methods are based on the same theoretical and clinical principles. They focus on prevention and promotion, on family and child resilience, the recognition of the role of stigma in families and health services and respect and open communication concerning everyone’s own experiences and needs. The methods are transparent and time-limited.

The methods include Let’s Talk about Children, a low threshold discussion about children with the patient and partner, The Family Talk Intervention (Beardslee et al) involving all family members, Vertti support groups for children and parents, Effective Child & Family Network meeting to build a supportive network around the family and guide books for parents and children. More methods are in the process of development.

The Effective Child& Family Trial studies the safety, feasibility and effectiveness of the Let’s Talk and Family Talk Intervention when they are carried out as part of the adult patient’s treatment protocol. Both interventions proved to be safe and feasible in the Finnish family and service culture. They are received positively by both family members and clinicians. The clinicians in psychiatric service for adults report increased work motivation and joy related to using the methods.

The implementation of the work has expanded through the specialized psychiatric services countrywide. Many (not all as yet) psychiatric clinics have trained their staff in the methods and include attending to the patients’ children’s needs in their quality guidelines. At the present, we are planning a new wave of implementation to more systematically reach the community health clinics, substance abuse services and somatic health services.

Thank you to Dr Tytti Solantaus for her advice
The Finnish Central Association for Mental Health is a support and advocacy organisation promoting the rights of people living with and recovering from mental health problems.

The Finnish Central Association for Mental Health consists of 10 local, regional and national mental health associations from all over the country.

Outi Stahlberg, Rehabilitation Coordinator of Family Work, Finnish Central Association for Mental Health sent a report on a program for children who have a parent with a mental illness titled ‘Let’s Talk About Children – when the parent has mental health problems’. The report was written by Dr Tytti Solantaus and dated 1 March 2006.

The report was initially developed to provide a tool for the health care sector and to assist professionals in treating parents with mental health problems. The method can be applied irrespective of the form of treatment (outpatient care/institutional care, primary health care/specialised psychiatric care) and of the worker’s training and title. No therapeutic training is required for the implementation of the method, and can also be used by social and educational sectors.

In Finland a worker treating a parent with mental health problems is obliged by law to assess the need for care and assistance of the dependent children. This report gives health care professionals a means of approaching the subject of children with respect given to both the parent and the children.

Let’s Talk about Children involves the whole family, regardless of the family’s situation. It gives examples of scenarios and advises methods of discussions for the worker. It also gives questions to ask for specific age groups.

Outi Stahlberg uses this resource every day in his work.

Dr Tytti Solantaus is presenting her program at the COPMI Conference in Australia in 2009.

Thank you to Outi Stahlberg for his advice, and acknowledgement to Dr Tytti Solantaus, author of the Let’s Talk About Children Report

© Artist Pauline Miles
Le Biceps was created 8 years ago in the “Bureau Central d’Aide Social” (a private foundation of Welfare) and was created as a preventative measure to help and inform young people who have a parent with a mental disorders. Le Biceps is now recognized and integrated into the landscape of the Geneva social psychiatry, the associative network and the specialized areas.

Le Biceps is a place of support and information for children, adolescents and young adults facing mental disorders in their family. Its purpose is to provide a neutral, independent, confidential and free place to children, adolescents and young adults (as far as 30 years old) for facing the daily and future plan.

Children receive support according to their needs. Le Biceps offers some flexible meeting in a framework which is friendly and support, focused on the transfer of tools and giving of information about mental disorders and about their implications on the family relations.

Le Biceps check that in his daily the young person has support, trusted adults, accommodation, entertainment and other necessities. They also ensure that all network resources (welfare, educational and medical) are explored.

Children or young people can come alone or accompanied. Le Biceps offers psycho-educational consultations with short or middle term, according to request or needs. It also proposes in longer term support groups for children and teens (during groups they work on identifying and managing emotions as anger, joy, sadness, fear etc. and also focus on self-esteem and communication skills). These support groups and solidarity between peer allow for a reappropriation of self and prove to the young people that they are not alone to live with a parent who goes badly.

**Network**

The service is closely related to the network of psychiatry Geneva (the psychiatric units of the hospital of Geneva, various associations of “Grepsy”, etc). and is known in Genevan institutions of health and youth. Le Biceps has received in 2001 approval from the Ethics Commission of Psychiatric Hospital.

The service also responds to professionals (curators, psychologists, social workers, school nurses, school counsellors, etc).

**Le Biceps offer**

- Offer a place where they can be listened to, offered assistance and receive information;
- Assess the situation and immediate needs of young people
- Discuss with the young people the way of daily managing and of representing itself the psychical disorders of parent
- Look for practical solutions to optimize the family balance
- Discuss the tools of communication and behavior appropriate to the situation of crisis
• Provide information about mental disorders, treatments, and therapeutic issues
• They also discuss issues such as school problems, relationships, stress, lack of concentration, anxiety, depression, loneliness or other issues that the young person may be experiencing.
• If necessary, orientate (guide and assist) the young to other professional of network (eg psychotherapeutic support)
• More widely the service participates in awareness campaigns to break with the taboos which persist concerning the mental disorders.

Film
A documentary film "A secret too heavy to bear" which deals with mental illness in the family can be viewed at their premises on request.

Thank you to Anne Dupanloup for her advice
GREECE
OVERALL INTERVENTION INTO THE FAMILY WHICH HAS A PSYCHIATRIC
CASE HISTORY, AIMING TO SUPPORT THE CHILDREN.
V. Melissi, A. Frangouli

The S.S.P&M.H is ruled by basic principles:

- Aimed at the social – community psychiatry, with reference to the catchment area, of the psychiatric services provided, thus leading the local population to feel they have prevention and treatment services of their own, and the possibility to appeal to them. At the same time, the therapists providing these services feel they belong to the local population.

- The prevention and the gradual development of the out-hospital treatment.

The S.S.P & M.H offers a range of services for people with a psychiatric illness through the rural mobile psychiatric unit, which has 11 teams covering the remote area:

The mobile unit has handled cases of families which came to the attention of the Prefecture’s social services, the police or the district attorney, since they received referrals of children who were estimated to be in high risk.

For almost every case where the unit was called, usually by the above mentioned services, it was found out that there was a psychiatric history from the parents’ side.

An important element of the mobile psychiatric unit team work offered to families with psychiatric history is, the therapeutic intervention to all the members of the family, with their cooperation in one hand and on the other hand the successful link and network with the local community services.

It is a procedure which takes time, needs patience and insistence on a clear therapeutic plan based on the community support.

Model of support:
The model of support followed is:

1. The Mobile Psychiatric Unit receives the request;
2. Visit at home and cooperation with the family;
3. Evaluation of the family situation;
4. Cooperation with the Social Service, the local services, such as the town hall, the school, the district attorney, when necessary;
5. A therapeutic plan is suggested, where usually the parents are followed up by regular psychotherapy sessions and parallel medication. The professionals responsible are the psychiatrist and/or a psychologist, and/or a social worker and/or a nurse.
Support offered:

- Sometimes support is offered to the family on covering the daily needs (food, cleaning, well-being);
- The children usually are under speech and language therapy and receive support on their school duties;
- Psychological help is also offered where necessary;
- The community and the school support the therapeutic team and the family as member of the community in which they live.

Example:
Within a year, the mobile unit handled three families that were referred by the social services. One of these cases was about a family living in a distant area of the prefecture, with four children aged between six and twelve years old. The two younger children suffered from serious learning disability and are attending the local special primary school. The request concerned the mother, as she herself had asked for help, claiming abuse by her husband.

The mother, the husband and the children had all been examined by a psychiatrist, a psychologist and a social worker who visited the house. When information was collected from the school and the local authorities, it was concluded that the situation in the house was tense, the mother was regularly abusing the children while she herself presented significant symptoms of psychotic syndrome. The father, on the other side, had a mild mental retardation, but was able to care for their children.

Pharmaceutical treatment and psychological help were suggested. They were denied by the mother. She stopped taking the children to school and threatened to leave the house, taking with her the two elder boys of the family. The eldest of the sons used, during that period, to threaten with a knife the younger children of the family.

It was suggested that the mother should be hospitalized, which happened, while at the same time, and with the help of the hospital's psychiatrist where she was hospitalized, meetings were set between herself and her husband, her relatives and a team from the mobile unit, in order to establish the cooperation of the mother. During this time, the children received help, with the father’s cooperation, in the psychological, learning disability and speech therapy field, while more meetings - systematic cooperations were also set with the children’s' school.

The case management was successful, the parents finally cooperated and were able to take care of their children, while the team’s cooperation with the local bodies helped to prevent the deterioration and the stigmatisation of the family, and of the children in particular.

Thank you to Athena Frangouli for her advice
Netherlands
Lately there is a development that groups with certain risk for health problems also can get included in health insurance. This means that people get registered as a client of a mental hospital.

*Thank you to Marion Heijmans from Mondriaan Hospital for her advice*
The KOPP program in the Netherlands aims to work towards the prevention of problems that can be developed by these children by:

- Enlarging the child’s social skills
- Supporting the competence of the parents
- Stimulation of a supporting environment
- Reducing the child’s exposure to stressing circumstances
- Making the parents and children aware of the risk and protective factors
- Intervening as early as possible

They use a multi-component approach in prevention for children of mentally ill parents.

KOPP has a range of resources available including videotapes, brochures for different age groups, audio cassette for immigrant families, information sheets about different mental disorders, a brochure for pregnant women or women with an infant.

Preventative methods used:
- Play and talk groups
- Mother toddler group (mothers and children 1-5 years)
- Support groups
- Information: brochures
- Websites
- Chatbox on line course
- E-mail service
- Early treatment

Support and preventative interventions are divided into groups:

- Children aged 6 - 8, 8 – 12 and 12 – 15 years
  Aims: Understand the parents illness, diminishing negative self-esteem, give support
  - 10 meetings and 2 meetings with parents
  - Activities are combined with discussions
  - Information about the illness, talking to friends, hospitalization etc.
  - Activities: acting, making a video, baking pancakes
• Adolescents 16 to 23 years
  Aims: Understand the parents illness, diminishing negative self-esteem, give support
  o Plus minus 8 structured meetings
  o Themes: Information about the mental illness, feeling of responsibility, feelings of guilt and shame, leaving home
  o Exchanging experiences

• Parents and children / family
  o Psycho-educational family program
  o Information for the children
  o Mother-baby programs
  o Mother toddler groups
  o Parent groups
  o Information
  o Websites
  o Telephone hotlines for families

• Home Visits
  Mentally ill patients with children (0-21 years) are offered two to three home-visits.

  A prevention specialist:
  o Gives information
  o Offers emotional support to the children
  o Talks how they can deal with the parent
  o Supports the patients in the role as a parent
  o Gives brochures

• Psycho-educational family program by William Beardslee
  Goals: To increase families understanding of parental affective disorder
          To prevent depression in children

  This program offers 6 – 10 home visits which consist of a combination of meetings with parents, individual meetings with each child and a family meeting.

  Core components:
  o Focus on increased understanding within the family
  o Focus on individual life experience
  o Construction of a history
  o Development of shared understanding of the illness of the parent
  o Helping parents to understand and address the impact of depression on their children

• Parents Course
  Aims: Supporting the parent in raising the children
  6 meetings with themes of:
  o What and how do you tell the children about mental illness
  o What is important in the child development
  o Role of family and friends in taking care of the children
  o Exchanging experiences
• Mother-baby intervention
  Depressed mothers and baby’s until 10 months
  Aim: Reinforcing positive interaction between mother and infant and reinforcing positive development of the child
  8 – 10 home visits by a prevention worker
    o Video-feedback
    o Modelling
    o Pedagogical support
    o Changing negative ways of thinking
    o Baby-massage

• Professionals
  o Focus of children of patients
  o Case management and basic care
  o Consultation to primary H care
  o Investment in prevention
  o Training / education
  o Routines / screening
  o Training in interventions
  o Websites
  o Conferences

• Training ‘talking to the children’ – for adult mental workers
  4 meetings offering information, role play, discussions, and materials

• Intervention Network
  o Additional support workers
  o Family / consumers organization
  o School mental health education
  o Mass media approach

Process of supporting the children and family - implemented as home visits

Registration of the
A special KOPP team
Information for the children (3 home visits) or the psycho-educational family program
After the home visits there are several possibilities for the parents and the children

Submitted publication for AeJAMH November edition.


Thank you to Karin van Doesum for her advice
In the Netherlands the majority of the hospitals have a system for children who live and sometimes care for a parent with a mental illness. They know there is a bigger risk for them to resolve problems (of all kinds).

All are prevention interventions with the targets:

- Prevent development or health problems within children who grow up with a mentally ill or addicted parent. (drug/alcohol abuse);
- Decrease seriousness of problems;
- Perceive problems and start help and support as early as possible.

**Training Groups:**
They have training groups for:

4 to 8 years
This is 15 times (11/2 hour) and conducted in local areas, with the aim of social building. They use the ‘Mouse’ technique (a puppet who talks with the children) where they talk about emotions, stress and excitement at home. Parents must attend 5 times.

Initially the Social Worker goes to the home to discuss the program and listen to problems parents’ experience. They try to find solutions. (support, healthcare, housing, financial etc)

8 to 12 years / 12 – 16 years
An education package which is for 8 times (11/2 hours). In these sessions they talk about different things happening with their father or mother and how they are coping. Issues discussed include:

- What is going on with your parent and what do you notice?
- How do you cope with it? (worries, run, hide, scared, angry, sad, adapt, loneliness, shame etc.)
- How to change coping strategies that can damage you in the long term? (talk with somebody you trust, ask questions and get information, make friends and have fun, distraction, seek for help if needed, be aware you are not the only one)
- Skills to make friends, to talk, how to relax etc.

Parents attend one or two times and learn:

- Give your child an explanation of what is going on with you. Do not hide it.
- Tell them it is not their fault, you seek for help. (it is not their responsibility to make you feel better or to take care of you. They may help but not all the time)
- Quality time, attention and positive stimulation of your child
- Seek for help and support to give your child what it needs to grow if you are not always capable for it. (social network or regular institutes)
- Do not feel ashamed, guilty or sad about that. You do whatever you can.
- Emergency plan to protect your child when symptoms get bad.
16 to 25 years
Also 8 times we talk about the same subjects as mentioned but also a lot about how they can make themselves loose of their sick parent and start their own life. Often it is very difficult for them. They feel responsible.

On-line and Anonymous Chat Room
Also available online in closed and anonymous chat rooms lead by us. (www.kopopstoring.nl)

Parent Groups Face to face meetings with parents who cope with mental problems or addiction. 8 times 1 ½ hour) Subject:
- Guilt feelings about you’re sickness towards your child and parenting
- Worries about heredity
- Talk with your children about you’re sickness: how, what and when
- Social network; help and support in your own network
- Parent skills: structure, ruling, support, quality time etc.
- Emergency plan to protect your children when things get seriously bad (illness/addiction)

Mothers/fathers – Baby
They have a course for mothers who have mental problems or addictions and this is conducted in groups. The course is for mothers and fathers, and runs for 8 sessions. Discussions are in a positive context about their doubts, insecurities and what can be done. They also discuss the importance of the first 2 years of a child’s life is. (importance of attachment of the child and how do you stimulate that).

Thank you to Marion Heijmans from Mondriaan Hospital for her advice
Mission
The Trimbos Institute seeks to enhance quality of life by engaging in the development and application of knowledge about mental health, addiction and associated physical illnesses.

The activities of the Institute are intended to contribute to and facilitate changes in mental health and addiction care in order to elicit individual health gains within the Dutch population, promote more effective treatment methods and provide models for more efficient care.

With a focus on knowledge sharing, the Trimbos Institute aims to undertake evidence-based activities which are both innovative and implementable within professional settings.

Output
Each of the 11 programs runs several projects a year. The output typically includes research reports, articles in peer-reviewed journals, new interventions and implementation strategies, policy evaluations and recommendations, monitoring reports, seminars, conferences and training programs.

Core Tasks
The Trimbos Institute is the main intermediary between policy, practice, research and the general public for mental health and addiction problems.

The core activities of the Institute include:
- monitoring and detection of psychological and addiction problems;
- informing professionals, politicians and policy-makers about the mental health of the Dutch population;
- conducting research on the organization, accessibility, quality and effectiveness of prevention, treatment and care;
- development and evaluation of new methods, protocols, guidelines and programs for prevention, treatment and organization of care;
- public relations and information with regard to psychological problems, alcohol and drugs;
- developing and conducting courses and training programs within the domains of mental health care and addiction care to help care providers improve the quality of their work;
- international networking and collaboration.

The Trimbos institute coordinates activities in the Netherlands concerning COPMI/FAPMI.

There is a platform on copmi/fopmi/fapmi programs, and these meetings are held 3 times a year at their institute. Participants are representatives of all organizations working with these families. The aim is to share knowledge, make a uniform and evidence based intervention network for these families and standardize interventions for this target group. Some of the interventions mentioned below are developed by
members of this platform combining best practices into one standardized training practice based evidence.

The standardized programs on offer in the Netherlands are:

<table>
<thead>
<tr>
<th>Program Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kipizivero information</td>
<td>Trimbos-instituut has developed a series of information leaflets for parents with mental illness about raising children. The series has several issues/versions: pregnancy, baby, toddler, primary school child, teenagers. The information books are for parents &amp; family, for children explaining what is happening in their family, for professionals. The series has been translated in German.</td>
</tr>
<tr>
<td>Kopstoring</td>
<td>Online information for children, chat box session with professional, forum to share experiences with other children.</td>
</tr>
<tr>
<td>COPMI-teenager group</td>
<td>Course for teenagers with parents with mental illness of addiction problem. The training offers the children a possibility to talk about the situation in the family and offers coping skills.</td>
</tr>
<tr>
<td>COMI- children’s group</td>
<td>Course for children of parents with MI/AP.</td>
</tr>
<tr>
<td>Kopopouders.nl</td>
<td>Online parenting support for COPMI-parents to provide a better parenting environment for their children, a pilot study showed promising results. Please see <a href="http://www.kopopouders.nl">www.kopopouders.nl</a>. The site offers information, video clips, mail service for questions, forum, and an online course.</td>
</tr>
<tr>
<td>Kopopouders</td>
<td>This is the same course, but offered face to face and not online.</td>
</tr>
<tr>
<td>Moeder baby interventie (mother-baby intervention)</td>
<td>Video interaction program targeting depressed mothers of young babies to enhance sensitivity and prevention of negative effects of the depression on interaction between mother and child.</td>
</tr>
<tr>
<td>Beardslee family intervention</td>
<td>Home visits family intervention for families with a parent with depression or anxiety disorder.</td>
</tr>
<tr>
<td>Gezin aan Bod (Strengthening families)</td>
<td>A Dutch translation of the American program Strengthening families by Carol Kumpfer.</td>
</tr>
<tr>
<td>Piep zei de muis</td>
<td>Piep is a community program targeting young children 4-8 years who are living in low SES areas. The</td>
</tr>
<tr>
<td><strong>(Piep says the mouse)</strong></td>
<td>program enhances protective factors in the neighborhood and decreases risk factors, combined with training of coping skills for children and parenting &amp; coping skills for parents.</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Platform</strong></td>
<td>There is a platform on copmi/fopmi/fapmi, these meetings are held 3 times a year at our institute.</td>
</tr>
</tbody>
</table>

*Thank you to Paula Speetjens for her advice*
New Zealand
New Zealand Structure

Thank you to the Ministry of Health in New Zealand

Ministry of Health structure diagram
1.4.3 Sector structures

Figure 1.3 shows the structure of the health and disability sector in 2006 under the New Zealand Public Health and Disability Act 2000.

Figure 1.3: Structure of the New Zealand health and disability sector 2006
Networkmosaic is an initiative in the Northern Region NZ with a focus on young people with family/whanau members affected by mental health and/or addiction issues. A steering group of interested providers and agencies identified key functions of Networkmosaic as:

- Multi-sector professional networking and training.
- Web-based information and resources for workers, young people and their families that recognizes the diversity of New Zealand Cultures;
- Advocacy for mental health and addictions issues affecting families and whanau;
- Linking international research and best practice, tools and resources, and New Zealand initiatives.

The network aims to acknowledge and strengthen the wealth of professional expertise and experience which already exists within health, social services, education, justice and community development agencies. Its primary focus is to develop a training and communication network across the northern region to share resources, and connect people who encounter children whose family and whanau are affected by mental illness or addiction issues. Quarterly training forums are open to non-members at $20 per person, and topics are selected by members request.

Membership costs $30 per agency per year, to help maintain the running costs of the network, although the initiative relies greatly on reciprocity and sharing of knowledge and resources. Member agencies and contact details are listed on the website.

Network Mosaic is funded by Supporting Families in Mental Illness Auckland, a not-for-profit organisation providing support, information, education and advocacy for families and whanau supporting someone affected by mental illness.

Thank you to Emma Dore for her advice
Tu Tangata Tonu
Kari Centre

Email: SeemaW@adhb.govt.nz
Telephone: +09 623 4646 extn 28727

Tu Tangata Tonu is a Pilot Project from Jan 2008 – June 2009, to Scope, Plan, Implement, Evaluate & review supports and interventions for children of parents with a Mental Illness within ADHB.

Research shows that this group of children have higher rates of emotional, developmental and behavioural problems; with 25-50% likely to experience some form of psychological disorder compared with 10-20% of the general population (Farrell et al, 1999). They have an increased rate of psychiatric disorders based on both genetic and environmental grounds (Beardslee et al, 1996; Hammen, 1991; Weisman et al, 1997). These children are also at greater risk of having lower social, psychological and physical health than children in families not affected by parental Mental Illness (Beardslee et al, 1998; Brotman et al, 1998; Cicchetti et al, 1998; Klimes-Dougan et al, 1999; Oyserman et al, 2000). In addition, there is a higher incidence of abuse and neglect, as shown by a New Zealand study where 33% of CYFS cases had at least one parent with a mental health problem (Cruse 2005).

Policy and practice have identified the importance of development of Services for early intervention with this population, both in terms of short and long term outcomes.

Project Coordinators
The Project is Coordinated by Seema Woollaston (Social Worker, 0.5FTE), and the Project Clinical Service Coordinator is Luci Falconer (Clinical Psychologist, 0.3 FTE). Both Coordinators are based at the Kari Centre, Child & Adolescent Mental Health Service at ADHB.

NGO
The project coordinators are working collaboratively with Connect (formerly Action for Mental Health Service), a Non Government Organisation that has been contracted by ADHB (1.5 FTE) to provide support to children of parents with mental illness.

Steering Group
The Steering Group meets monthly and is responsible for the decisions made for the Project.

Interest Group
The Interest Group consists of a group of clinicians and a peer representative from Kari Centre who contribute to the planning and delivery of interventions. Practice issues within Mental Health Services are also discussed. Clinicians from other ADHB Mental Health Services are welcome to be a part of the Interest Group and are invited to contact the Project coordinator for information.
Interventions
The following diagram summarises the various levels of interventions planned within the Project:

Client Interventions  Target Population  Service Interventions

- Parent group
- Children’s group
- Adolescent group
- Psychoeducation packages/resources/information
  Phase Two  Phase Three

Kari Centre

- Clients/families
- Clinicians/keyworkers

ADHB Adult Mental Health Services

- Clients/families
- Clinicians/keyworkers

Pathway for assessment and intervention at Kari Centre

- Staff survey
- Workforce development eg staff training/liaison
- Revising Documentation to identify and include children
- Pathways of referral to appropriate Services eg. Kari Centre/NGO/CYFS

Review & Evaluations
Group interventions will be evaluated on a pre and post basis, and consent will be gained from participants to be contacted for longer-term follow-up. A proposal for ongoing Support Services for this group of families will be made at the conclusion of the Pilot Project. It is hoped that this Service will become an ongoing Service within ADHB.

Thank you to Seema Woollaston for her advice
Northern Ireland
The Young Carers Project covers 3/5 of Northern Ireland, together with their partner agency, Barnardo’s serving the other 2/5.

The service is split on a geographic basis. However, there is a degree of flexibility and choice for families living in boundary areas.

The services they provide include:

- Outings and activities on a group basis, or if there is a need, on a 1 to 1 basis or small groups;
- Activities two times per month, with the aim of improving confidence, such as abseiling and canoeing. These activities give the opportunity to meet with other young carers;
- Special activities are offered such as outdoor pursuits, dance and drama and arts activities on an ongoing basis;
- Issue based group work focusing on living with a sibling who has autism or a parent with mental health issues as the need arises;
- Skill base group work, for example:
  - First Aid training
  - Cooking
  - Life Skills that help assist in their role
  The type of group work is based on what the young carers would like and request;
- Group work on particular issues, for example, for mental illness they link in with psychological services, and bring in the required expertise. At these sessions they focus on building resilience, coping skills and information on mental health;
- Intense 1 to 1 support – school problems / self protection work;
- Preparation for Independent Living.

After three months they review the current plan with the young carer and the family and amend as necessary.

**Transition into the adult system**

When a young carer turns 16 they begin transition work to advise and ease into the adult system in readiness for when they turn 18.

- They assist with CV preparation;
- Interview skills;
- Training placement – Working out schedules;
- Help place into appropriate workforce/study.

**Transport**

As some young carers are unable to have transport they provide transport as required and cover the costs for this.
Hidden Carers
To find young carers who are unaware of the support systems available, they:

- Conduct awareness raising amongst professionals to encourage them to think about the whole of family, not just the client. To ask the question do they have children, and do the children undertake a caring role.
- Awareness raising in schools. It is planned to distribute to all schools large posters on the services available. The poster includes a 5 digit text number enabling the young person to discretely (if they wish) text when they are able to, and then Action for Children can contact them. Young carers have advised that posters are more preferable than leaflets, as some young carers like to remain anonymous and never pick up leaflets.
- Posters in libraries, pharmacies, community centre and other public areas.

Thank you to Paul McConville and Julia McKeown for their advice

© Artist Pauline Miles
Scotland
National Lead Policy Maker
Health and Wellbeing Dept & Education and Lifelong Learning Dept. – Scottish Government

Regional NHS Boards
Have a role in determining strategic delivery of national priorities and keeping the overview of locally commissioned health services

Locally
Mental Health Divisions, Community Health & Care Partnerships which involve all local partners including health and local authorities through social work and education departments. They provide services directly to young carers, through assessments, information and advice, some through services to support children and young people, breaks from caring etc. Some of these organisations also contract out support to the voluntary sector. Each area has strategic duties for commissioning and delivering services in its own area.

The voluntary sector provides a lot of support to carers which are very diverse. They are national organisations with local branches and local organisations.

Thank you to Fiona Collie for her advice
The Young Carers Project in Dundee has been successfully working with young people since 1999.

They are currently funded by The Fairer Scotland Fund, Comic Relief, Dundee Community Regeneration Fund and the Henry Smith Charity,

Referrals come from professionals, parents / carers and young carers themselves.

The referral will be allocated to a Keyworker which will include a house visit to discuss their needs with the young carer.

Targeting hidden Carers
Targeting hidden Young carers is primarily achieved through awareness raising throughout the community and especially through schools work. They have produced:

- Schools pack and gave a free copy to every school in Dundee. A copy of this pack can be downloaded from the above website;
- PowerPoint presentation for trainee teachers.

They also generate publicity in the local press making people more aware of who and what young carers are.

This service offers:

Young Carers

- One to one support aims to work with the young carers to achieve the goals that they identify with the Keyworker;
- Group work and family support to help them cope with the challenges they face as young carers, for example, attendance at school, low confidence and low self esteem and difficulty in building relationships with peers;
- Group work – A weekly group for young carers is run and a monthly drop in / group session for those at secondary school. The groups aim to assist young carers in working towards achieving their desired goals;
- Once a month a Young Carers Forum is held giving young carers a voice, and the chance to talk about their experiences and gives them the chance to get involved in planning events and making things happen.

UPBeat
This service supports young carers aged between 16 and 21 to enable them to access employment, education or training. UPBeat supports them in personal development, entitlement to benefits, CV / interview skills, Youth Achievement Awards and building their confidence and self esteem.

They hold residential camps where young carers can gain experience in teamwork, peer interaction, healthy eating, routine setting and new experiences, cooling sessions, relaxation and pampering sessions.
They have also developed a plan to support young carers as they move from primary to secondary schools. One of the recommendations to schools is that they introduce new young carers to young carer’s link or named person in secondary school.

**Family Support Work**
Families are offered this service that would benefit from the extra support of providing information and advocacy.

**Community**
Awareness raising workshops are held throughout the local community in other agencies, at local community fairs and other events.

**Schools**
- The Education Resource Pack was published and disseminated to all primary and secondary schools in Dundee.
- School Workshops – Workshops are done in schools in Dundee raising awareness with students on young carer’s issues and the support available.
- They have developed a resource for working with young carers in schools.

**Professional Training**
Deliver professional training including social work staff and student nurses. The training is offered at no cost.

Dundee Young Carers work in partnership with Siblings Group and Barnardo’s Family Support Team and Dazfest, a music event which the organisation and other voluntary organisations delivered in the city.

**Staffing**
They have:
- Development Workers,
- 3 Youthworkers
- 1 Family Support Worker
- 1 Information Officer

They used to have one staff member responsible for working with all the schools, but have now allocated each cluster of schools across Dundee to a specific worker. They have found this works a lot better with the personal contact that individual workers can build up in schools with the right people.

They are also a part of the wider Dundee Carers Centre, and because of this they have in-house access to Welfare Benefits advice, an adult outreach team and various other services.

*Thank you to Tim Mineard for his advice*
Edinburgh Young Carers Project is a registered charity in Scotland.

It was established in 1994 as a community development project in North East Edinburgh and expanded in 1996 to provide support to young carers from across Edinburgh. It is managed by a voluntary Board of Directors and employs a Head of Service, five members of staff and sessional workers.

The support that Edinburgh Young Carers Projects offers the young carers, includes:

- **Individual Support** – One to one time with a worker;
- **Limited service**, with priority given to young people whose needs are not met fully within group work. This is also offered as a one to one support;
- **Young Carer Groups** – Organised activities, discussions, support and a chance to meet other young carers and have fun;
- **Residential and Day Trips** – Time out from home. A chance to try new things and have fun. The trip can be for a week, weekend one day and open days for young carers;
- **Information and Support** – The aim is to support young carers and their family members, including the person being cared for, to find local services that will meet their specific needs;
- **Young Carer’s forum** – An opportunity for young carers to have their say and take action on what matters to them. For your carers aged 12 years and over who wish to speak for and on behalf of other young carers. Speaking up for the rights of young carers and having a say in the running of the project, including interviewing staff who work for the project;
- **Awareness Raising** – Campaigning on behalf of young carers locally and nationally. Through networking and partnership with other organisations, staff from Edinburgh Young Carers aim to highlight young carers issues and inform other professionals in order to help identify ‘hidden’ young carers.

*Thank you to Audrey Peacocke for her advice*
Mellow Parenting is a 14 week one day a week group designed to support families with relationship problems with their children under 5. Separate programs have also been developed for infants, toddlers, fathers and grandparents.

Mellow Parenting has been shown to be effective in engaging hard to reach families with children under five, and in helping them make changes in their relationships with their children.

An evaluation by the Department of Health (UK) has shown that, compared with other parenting programs run in family centres, the program improves:

- Mother child interaction;
- Child behavior problems;
- Mothers’ well being;
- Mothers’ effectiveness and confidence in parenting;
- Children’s language and non verbal abilities.

As well as the core Mellow Parenting Program for under fives, programs based on the same principles have been developed for babies, fathers, kinship carers, couples and a model has also been trialed for fathers in prison. A parallel therapeutic program is also in development for children in groups as is an activity pack for parents and children.

Mellow Parenting and its related programs combine personal support for parents with personal video and direct work.

Components of Mellow Parenting

- Emphasis on parental engagement and empowerment;
- Personal group for parents while children are supported in children’s group;
- Shared lunch time for children, parents and staff;
- Lap games and songs to promote mutual enjoyment;
- Individual analysis of video tape of family mealtime;
- Activities and outings to practice new skills and build a repertoire of skills;
- Structured parenting workshop;
- Have a Go ‘Homework’ to reinforce new skills;
- Built in objective and subjective measures of change;
- A specialized version of Mellow Parenting has been developed for parents and vulnerable babies under a year;
- A special Dad’s Program;
- Groups for couples attending together.
Mellow Babies:
A specialised version of Mellow Parenting, based on the core principles, has been developed for parents and vulnerable babies under a year. The program addresses both adult mental health (post natal depression) and child protection.

The Mellow Babies program has undergone a randomized waiting-list controlled trial with clinically and statistically significant effects on maternal depression and mother-child interaction, and a reduction in the need for Child Protection Registration and compulsory measures of care.

The program has a one day additional training and separate manual. The program incorporates modules for adult mental health, child care skills, child protection and activities suitable for parents and babies. The program has been applied in a number of settings to include mothers with post natal depression and families with child protection concerns.

Research and development into a new Mellow Antenatal Program is also currently underway.

Kinship Carers
Groups often include grandparents or other kinship carers who are caring for children because of the incapacity or absence of their parents. However, a specialist program has been run specifically for grandmothers. This is understandably a complex intervention, in which carers have to reflect on their parenting, and face the failure of their child to tackle the tasks of being a parent, as well as the current issues of caring for a grandchild at a stage at which they expected to enjoy retirement.

Training of Practitioners
Frequent three day courses are run to train practitioners in the core Mellow Parenting Program who can come from a variety of child care and child mental health backgrounds. Support and supervision is offered to all those who have trained and are running their own groups either on-line, face to face, Skype and telephone. Regular Practitioner Days are held to update practice and offer networking opportunities.

Translations
The program is used widely throughout the UK, Iceland, Russia, Germany, Sweden and New Zealand. The Manuals have been translated into Icelandic, Russian and German, and will be translated into Bengalese, Swedish and Spanish in the near future.

Thank you to Rosemary Mackenzie for her advice

Charity Number SC037384
Orkney is an island community situated on the north of Scotland with a population of around 20,000. The majority of the population lives on the mainland with the remainder living in numerous small islands that surround the mainland. A sense of community is important in Orkney and many locals have more than one role in the community (paid and voluntary).

The main issue facing Young Carers in Orkney is greatly reduced social time with peers. Many are not able to socialize out of school because of caring commitments and family constraints and they can also be embarrassed to have friends around due to the situation at home. The lack of access to transport in many of the rural and fairly isolated communities also adds to this difficulty. To try and overcome this, transport is provided to enable them to attend.

Developing peer group support is at the heart of our Service which offers:

- Confidential support advice and a listening ear to young carers and their families.
- Free monthly activity sessions for young carers to meet, relax and have fun. Transport is provided as otherwise many could not attend and unfortunately this is the main cost of running the project. There are 2 each month, one for juniors and one for seniors.
  - Juniors – activities such as arts and crafts, swimming, cinema, dance, story time and treasure hunt at the local library, visit the museum etc.
  - Seniors – meeting at a local centre to play pool, table hockey and football, ping pong & also more specific activities such as archery, climbing, BBQs at the beach.
- One to one support for young carers who either need additional support or do not feel comfortable in a group situation.
- Referrals to more specialised support with a counsellor if needs be.

Our Service has just been awarded funding which allows us to go into schools to do workshops with each class in each school in an attempt to identify the great number of hidden Young Carers that are in Orkney. There are currently 29 Young Carers aged 6 to 17 registered with the Service but it is suspected that there are many more Young Carers in Orkney.

Scottish Young Carers Festival

Funding was received enabling a group of senior young carers to attend the annual Scottish Young Carers Festival. This event brings Young Carers from all over Scotland together to have a break from caring, to have fun, to try new activities, to make new friends and on a serious note to meet with Politicians and decision makers to discuss Young Carer issues.

The Service is currently working with Young Carers to set up their own website and they have attended a web design course to enable them to do this.

Thank you to Celia MacInnes for her advice
Slovenia has a population of 2 million people, and about 190 psychiatrists who work in 6 psychiatric hospitals or private practices, 130 clinical psychologists and 11 NGOs, which are the carriers of community care for people with mental health problems.

**Books**

Ozara Slovenia has published three books for children and adolescents of parents with mental illness. The books are intended to make the target group more familiar with the problems of mental health problems.

The books are titled:

- Daddy is never tired! (4-6 years);
- Daddy with wings (6-9 years);
- Story about Ms Squirrel and other animals in Mum's head (9-12 years);
- The last of this series, Downpur of Tears for 12 – 14 years is being published this year.

700 copies of these books were printed and distributed free of charge to Slovenian pedo- psychiatrists, clinical psychologists, psychotherapists and school libraries.

The purpose of the distribution of books is to help a child to understand their parent's health problems, which their parents or their friends' parents are facing. It helps a child to understand the behaviour of a person with mental health problems. It also helps to lessen the stigma, to improve social inclusion of people with mental health problems and contributes to better interpersonal relationships within a family.

All the books are the result of the Belgian KOPP project, and is a product of the cooperation between the Similes organisation and the Clavis publishing house.

**Comic**

Ozara has also produced a comic about depression, in cooperation with the best known Slovene children magazine "Ciciban", entitled "My mum is depressive". This comic is meant for children from 4 to 7 years.

This year they plan to prepare a comic about a father with schizophrenia and later a comic about suicide.

**Magazine for Parents**

In the appendix of the "Magazine for parents" we published directives for parents how to speak with their children about mental health problems.
Leaflets
Shortly, they will, in cooperation with the Chamber of Slovenian clinical psychologists, publish a leaflet about mental health problems for the youngest, which will be the first of its kind in Slovenia. It will contain short and appropriate information what is going on with their parents who are having mental health problems.

Puppet Theatre
They are also planning a puppet theatre on the basis of the Daddy is never tired! Book to present to children across Slovenia. This tells the story of a little rabbit, whose father-rabbit is suffering from bipolar affective disorder. Daddy's problems are manifested in working-fever, which is exchanged with depression and desinrest for work. In such circumstances the little rabbit can hardly understand the world, because daddy is often aggressive to mummy. In the family the relationships are confused, which start to get organised when mummy decides to get help. While daddy crawls into a hole, a doctor brings him a ladder – symbolic for help and new hope for the rabbit family.

Thank you to Bogdan Dobnik for his advice
SWAZILAND
Denise Mortlock, Projects Manager from the Claypotts Trust in Swaziland, runs the only support group in that country for people with mental illnesses as well as providing information as and where she is able to their families / caregivers. As well as this role Denise provides advocacy in mental health.

In this small country with the highest rate of HIV infection in the world, mental health issues are really not receiving the attention they deserve and yet given the massive numbers of HIV positive people suffering from depression as a result of their diagnosis, this should not be the case.

In cases where she sees children of mentally ill parents needing support, her sons speak to them and encourage them and mainly give them some hope. Along with this, she educates the children – in an age appropriate manner – on the illness as most of these could be genetic and they need to know as much about the illness in case they themselves need help in the future.

Thank you to Denise Mortlock for her advice

Defeat mental illness and its stigma through information-sharing, support and the encouragement of other sufferers, their caregivers and friends.
Switzerland
Verena Dyczmons has started a group of six people who meet once a month who have the same problems. They meet in the rooms of VASK Zürich. Verena was affected as a child, with a parent with schizophrenia.

As a child she felt torn between the strange family life and the ‘normal’ world outside. The question of where to belong is very often difficult, especially if the family is not talking about what is going on. The gap between friends is always there, because they do not understand the situation.

Verena feels that is it very important to have a fixed support group, which is part of the healing process in order to feel understood and belonging to somebody.

A self help group can also be a great support in developing a healthy attitude to feel less responsible for the parent and less guilty at all.

It is best if the group is led by someone who is in the situation, that than a professional. This would suit only the adult children. Her group, due to lack of support that was given to them as a child, has been in therapy for many years and are all struggling with life.

Verena reports that it is very important to reach the children when they are young.

It is very important to for the social and psychiatric services work together in order to build a network supporting the children and the whole family staying together at home.

Verena also feels that it is very important to reach children in schools and clinics, as most parents, especially those with schizophrenia, try to hide the problems, so the programs do not reach children, unless parents are willing.

Thank you to Verena Dyczmons for her advice
United States of America
The vision of the American Association of Caregiving Youth (AACY) is to be the national resource for the support of youth who are both students and caregivers within their families so they restore a bit of childhood and achieve success in school and in life.

AACY strives to address the needs of pre-teens, teens, families, and professionals through education and awareness, research, and direct services in cooperation with social, education, healthcare, government, and community corporations, organizations, and agencies. AACY seeks to utilize existing resources on a local, regional, and national level to effectively promote the valuable role a caregiving youth has within the family, in an aging society and in our health delivery system.

The AACY mission is threefold: 1) to increase awareness about youth caregiving and foster the replication of the Caregiving Youth Project model within Florida and the US; 2) to provide direct and indirect support services for youth caregivers and their families; and, 3) to establish the Institute on Youth Caregiving.

The AACY objectives are for youth caregivers to be emotionally and physically healthy, receive the education they deserve, and be respected and recognized for the skills they are learning and the contributions they are making for themselves, their families and for society. In order to maximize their experience both the public and professionals need to understand their issues and needs, including when appropriate, government policy changes.

AACY provides the following:

- **Education and Awareness**
  - Supports student-caregivers through teacher awareness and knowledge, school support services, and other cause-related professionals, religious leaders, and organizations;
  - Increases community, professional, and government awareness on short and long term caregiving issues and ramifications on dual role youth;
  - Works to qualify young caregiving hours at home for student community service hours;
  - Promotes public awareness through the pursuit of education, multimedia and fundraising initiatives; and
  - Develops literature.

- **Research**
  - Verifies validity of student self-reported data;
  - Expands existing data to understand the household tasks, responsibilities and decisions of students who are caregivers by frequency, difficulty, duration, and amount of stress encountered;
  - Determines the most effective ways to assist student-caregivers in recognizing their dual role of student and caregiver;
• Assesses and identifies the emotional, physical, psychological, spiritual and financial stressors faced by students in their caregiving role; and
• Gathers information from youth about their perceptions of student-caregiving responsibilities.

• Direct Services
  • Continues the Caregiving Youth Project in Palm Beach County
    - In school
    - At home
    - Out of school;
  • Provides a secure website for student-caregivers to utilize as an interactive resource for education, support and communication;
  • Develops additional services to assist families in supporting their children in their dual role;
  • Partners with social, healthcare and community agencies to form a network of wraparound services for caregiving families; and
  • Creates individual needs-driven focused solutions of support.

Thank you to Connie Siskowski for her advice
The Institute for Community Living, Inc
Emerson/Davis Family Centre

Web: www.iclinc.net
Email spappas@iclinc.net
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The Institute for Community Living is a not for profit organisation that began in 1986 by assuming sponsorship of a 150 bed residential program serving people with serious mental illness in Brooklyn.

ICL’s Child and Family Services Division operates over 100 residential supported housing units for families. Family Supported Housing helps parents with a mental illness to keep their families intact and to parent their children. Parents receive assistance to recognize their children’s development progress, identify their current needs, and improve their parenting skills. Home assessments assist parents with various issues in their home environment. In all interactions, the staff help parents build the confidence they will need in order to maintain living independently in their community.

ICL’s Family Housing includes their flagship program, Emerson Davis Family Center, a four-story apartment building located in the historic Clinton Hill section of Brooklyn, as well as scattered site supported housing apartments in the community.

To qualify for admission, the parent must have a mental illness and a history of homelessness, and may also have a history of substance abuse and for a limited number of beds there is an additional admission criteria of being HIV+. They must be stable and drug free. Applicants pass through a two-stage interview process to make sure they understand the program, and that it is a right fit. The individual must have custody (or be in the process of getting custody.) For Emerson Davis specifically there is a limit of two children twelve years old or younger due to space constraints. These limits do not apply to the scattered site apartments.

The Emerson Davis building consists of 16 two-bedroom apartments for single-parent families, and 22 one-bedroom apartments for single adults working on regaining custody of a child or children, and is conveniently located near stores, buses and subways. The front door is staffed around the clock, making the building secure and providing support for residents 24 hours a day. There are several public spaces including a lounge, community room, laundry room and childcare facilities. Desktop computers and a library of software are available to all residents.

Program fees are determined by level of income.

ICL staff offices are on site. An important feature of Emerson Davis is the sense of community shared by its residents. Neighbors may socialize or may help one another
with childcare and other needs. Parents are encouraged to attend weekly resident-led community meetings where common concerns can be addressed.

Other groups which are led by staff include parenting and substance abuse. Occasional field trips, performances, and special events are open to all residents.

On admission, residents develop a written service plan, which states the parent’s goals in areas such as parenting, education, vocational skills and daily living skills. This plan is reviewed and updated periodically. It also includes the goal to move into more independent housing usually in about 18 – 24 months. It does not provide permanent housing, but readies its clients for more independent living, either the family supported housing program or independent living.

Each resident has a case manager working with them.

The residence is staffed 24 hours a day by trained workers. Staff includes a clinical coordinator, front desk workers, an entitlements counsellor ensuring that all residents obtain all benefits to which they are entitled, therapist, tutor and child care workers.

Emerson Davis offers many resources for parenting and child development. The staff help parents recognize the children’s progress, identify current needs and meet those needs as well as maintain their own wellness. Staff also provides assistance to parents in obtaining community-based services, such as daycare and schooling. Staff help parents build the confidence they will need to function well as parents once they progress to more independent living.

Thank you to Stella Pappas for her advice

© Artist Pauline Miles
HOPWA is a supported housing program providing a quality apartment and services including home visits, group activities, outings, education, case management, and support. The program has a capacity of 15 single women and 15 mothers with children.

To qualify, the individual must be HIV/AIDS and suffer from an emotional or mental disorder such as anxiety, depression or a psychotic disorder. They must be stable and drug free. Up to two children, aged 16 or less can be accommodated per household.

The program helps parents to recognize their child’s development progress, identify their current needs, and improve their parenting skills. Home assessments assist parents with various family issues in their home environment. Through group meetings and individual contacts, parents receive counseling, support, and guidance. Staff also provide assistance to parents in obtaining community based services, such as daycare and schooling.

Thank you to Stella Pappas for her advice
This new innovative program by mothers aims to give each resident a source of support she can more readily trust – another woman who has gone through similar struggles. The Peer Advocates in the program are women and mothers like Ligia who have received services from ICL Emerson and are now, with continued support, living independently in the community in scattered site apartments.

The program could play a critical role in helping women engage more effectively in the services ICL Emerson provides, which help single parents with mental illness reunite with their children.

The program will empower both the Peer Advocates and the women they support. This potential for mutual growth is what makes peer advocacy invaluable.

Thank you to Stella Pappas for her advice
The Invisible Children’s Project (ICP) works to empower parents to meet their children’s needs and to improve the overall health of their family, thus preventing child neglect, abuse, infant mortality, childhood injuries, future mental illness and striving to maintain the family unit intact.

ICP is located in:

- MHA of Charlottesville-Albemarle, Charlottesville, Virginia;
- MHA of Columbia-Greene Counties, Hudson, New York;
- MHA of Greater Knoxville, Knoxville, Tennessee;
- MHA in Passaic County, Clifton, New Jersey;
- MHA of the Southern Tier, Binghamton, New York;
- MHA of Dutchess County, New York;
- MHA in Passaic County, Clifton, New Jersey;
- MHA of Sacramento, California;
- MHA of Southeastern PA;
- MHA of Texas.

ICP works with the whole of the family concept. Case Managers are available 24 hours a day, 7 days a week for families. Contact in the home is a minimum of two times a month, normally weekly.

There is no time limit for families attending ICP. The program can service up to 18 families at a time.

**Services offered**

- For Parents
  - Respite child care;
  - Planning for parental hospitalization;
  - Support Groups;
  - Vocational and educational training;
  - Medication counseling and management;
  - Legal and other advocacy;
  - Parenting education;
  - Budgeting and Financial planning (provide referral to budgeting and financial planning programs as needed);
  - Transportation to appointments if needed;
  - Assistance with scheduling medical appointments, accompanying clients to appointments if desired, maintain contact and facilitate communication with psychiatrist if desired.
• For children
  o Advocacy on behalf of the child;
  o Supported education services;
  o Art therapy;
  o Horseback riding/animal assisted therapy;
  o Support groups;
  o Visiting hospitalized parents;
  o Homework assistance provided by respite workers.

• Family
  o Affordable housing;
  o Family case management;
  o Family unification / reunification;
  o Social family gatherings and trips;
  o Referral and linkages to community resources;
  o 24 hour emergency services;
  o Crisis financial assistance.

Education Services offered

• Wellness Recovery
  This program is available to participants of the ICP as well as non participants. It is a 5 weeks group that focuses on recovery from a mental illness. It is a self sufficiency program that incorporates consumer commitment as its basis for outcomes. The program is facilitated by a mental health professional. Sessions include:
  o Daily maintenance list;
  o Triggers;
  o Early Warning Signs;
  o What to do when things are breaking down;
  o Crisis planning.

• Parenting Skills for person with mental health concerns
  A 12 week group that focuses on increasing the client’s understanding of mental illness and its effects on parenting. Its focus is to improve the nurturing and bonding qualities of parenting. It also assists parents with recognizing behaviors in children that may be more than typical misbehaviors.

• Freedom, Self-Advocacy
  An 8 week group that teaches participants how to be a better self-advocate in their communities, for example, parent / teacher interview, having effective and successful doctor appointments etc). Its focus is to improve self sufficiency.

Other courses include:

• Sexual trauma support group;
• Self care group;
• Baby and Parent Play Time.
Goals of the program are
- Provide comprehensive, strengths-based long-term, and family-centered treatment;
- Combine “best-practices” in services, advocacy, consumer involvement, and cross-systems collaboration.

Program Values
- Treat the family as a whole;
- Pay attention to ‘ Invisible children,’ intervening early in families to prevent negative outcomes for at-risk kids.

Joining ICP process

To be selected families must meet criteria for serious and persistent mental illness.

ICP staff meet with perspective clients in their homes to determine need and interest

Families are referred to ICP staff via Single Point of Accountability

Referrals
Referrals are received by Department of Social Services, mental health system, homeless shelters, schools, Family Court Judges

Evaluation
A positive evaluation has been achieved through the New York Psychiatric Institute; MHA in Orange County, Inc. University of Massachusetts

Thank you to Nadia Allen, Executive Director, MHA in Orange County for her advice.
This program supports children of parents with a mental illness. The program has been replicated by agencies in the United States by programs serving children with parents with a mental illness where the child does or does not have a special need.

Mary Jo Alimena-Caruso received the National Award for Innovative Service Design for the CareBreak respite program in September 2009.

The Watson Institute, through its family of schools and services, helps children and youth with special needs to achieve their fullest potential in all aspects of their lives. Watson strives to provide programs that service the needs of individuals.

The Watson Institute provides respite that utilizes a volunteer/mentor respite model called CareBreak. Mary Jo Alimena Caruso, Coordinator of the CareBreak program since 1998 developed a volunteer/mentor respite model based on a foundation of values drawn from the concepts of Citizen Advocacy and Social Role Valorization. The CareBreak volunteer/mentor model is utilized to provide once weekly respite visits for 4 hours. The CareBreak respite volunteer is recruited and carefully screened and trained by CareBreak staff where they are then matched with a family caring for a child with a disability. The CareBreak respite typically takes place in the family’s home and community by the volunteer mentor who is asked to make a six month commitment.

The CareBreak Philosophy: CareBreak seeks to created relationships by reconnecting individuals with disabilities and their families who have become isolated from the ordinary community. CareBreak’s practice of matching a volunteer or mentor to a person with a disability is based on Citizen Advocacy’s premise that devaluation of a person or group by society has profoundly negative effects on their lives. By introducing a volunteer mentor, CareBreak seeks to challenge this devaluation by connecting a ‘devalued’ person with a ‘valued’ person, prompting the community into valuing the ‘devalued’ person. Volunteers and individuals are brought together by a careful process of matching that includes similarities, strengths and community as opposed to time on a waiting list or other impersonal factors. Just as a Citizen Advocate is asked to represent the rights and interests of another person as if they were one’s own, CareBreak volunteers are asked to build a relationship with the individual based on mutual interests and capacities, not just need and time availability. This process benefits not just to the devalued person, but to the valued person, the group of people that this devalued person has been seen to belong to, and the community as a whole. As a result, CareBreak volunteers provide much more than the gift of time. They provide a meaningful connection and greater access to the community. In return, the CareBreak volunteer’s life is also enhanced through the satisfaction of time well spent and a mutually beneficial relationship.
CareBreak’s Mission and Vision: CareBreak’s mission is to offer a family-centered service that provides quality respite time for parents or primary caregivers and children with disabilities through meaningful experiences offered on a one on one, consistent, continuing basis in the child’s home and community. CareBreak’s vision is to promote interdependence and self-esteem for children with disabilities through creative and caring opportunities introduced by a volunteer mentor. As a result of the CareBreak, the child thrives, the parents get a much needed respite, the volunteer feels the satisfaction of making the difference in the lives of a family and the community as a whole benefits and grows stronger.

CareBreak’s guiding Principles: CareBreak provides the opportunity for individuals with disabilities to obtain socially valued roles. Social Role Valorization or SRV is the name given to a concept for transacting human relationships and human service, formulated by Wolf Wolfensberger, PhD. His definition of SRV is: “The application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people”. The major goal of SRV is to create or support socially valued roles for people in their society, because if a person holds valued social roles, that person is highly likely to receive from society those good things in life that are available to that society, and that can be conveyed by it, or at least the opportunities for obtaining these. In other words, all sorts of good things that other people are able to convey are almost automatically apt to be accorded to a person who holds societally valued roles, at least within the resources and norms of his/her society. CareBreak volunteer mentors are not typically human service professionals. They are bankers, realtors, engineers, teachers and other professions. What they have in common is their socially valued roles and their desire to form a relationship with a person with a disability and provide respite to family caregivers through their gift of time. The CareBreak provides unlimited opportunities for individuals with disabilities to experience and obtain socially valued roles.

The CareBreak program works with the following principles:

- Individuals caring for family members with disabilities need a break in order to regroup, refocus and reenergize
- Individuals with disabilities need a break from their family caregivers
- That respite break should be meaningful and valuing to the individuals with no “strings” attached (i.e. caregivers should not be required to attend groups or classes during the respite, individuals with disabilities should not be required to engage in therapy or services as a break)
- The respite should be developmentally and socially appropriate and provided in as valued a manner as possible:
  - For young children 0-6 years: respite is best provided in the family home or immediate community where they feel safe, secure and can develop an enjoyment of their nuclear family unit and resources. Respite providers take on the role of extended family or trusted companion.
  - For children 7-13 years respite is in the home or community and can involve activities that expose the child to new things or introduce the child to new people while overall increasing visibility and connections to the community. Respite providers take on the role of extended family, trusted companion, mentor or friend.
  - For teens to adults, respite is provided in the home or community with more emphasis on community and looking at what is developmentally appropriate for an individual of that age and what supports are needed to achieve the activity. Respite providers take on the role of mentor. They
are someone who can closely identify with the individual and provide a valued role in their life which lends to an increase in the potential of valued roles for the individual with a disability. These mentors are also more developmentally appropriate and culturally acceptable within the social settings in which they may participate.

- The respite should be as person centered and individualized as possible
  - Ideally, getting to know the person with a disability, their interests, passions, gifts and support needs and finding a community activity that would match would give the person an enjoyable time and the caregiver a break.
  - Knowing that a naturally occurring community activity is not always available, the next step would be to identify people and places to provide respite services that would be guided by the premise of providing a “meaningful day”.
  - The idea of a meaningful day is guided by the principles of Social Role Valorization. SRV does not in itself propose a ‘goal’. However a CareBreak volunteer mentor who consciously or unconsciously has a goal of improving the life of an individual who is devalued may choose to use insights gained from SRV to cause change.

Providing Awareness and Leadership: The CareBreak Program, by nature of its intimate design is not able to serve all families and may not be a “fit” for families who are not comfortable with having services offered in their home and immediate community. In addition to offering the CareBreak model, MaryJo Alimena Caruso works to insure the respite needs of individuals across age and disability are effectively understood and met with appropriate resources. She presides over a regional respite alliance that collaborates to address funding and access to services and chairs a statewide respite coalition that seeks to strengthen the infrastructure of respite resources across the Commonwealth of Pennsylvania. These two resources provide family caregivers with other options for respite care other than CareBreak, such as voucher system based on available funds obtained through fundraising that provides vouchers to families to purchase care. The care can be provided by agencies that are formal human services or intentional communities where individuals needing respite can go and stay for a few days or a bit longer living with people and without disabilities. The vouchers can also be used for paying an extended family member or neighbor chosen by the immediate family as they tend to know the individual well and can provide respite with the least disruption and the greatest safety / sense of security for the family.

Benefits of the CareBreak: Through a foundation of values and a careful matching process, CareBreak is able to make connections that are meaningful to the individual with a disability as well as the family member. The mentoring model lends itself to community building and inclusion as the CareBreak volunteer mentors and person with a disability enjoy outings where the individual can become known, understood and supported. The careful screening, training and matching process utilized by CareBreak results in a high retention level and matches that far exceed the expected six month commitment. On average University student mentor / respite providers continue their match for three years. Adult volunteer mentors over the age of 22 who provide respite average a five year length of stay with their CareBreak family.
When matching individuals Mary Jo Alimena Caruso finds that using SRV principles as a foundation and Citizen Advocacy methods as a resource, the CareBreak program is very successful if success is defined as:

- Matches that are satisfactory to the individual with a disability, family and respite provider. Satisfactory scales include safety, enjoyment and ease of use.
- Matches that involve individuals with and without disabilities experiencing socially valued roles in the home and community.
- Matches that provide a respite to the family caregiver AND individual with a disability.
- Matches that exceed the commitment that is asked of them

**Universality of the CareBreak Model:** In addition to coordinating the day to day programmatic aspects of CareBreak, Mary Jo Alimena Caruso has developed and implemented a model replication process that allows an individual or organization to learn every aspect of developing and sustaining a volunteer mentor respite program from startup to fiscal and programmatic maintenance. The Model Replication Training walks interested parties through the entire process which includes every step from startup, recruiting, screening, training and matching the volunteer mentor; referral, intake and assessment of families; and retention, quality assurance and outcome measurement. The Model Replication process also provides every form, document, piece of paperwork and quality monitoring tools utilized by CareBreak to run the program and promote the health and safety of participants. The Model Replication materials can be adapted and modified to suit agency needs or address specific populations across age and disability. The materials have been accessed by organizations around the United States who have created programs based on the CareBreak programs in their communities. In addition, the CareBreak volunteer mentor training for respite providers was the model chosen by the National Easter Seals Generations and Autism Connect curriculum designed to train volunteers interested in working with children with autism throughout the United States. These materials and the Model Replication training are available by contacting Mary Jo Alimena Caruso at The Watson Institute. For more information about Social Role Valorization or to find an SRV training in your area go to [www.socialrolevalorization.com](http://www.socialrolevalorization.com) or email John Armstrong at [jarm@socialrolevalorization.com](mailto:jarm@socialrolevalorization.com). To learn more about Citizen Advocacy go to [http://www.savannahcitizenadvocacy.org/](http://www.savannahcitizenadvocacy.org/) or contact Tom Kohler at [tomkohler@bellsouth.net](mailto:tomkohler@bellsouth.net). To better understand how these concepts can be synthesized into the work that you do, contact Dr. Guy Caruso at [guycaruso@aol.com](mailto:guycaruso@aol.com).

Thank you to Mary Jo Alimena-Caruso for her advice
The Kidshops program is for school aged children who have a sibling or parent with a mental illness. They come together and through play, team building exercises, art and discussion they learn that they are not alone. The program is free and is facilitated by young adult volunteers who themselves have a sibling or grew up with a parent who has a mental illness.

The program is held on Saturdays and the session goes from 10:00 am to 2:00 pm. Food (usually pizza) and drinks are provided.

At the meetings activities are held, for example: relaxation exercises, art projects such as “What’s Your Handle” (personalized door hangers), ME Collage (using pictures and words from magazines that describe themselves), The Graffiti Wall, games such as Knots, various forms of tag and different relay races. Many of the ideas for games come from the kids themselves.

Fact Sheets are also available, giving information on the mental illnesses, plus examples and photos of well known celebrities who also have that particular mental illness, such as bipolar, depression, eating disorders.

Each week they work on a project that gives way for discussions on feelings about the family member who has a mental illness. They share their stories, discuss the challenges and learn coping skills.

When their meeting is finished, they take home a “tool” from the ‘toolbox’, such as:

- A magnifying glass to help look for the good qualities in a person
- A Gumby to remember to be flexible

Most of the meetings are held in the Metro area. Most of the children who attend are from families who self identify. Sometimes they will find out about the program from a school social worker or therapist, but mostly they find out from NAMI communications.

*Thank you to Sue Abderholden for her advice*
The Sibling Support Project is a US-based national effort dedicated to the lifelong concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

The Sibling Support Project provides training to local service providers on how to create community based peer support programs for young siblings; hosting websites and listservs for young and adult siblings; and increasing parents’ and providers’ awareness though books, materials and workshops.

At the Sibling Support Project’s workshops, participants learn:

- What to do about the concerns often experienced by brothers and sisters: peer issues, resentment, loss, and concerns about the future;
- How to increase the unique opportunities often experienced by siblings, including compassion, advocacy, insight and tolerance;
- Strategies to decrease sibling’s concerns and increase their opportunities
- How to help your agencies provide “sibling-friendly” services;
- How to plan and run Sibshops, the award-winning, kid-friendly mix of peer support and recreation.

There are now 260 Sibshops worldwide, with 240 in the United States. Although most Sibshops are for siblings of kids with various developmental concerns, around 20 are for sibs of kids with health concerns and 5 are for siblings with mental health issues.

Sibshops provide participants with validation, support, and information – all in a lively recreational context that emphasizes wellness. The model can be easily adapted for other ‘special needs’ and to include other family members, for example, cousins and young carers. Sibshops celebrate the many contributions made by brothers and sisters of kids with special needs. They reflect a belief that brothers and sisters have much to offer one another. Sibshops are a spirited mix of new games (designed to be unique, off-beat, and appealing to a wide ability range), new friends, and discussion activities.

The Sibling Support Project’s has conducted trainings and workshops Canada, England, Ireland, Japan, Iceland, Guatemala, Italy and New Zealand. The Project’s sibling-related books include Thicker than Water: Essays by adult siblings of people with disabilities; The Sibling Slam Book; Sibshops; Views from our Shoes; and Living with a Brother or Sister with Special Needs. To learn more about the Sibling Support Project visit http://www.siblingsupport.org

Thank you to Don Meyer for his advice
Wales
National Lead Policy Maker
Welsh Assembly Government which has devolved power on health, social services, education, transport and local government. Currently seeking new powers to support carers (including protection of young carers from inappropriate caring responsibilities. There is a designated Carers Champion at cabinet level in the government.

Regional Strategic Health Authorities

Local Health Boards have a role in determining strategic delivery of national priorities and keeping the overview of locally commissioned services.

Locally

Local authorities through social service, education, housing and leisure departments. They provide services directly to carers, through assessments, information and advice, some through support groups, etc. Most of the local authorities also contract out support to the voluntary sector.

Each area has strategic duties for commissioning and delivering services in its own area.

Each local authority in Wales has an elected member designated as a Carers Champion.

The voluntary sector provides a lot of support to carers which are very diverse. They are national organisations with local branches and local organisations.

Thank you to Roz Williamson for her advice
In Cardiff, Wales, it was identified that there was a lack of coordinated response to the needs of young carers as a group, and in response to this, a task group of the Children and Young People’s Partnership involving interested parties from all relevant sectors came together to produce the Cardiff Young Carer’s Strategy.

The strategy aims to provide effective approaches to a range of issues affecting young carers in Cardiff, forming the framework to provide greater opportunity and support for young carers both as children and in their caring role.

Cardiff Council has worked in partnership with young carers and statutory and voluntary organisations to establish the joint Young Carers Strategy. A plan of action, which addresses the unmet needs of Cardiff’s Young Carers, accompanies the strategy.

The strategy aims to raise the profile of young carers throughout all agencies and organisations who have signed up to partnership, working to ensure the best possible outcomes for Cardiff’s young carers.

The strategy consists of the following sections:
Section 1 Background
Section 2 Legislation relevant to young carers
Section 3 The needs of young carers
Section 4 What is currently in place for young carers in Cardiff
Section 5 Identifying young carers, assessing and meeting their needs

Legislation relevant to young carers
In Wales there is a legal framework in relation to young carers which is extensive and complex and the local authority must act within a clearly identifiable statutory framework. The following sections summarises the main pieces of legislation that impact on young carers:

- Welsh Assembly Government and the UN Convention on the rights of the child
  The Welsh Assembly Government has formally adopted the UN Convention as providing the underpinning principles for services for children and young people. Within this context the Welsh Assembly has adopted seven key aims for all services dealing with children and young people. These include ensuring that all children have a flying start to life and the best possible basis for their future growth and development. They also cover provision of care and other services; protection from abuse; victimization and exploitation; access to play; the need to respect and listen to children and child poverty.
Relevant Legislation
The duties and powers of local authorities to assist young people with caring responsibilities are established in a number of key pieces of legislation, and further development in the Department of Health’s Guidance and Practice Guidance to the carers (recognition and Services) Act 1995. Guidance has been issued by the Social services.

- Carers (Equal Opportunities) Act 2004
- The Carers and Disabled Children Act 2000
- The Children Act 1989
- Framework for the Assessment of Children in Need and their Families
- Carers (Recognition and Services) Act 1995

This strategy seeks to address current gaps in provision by ensuring that the mechanisms are in place to identify need and to develop new services and more robust ways of working in partnership in order to ensure that the diverse needs of young carers are appropriately met.

Services Currently Available
In Cardiff the following services and information are currently available:

- Young carer’s project based in the voluntary sector with Crossroads;
- Cardiff City Youth Service run a young carers Junior and Youth Clubs on a Friday evening;
- Crossroads offer support to some young carers and their families by providing a community based respite service;
- A young carers leaflet and detailed information booklet has been published.

Issues affecting young carers on transition from Primary to Secondary School by Lesley Noaks and John Noaks, April 2009

This is a report is from research undertaken on young carers in Cardiff, the need arising to assist in clarifying how they can be supported in their roles as carers by schools and other agencies.

Recommendations
The report includes recommendations, which include the following:

- ID card;
- Transition protocols;
- Training;
- Celebration of the young carer role;
- Multi Agency approaches;
- Designated teachers in schools;
- Peer support.

The research contains Appendix of the Audit 2009, Focus Group Schedule, Young Carers Focus Group, Young Carers Questionnaire; Staff Discussion Group Questions.
Publications and Resources
Cardiff has developed two publications, one for young carers and the other for people working with young carers, including teachers. The publications were designed by young carers themselves:

- The Way It Is Young Carers Training Pack
  The pack was developed over three years and consists of workshops and activities which have been aimed at a variety of audiences, ranging from MP’s to peer buddy groups in schools. They have received an overwhelming response and have identified countless opportunities for future work with, and on behalf of young carers.

  The resource includes different types of learning methods and many activities which are interactive and discussion based. They have an involved and moving.

  This is an accessible tool for teachers, support workers, youth workers and anyone who may have contact with young carers.

- Cardiff Young Carers – The Way It Is
  This publication is an excellent resource for young carers giving advice on a range of issues, including Bullying, Looking After Yourself and Feelings and How to Deal with them. The booklet’s design is colorful, easy to read and understand and is very practical with the information it is delivering.

Thank you to Gareth Williams for his advice
Cardiff Schools and Lifelong Learning Service recognizes the crucial role for school in working to encourage young carers to identify themselves to school staff, particularly when they require additional educational support. Once young carers are identified teaching staff and all educational professionals will have a key role in working to support these children and young people.

Outcomes:

• The implementation of the Yong Carers Strategy is intended to achieve the following outcomes:
  o The improved attendance and attainment of young carers
  o Young carers have their needs assessed
  o Young carers have their assessed needs met
  o Improved awareness amongst professionals and other young people
  o Improved awareness by young carers of their entitlements

The following indicators will assist in quantifying the above outcomes:

• Attendance levels of young carers
• Attainment levels of young carers
• Number of Assessment on young carers carried out by Children’s Services
• The range and number of services available to Cardiff Young Carers
• The level of recorded unmet need
• The number of awareness raising training sessions provided to professionals
• Range of promotional/information material available for young carers

The following performance measure will ensure that they are able to monitor the effectiveness of the strategy and whether it has achieved its desired outcomes:

• % of young carers achieving % of school attendance
• % of young carers achieving a recognized qualification
• % of young carers referred to Children’s Services for assessment
• % of young carers who have been assessed by Children’s Services
• % of young carers who have been assessed and continue to receive a service from Children’s Services
• % of young carers who assessed needs could not be met
• Attendance levels of professionals at awareness raising training sessions
• Number of leaflets and information booklets sent on request to young carers
Powys in Mid Wales is a very sparsely populated area (defined as deeply rural) and most services are provided through Outreach Workers, surgeries in schools and after school clubs for young carers. They support over 260 young carers up to the age of 18 and about 1/3 support someone with a mental illness.

There are 22 High schools in Powys scattered over 2000 square miles. The three Young Carer Outreach Workers have contact with 18 and hold surgeries in a private room where young carers can visit them during breaks or free lessons. The Outreach Worker will also liaise with school staff where necessary and advocate on behalf of the young carer. However, depending on the culture of the school, some young carers may prefer school staff not to know.

They enable young adult carers to access existing facilities by working with partners to make their services more accessible and responsive to the needs of carers. Often further education and / or training will require the young carer to move away from home and this has to be managed carefully.

Most work is 1:1 mentoring, advocacy and future planning using a support plan.

They provide a trusted adult (outreach worker) to inform, guide and support that young person. This has been shown to be a significant factor in the development of resilience amongst young carers.

When they have the funds they also provide residential experiences from writer’s courses to skiing trips in the French Alps and many activities in between.

This is effective in developing self confidence and recognizing their role. For young carers who have significant difficulties they use two tools to measure:

a. Their level of caring and  
b. The impact of their caring role

One of the most important areas for these young carers is their transition to adult hold which they support through a dedicated young adult carers group.

Questionnaires are available on request to Gyles Palmer at gyles@powyscarersservice.org.uk.

Thank you to Gyles Palmer for his advice

Charity Number 1103712
The Cardiff YMCA has recently commenced a new project called "Time 4 Me". This is a new project that will deal with currently unmet needs of young carers from 7 up to the age of 18 years.

The project was established following engagement with the Cardiff Young Carers task group and in response to the Cardiff Young Carers Strategy.

They are also conducting awareness sessions in a high school in the hope that this will draw out some new hidden young carers. They are currently focusing on one secondary school in particular in which they are aware of high levels of young carers.

The project will work closely with the Crossroads Young Carers Project and agreement has been made that the two projects will work with different parts of Cardiff to give the best support available to the young people who join the projects. They are also in partnership with Cardiff Young People’s Forum, South Wales Fire & Rescue Service, Cardiff Young Carers Youth Club, Rotary Club, Social Services and more.

The criteria for a young carer to be referred shall be in line with the definition of a young carer which is:

A child or young person under the age of 18 who may care for a parent, sibling or relative that suffers from a disability, illness, mental health problem or drug/alcohol problem. They may be giving personal or physical care, emotional support taking on family.

The project will also aim to raise the profile of young carers which in turn will hopefully mean that more young carers and their families will be more willing to self identify themselves which will enable them to access the support that is in the area.

The project will work with young carers on a one to one basis and in small groups; the project will work with the young people to identify their needs and what activities that they would like to do. The main aim of the project is to provide a safe environment for young carers to take a break from their caring responsibilities and have some fun with other young people in the same situation.

**Homework groups**
To help them to build up their confidence and also their network of friends.

**C-Card**
The project is keen to provide a C-Card which is a young person’s confidential service which provides information on Sexual Health and Safe sex and provides young people with free condoms if they require them, as young carers are seen as a disadvantaged group and because of their caring responsibilities are less likely to access such services.
South Wales Fire and Rescue Service
They have developed a partnership with the South Wales Fire and Rescue Service looking at creating a training program for young carers looking at protection, detection and escape from fires in the home. Their training means that the young carer will have adequate knowledge of what to do if a fire was to break out at home when they are caring for someone.

Awareness Raising
Among relevant agencies, young people, professionals and the general public.

The project has been created to address a need to reach out to many more young people in Cardiff who assume great responsibility for the physical and emotional care of a parent or other family member and make a real difference, in particular, to those who are most vulnerable and isolated.

Thank you to Julie Griffiths for her advice.
Countries with no service available

We have been advised that these countries currently have no services. If you do know of a service within that country, would you please be able to advise us so that we can inform the contact in that country.

We can be contacted by emailing reception@waamh.org.au.

Latvia
Luxembourg
Malta
Morocco
Poland
Slovakia
Spain

Funded by the Australian Government under the Mental Health Respite Program