

Highland Users Group – Presentation

Summary

This report introduces a presentation by the Highland Users Group (HUG) on their recent report on mental health and young people.

1. Background

- 1.1 The Joint Committee has received previous reports on “The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care”, published by the Scottish Executive in 2005. This addresses a range of mental health needs, including: mental health promotion; preventing mental illness; and supporting, treating and caring for those children and young people experiencing mental health difficulties.
- 1.2 The importance of involving and engaging children, young people and carers in the development of child and adolescent mental health services is a priority for government. This approach is already well evidenced in Highland through the work of Highland Children’s Forum, Who Cares? Scotland and the Highland Users Group (HUG).
- 1.3 HUG is a network of people who have used mental health services in Highland. NHS Highland commissioned HUG in 2007, to provide a user perspective of the needs of young people who are affected by mental health problems.
- 1.4 The HUG report, ‘Young People and Mental Health: the views of users of mental health services on the issues of young people and mental health’ is attached, and will be presented at the Committee.

Recommendation

The Joint Committee is asked to consider issues raised by this report.

Bill Alexander
Head of Children’s Services



YOUNG PEOPLE AND MENTAL HEALTH

The views of users of mental health services on the issue of young people and mental health.

FEBRUARY 2008

Highland Users Group can be contacted through:
Graham Morgan, Highland Community Care Forum, Highland House,
20 Longman Road, Inverness IV1 1RY

Telephone: (01463) 723557

Email hug@hccf.org.uk

www.hug.uk.net

CONTENTS

What is HUG	3
Introduction	4
What are the main things that could help young people with mental health problems?	5-7
What doesn't help?	8-10
What are the main needs of young people with mental health problems?	11
Mental health services for young people	11-12
How can young people access mental health services?	13-14
The effects of stigma	14-15
What can schools do?	15-16
How can family help?	16-17
The help that friends can offer	17
Access to specialist in-patient services	17-18
Young people in adult wards	18-19
What do young people need that is different?	19-20
Involving young people with mental health problems in speaking out about their care	20
Other issues	21
Conclusion	21-22
Appendix 1: A young person's story	23-24

Appendix 2: A young person's story	25
Appendix 3: Parents' Stories	26-27
Appendix 4: HUG's educational work with young people	28
Acknowledgements	29

What is HUG?

HUG stands for the Highland Users Group, which is a network of people who use, or have used, mental health services in the Highlands.

At present, HUG has 343 members and 13 branches across the Highlands. HUG has been in existence now for 11 years.

HUG wants people with mental health problems to live without discrimination and to be equal partners in their communities. They should be respected for their diversity and who they are.

We should:

- Be proud of who we are
- Be valued
- Not be feared
- Live lives free from harassment
- Live the lives we choose
- Be accepted by friends and loved ones
- Not be ashamed of what we have experienced

We hope to achieve this by:

- Speaking out about the services we need and the lives we want to lead.
- Challenging stigma and educating the public, professionals and young people about our lives and experiences.

Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

HUG's aims are as follows:

- To be the voice of people in Highland who have experienced mental health problems.
- To promote the interests of people in Highland who use or have used mental health services.
- To eliminate stigma and discrimination against people with mental health problems.
- To promote equality of opportunity for people with mental health problems irrespective of creed, sexuality, gender, race or disability.
- To improve understanding about the lives of people with a mental health problem.
- To participate in the planning development and management of services for users at a local, Highland and national level.
- To identify gaps in services and to campaign to have them filled.
- To find ways of improving the lives, services and treatments of people with mental health problems.
- To share information and news on mental health issues among mental health service user groups and interested parties.
- To increase knowledge about resources, treatments and rights for users.
- To promote cooperation between agencies concerned with mental health.

Introduction

Early in 2007 HUG was approached by NHS Highland who were interested in finding out about the needs of young people who are affected by mental health problems.

This was at the same time that a review of child and adolescent mental health services was being carried out.

Initially we wondered how we could look at this subject as HUG has very few young people as members.

However we did know that many of our members had experienced mental illness when they were teenagers or younger and that they knew young people who currently had mental health problems or had children of their own with mental health problems.

Because of this we agreed to consult our membership on this subject and were pleased to find that there was direct experience, which was very recent, in the great majority of our meetings. This means that we feel this report has some credibility and reflects the views of much of our membership that young people's mental health is very important and has been neglected as a policy area until recently.

However we know that this report supplies a perspective which is mainly influenced by an adult reflection on the past or a carer's view and as such may be slightly out of date or not a direct user view.

It would be much better to find out the opinions of young people with direct experience of mental health problems themselves. This would fit with our ambition to find a way of establishing a young persons' HUG which could act as a direct and credible voice for young people.

We held 14 meetings on the subject across the Highlands and based our meetings around a series of discussion points which were influenced by suggestions from NHS Highland. In total 81 people participated in these conversations.

This report is a distillation of their views and has been ratified by our committee (the HUG Round Table)

Many of the suggestions for increasing awareness are already carried out by the HUG Communications Project, which has a mental health educational programme for young people, delivers mental health awareness training, works with the media and produces educational and training resources.

Where this is the case there is a reference to '*Appendix 4*', which describes some of HUG's work in this area.

What are the main things that could help young people with mental health problems?

There are many things that could help young people with mental health problems.

It is important that there are local resources for young people across the Highlands that young people can access easily. It is also important that the stigma attached to mental ill health and young people is addressed. The Eden Court/HUG play 'STIGMA' was known about and thought to have helped a lot of young people understand more about the lives of people with mental health problems.

Family can be crucial in helping young people as can anyone else that young people feel close to.

Although family can be crucial to the wellbeing of young people they often don't know much about mental illness or have the tools or support that will help them to help their children. They need these, and with the right support and information could make a big difference. Advice for the wider family could be very helpful, including access and information about services such as 'Parent Line' which they may turn to if they need help with their children.

Young people can also need access to support and advice and this can be provided by primary mental health workers, although it can sometimes be hard to see such people because there are so few of them and they are so busy. Sometimes the difficulty of seeing professionals is such that they almost seem to be unhelpful. Knowing that such professionals exist, but not being able to access them when needed rather than when they are finally free, can be very frustrating.

It is really important that young people realise that there is nothing to be ashamed of when they develop mental health problems and that they have good information about them. *(See Appendix 4)*

It would be good if young people had better access to people with the expertise to provide 1:1 sessions with them.

Ideally all young people would have age appropriate education on mental ill health and mental health so that they have a greater understanding of the subject. This should be part of the national curriculum and should start in primary school where it could look at basic issues around emotional literacy. Education and information not only helps spot problems and gives people the knowledge they need to seek help but can help young people accept and recognise what they are going through. *(See Appendix 4)*

"Education in schools so that young people know what mental illness is. It can be frightening and bewildering. The children need to know that there is support and hope of recovery."

There should be better media coverage of the subject as a way of raising the population's knowledge of mental health and ill health especially in young people. *(See Appendix 4)*

It would be good to continue to get users of mental health services and professionals to go into schools and youth clubs so that young people can learn directly about mental

health and to continue with efforts to reduce the stigma of mental ill health. It may be good to have a zero tolerance approach to stigma as well as bullying. (See Appendix 4)

However it is important that education also makes it clear that unhappiness is not always illness:

"People need to know that you can feel miserable and that that is OK."

It would be very helpful if school staff had enough knowledge to be able to notice that a child is getting into difficulty and needs help. They would need to spot problems, have an idea of how to help and know who to contact when specialist help is needed. This would be especially important for guidance staff. General mental health awareness training for all staff who come into contact with young people with mental health problems would be very helpful. (See Appendix 4)

There was a suggestion that staff and students had access to mental health first aid courses to help both understand the reality of mental ill health. However if staff who work with young people at risk of mental health problems are expected to take on a role in this then we need to know that they in turn will have access to the support they need to help them deal with young people with mental health problems.

Some of our members talked about how important it is to have someone who will listen and take young people seriously. It is important that there are people who can support them through their journey and do their best to provide what the young person feels will help them. We need to help young people know that they can ask for help and need to have adults available who they trust and know that they will be safe with. However, they also need to know that if they take the step to ask for help then something will be done.

"Let them know that they are not in this alone by talking to them and making them more aware."

Although it is a stereotype that young people are heavily influenced by the drug and alcohol culture there is no denying that it is a problem for some, which can exacerbate or trigger mental illness. Young people still need education and assistance in this area.

There could be more activities and things for young people to do. Activity and occupation can promote wellbeing while having nothing at all to do can make life harder to deal with.

If adults could look at their own attitudes then they may help more:

"Find out what the problem is and what they want rather than assuming you know what is best for them. The assumptions we make about young people may be the problem itself."

Although the help of Social Work can be resented by some people they can also help with practicalities and keep young people engaged with the "real world". They have also helped some very young mothers keep their babies when otherwise they may have been taken into care.

Some young people are crying out for personal attention and guidance and if they get it can flourish. Every young person is an individual and has different needs. We need all services to accept that this is the case. It is important to 'recognise' the young person.

Some young people with mental health problems will need medication and, although it is not always helpful, some of them may reach a state where they need hospitalisation.

It is not always vital that support only comes from mental health professionals. Sometimes other people can be helpful - such as a young person's friends, the church or the wider family, including grandparents.

Members felt that there is a lack of accessible information about mental health and mental health problems that young people would want to use or which are readily available. *(See Appendix 4)*

"There is a shortage of knowledge of what is available. We need people to know what they can get. People with A.D.H.D. or autism get the help but not others."

Early intervention and work to prevent problems arising in the first place can be helpful if it is provided at the right point:

It could be very helpful if there were an independent non-stigmatised resource that young people with mental health problems could drop in to and socialise with each other. Ideally it would provide outdoor and creative activities and other things such as pool and other games.

"Creative expression – arts as therapy, people can open up at a distance."

Just as with adults, access to therapies that make people feel good such as relaxation, yoga, help with sleeping and help to express emotion can contribute to young people feeling better.

It may help if young people with mental health problems could be mentored by older young people who have reached a point of recovery or by adults who have also had experience of mental health problems. It would also be good if young people with a mental illness could help educate their peers. *(See Appendix 4)*

Some young carers can be at increased risk of mental ill health and could benefit from support. The Princess Royal Trust Young Carers' Projects can be helpful in this area.

We would like it if there were ready access to the full range of talking therapies such as person-centred counselling, cognitive therapies and so on.

Some young people can get into social difficulties if they have a mental illness, especially if they also have drug problems. They may have no family support and may end up homeless and extremely vulnerable. It would be good if there were safe places for young people such as these to go to and wide knowledge about such places.

It would also be good if they had room to think and space to talk to other people with a shared experience.

What doesn't help?

One of the problems for some young people with mental health problems is that they can find it hard to socialise and because of this can become very isolated and lonely. They may not be part of any groups and can sometimes end up being bullied and harassed by their peers. It would be good, if harassment is discovered, that the people who carry it out are made responsible for it.

"Sometimes young people with a mental illness do not mix; they can ostracise themselves and are not encouraged. They may end up very isolated."

There was also a feeling that many young people with mental health problems are very vulnerable and may drift into unhealthy activities such as substance abuse through peer pressure.

Some of the things that are distinctly unhelpful are not being believed or listened to and being criticised or dismissed. Constantly being roared at with "don't do this don't do that" could be replaced with encouragement. A lot of people felt that being told to "pull yourself together" was both tactless and unhelpful.

Sometimes (especially in the past) some teachers can be judgemental and unhelpful and don't acknowledge the reality of the impact of mental health problems on young people and may even make the assumption that rather than having problems for which they should be entitled to assistance the young people are 'bad' and ill behaved. It would be much more helpful if teachers and other adults could try to look at the causes of 'bad' behaviour instead of condemning it.

"You can be seen as moody and so the problem is not identified."

There is a view that the way some schools react to people with mental illness can be distinctly unhelpful in some areas, with a poor response to the stigma and sometimes abuse that young people can experience as a result of mental illness. *(Despite this perception we did find the majority of school staff who participated in the tour of the 'STIGMA' play were keen to assist and spread the anti-stigma message.)*

"Kids get pointed out as the nutter" [by their peers].

Sometimes young people with mental health problems can feel very exposed, for instance if they have to explain why they have had to leave class for help or to get medication from the office. Being seen as different, having to sit next to the teacher or being seen as stupid and disruptive can be deeply damaging to young people who are already suffering. This can be especially so in small communities.

"Stop ostracism by teachers. Some teachers are judgemental, they see behaviour as bad, not illness or emotion."

"Being visibly a person with mental problems is hard. Children don't want to be seen as special or seen as being a problem."

Sometimes characteristics such as nervousness and shyness can create its own spiral of suffering.

Some of our members said that mental health problems are not really a 'fashionable' topic amongst young people which may make it harder to talk about with them. (However we have found that if they are discussed in a fun or creative way then a great deal of interest can be sparked. (See Appendix 4)

Too many young people feel alienated and believe that no one cares about them. They often have nothing to do and nowhere to go to which does not help improve mental health. It does feel that young people are often looked down upon by the rest of society which is not helpful.

Sometimes community responses to young people can be seen as punitive and unreasonable, an example being given that; when a young person overdosed in a community centre (outside of Highland) all young people were then banned from being in this centre on their own.

"Young people in difficulty can behave differently and be misunderstood and therefore judged. They can have trouble on top of their mental health problems and not be accepted by their age group or adults."

Some young people can get into difficulties and end up heavily involved with the police and Social Work and although their help may in retrospect seem helpful and can stop young people from being taken into care it can also be resented:

"Social Work gets too involved and the police are always hounding you."

"Police and Social Work can tell you what to do. I don't want them in my life even though it's for a reason. You can get dictated to."

Members of HUG who became involved with the justice system when young described how vulnerable and exposed they could be to exploitative people and said that people in this situation need workers to seek them out and provide support rather than expecting them to seek out services for themselves. There was also a realisation that mental ill health can also be connected to difficult family circumstances and a poor environment such as bad accommodation. These problems can all reinforce each other and give young people, in these circumstances, a great disadvantage when moving into adulthood.

A practical obstacle in helping young people is that, despite the safety it creates, adults who wish to help young people can be put off by the need for "disclosure" checks when volunteering to help.

Some young people have no interest in the system and would reject any offers of help:

"But they don't want to be bothered about these things at this age, they reject it – as we get older we learn."

"You just want to blank it out and ignore it rather than being put among lots of other people with a mental illness."

"If children bottle things up too long it can damage them"

Sometimes it is the parents who are a part of the problem. It is also occasionally the case that some adults find it hard to acknowledge that young people can have a mental illness in the first place.

These problems may have various causes. They may be because the parents lack parenting skills or sometimes they may be because the parents have a mental illness themselves. When a child's parents are in a difficult relationship or have drug and alcohol problems then the child's mental health may also become delicate.

Sometimes the problem is about sexual, physical or psychological abuse in the family which makes staying at home difficult or impossible – we worried that young people didn't have enough knowledge about what to do when faced with this and that there should be plot lines about this in the 'soaps'.

A whole host of different circumstances may be having an adverse effect on young people but they may have considerable difficulty in expressing this despite evidently needing ways to address these problems.

On occasion the situation young people are in may be so extreme that they need to get away from the situation perhaps to a different school or even a different family. In these circumstances young people may be damaged by the lack of control they have and may have a great need to re-establish some control over what is happening to them.

Many young people with mental health problems can struggle with their education and may lose out on it and not gain the qualifications they might otherwise have got. They may just be unable to cope with the school environment and therefore miss large parts of their schooling. There is also a feeling that there is a huge pressure nowadays to do well academically especially at exam time.

"Young people are sometimes pushed too hard to do well at exam time and can then 'cop out of it'....they need some pressure to do well but this should be encouragement rather than pressure."

Connected to this is the wellbeing that can arrive from being able to achieve something or from being able to support another person.

There was also a feeling that in a society that has become increasingly affluent some children have ready access to money, and therefore drugs and alcohol, in a way they didn't in the past.

In some branches of HUG there was lack of awareness of what services existed for young people with a mental health problem and a belief that if there were services they were too few. There was a call to both expand and publicise what already exists.

We did feel that there was a big problem when young people left school or young people's services but still didn't feel connected with the adult world. We worried that young people with mental health problems between the ages of 16 and 23 may have particular problems and may not connect well with any services that are there to help. We also felt that these years could be crucial and that if young people at this age were able to get help before they became too damaged then they had a greater chance of recovery.

What are the main needs of young people with mental health problems?

We wondered what needs young people with mental health problems had and whilst agreeing that they probably had similar needs to other people and that these varied from person to person highlighted a few areas:

- Trust and understanding
- Acceptance of who they are and not being judged
- Being able to admit that they are not coping or even that they are different
- Being able to see humour in things and having the chance of some fun
- Support to remain with the family
- Confidence building
- To be listened to and heard
- To avoid the routine use of medication
- To be able to express themselves
- To know what help is there and what might help them recover
- To be able to have access to drop in's just for young people with access to advice and somewhere safe to talk
- Access to people (especially young people) who have recovered and may be able to give hope
- Information about drugs and alcohol and their effect on mental health
- To know that someone will be "there for them"
- Explanation of the illness
- Somebody who can convince them that there is way out at the end
- Encouragement to help them do whatever they are best at
- Awareness for all young people about mental health problems and other related conditions originating in childhood, such as autism and epilepsy
- Access to experts who can help and support
- Help for parents so that they can in turn understand and assist
- Not to be scared of mental illness and knowing it's a normal part of life
- Not having to face stigma, especially within the family

Mental health services for young people

Very few people knew very much at all about the sort of services that are available for young people in the Highlands. As a result, many of the suggestions people made were about activities which are already provided. It also means that some of the comments that we have about these services are based on limited knowledge.

Despite a general lack of awareness about the role of primary mental health workers there was agreement that they are very much needed across Highland and some worry that their service might be compromised due to the heavy demands placed on it. Some people had a lot of praise for them.

The fact that there is one primary mental health worker for each Highland area, such as Lochaber or Sutherland, is good but at the same time we felt that it was far too little to provide a comprehensive service for everyone who needs it. We felt that it may be almost impossible for this number of workers to be able to offer an accessible service for all young people with mental health problems and felt that some young people might be

at risk if the primary mental health worker was away for a long time perhaps through sickness.

Despite there being a recognition of the need and benefits of young people's mental health services there was also a feeling that lack of knowledge and lack of understanding could be barriers to help:

"My son felt that the psychologist was patronising but he doesn't know anything about him. We need to get to know about [the services]."

"He felt patronised when he was referred to Shenevall so he refuses to go and we can't talk about it."

We worried that, with the scarcity of young people's mental health services, it might be hard to help young people before they were damaged by their condition. We wondered whether, with only a few specialised staff, this could make young people's services slower to act than they would wish. We felt that it would be good to turn this around so that developing problems could be "nipped in the bud" before they became too serious.

We did worry that such services may be judged harshly as a result of the stigma around mental illness which could prompt people to fear the very people who are there to help.

We didn't know how wide a skill and knowledge base primary mental health workers have and wondered whether it would be useful (especially in rural areas) to broaden it beyond mental health and illness and areas such as addiction work and work in some of the other areas that may help young people.

It was felt that young people's mental health services could also (and might already) usefully work to reduce bullying in schools as well as help suggest to school staff and others ways of reducing the pressure that children are under.

It would be good if they could continue to train school (and also college) staff including classroom auxiliaries in mental health problems, how to spot them and how to seek or offer help as they could have a very useful preventative role. (See Appendix 4)

We thought that it would be good to do things that young people enjoy both as therapy and a way of creating a bond between them and the worker.

Although we need to help those affected by mental health problems it was also felt that it would be good to promote positive mental health amongst all young people.

An obvious area where young people's services need to work is within the families themselves.

We thought we could benefit from having doctors who specialised in the mental health of primary school children and also felt that there are probably a fair number of young people in primary schools who may benefit from the help of specialist young people's mental health services.

We would like young people's mental health services to consider establishing safe drop in spaces just for young people.

How can young people access mental health services?

We felt that it might be hard to get young people to access services if they are experiencing mental health problems and wondered what would improve this.

In some areas primary mental health workers are often in schools and very visible to the whole school population. We thought that this was very good as it made the workers more personable and tangible and demystified mental illness. By being well known (and hopefully well regarded) throughout the school, we felt that it would be easier for any pupil to approach them if they were having difficulties.

Combined with this is knowing that there is a service that young people see as something they can trust and feel comfortable about and not intimidated by. We need them to know that they will be taken seriously, that they will get both support and understanding as well as respect and honesty. It shouldn't all be about the negative and should also praise the young people for what they have achieved.

A few of us felt that the use of the word mental health in a service may in itself be off putting but others couldn't think of other ways of describing such a service.

We also felt that some services may be more appropriate with particular age groups, for instance by having facilities that allow young people to text specialist services.

We thought that it was very important to continue with the educational work of HUG in schools (as well as of professionals who work in mental health) so that young people have a basic awareness of mental health and illness and what it is like to experience it and therefore know when to seek help.

Equally we did feel that some of the young people who need help may be the very ones who don't seek it. Perhaps if we could give positive messages and promote the possibility of recovery people would be more inclined to get support. *(See Appendix 4)*

We were also keen for schools to continue with broader approaches that would seek to promote trust and understanding and reduce the harassment and abuse of children who are seen as different. If there was greater acceptance of people for who they are then it would be easier to seek help. Combined with this shift in attitude we needed to be sure that if young people are singled out if they were seen to be 'different' then there will be a response to this.

We did worry that children called out of class to see someone may find this awkward and worry about how to explain this. Some things might carry their own stigma, so, although seeing a learning support teacher may help with education it may also be accompanied by some negativity. It might be better for young people to access help out of school or after school time ends or in some way that keeps their confidentiality safe.

One way of accessing services is by helping the young people to want to seek help – if we force help on a young person they might quite understandably back away.

Accompanying this challenge to stigma around mental illness is a challenge to the stigma young people face because of their age. We felt we need a shift in societies' attitude to children, especially those that are seen as a problem.

Many of us felt that it would always be hard to persuade young people to seek help despite the progress that has been made in challenging stigma.

This may be a larger issue than can be solved in schools. In many ways we need the whole population to be aware of mental health problems and mental wellbeing. Efforts across the country to reduce stigma and increase tolerance will have a knock on effect on young people. *(See Appendix 4)*

Combined with efforts to educate the wider public is also the need to show that mental health is not purely connected with illness or ill health and that when we look at emotional health this is something that needs a holistic approach that addresses the need to look not only at our mind but our body and spirit.

Connected with the wider issues were worries that some of us had about families and parents. We worried that some families have their own ignorance and prejudices; some don't understand mental illness and what it is. They may keep it under wraps, find it scary and hard to face or be deliberately stigmatising of their children themselves. They may even blame the children for the state that they are in.

It may be an idea to concentrate some of our work on key people who would be very influential about passing on an awareness and anti stigma message.

Although one part of this problem is about persuading young people and those around them of the importance of seeking help when they need it, another element is that people are more likely to seek help if the services are visible and there when young people feel they need them rather than when the workers are available. There is a feeling that this is not the case and therefore access is always going to be difficult until there are sufficient services available locally for people to use.

Young people need easy access to information about illness and services in the first place but this information needs to be appropriate as, although many of us think that young people have a huge need to learn about drug and alcohol abuse, a large number of us also think that they may know more about it than we do and that sometimes information in the wrong format can be counterproductive.

We also felt that if we could make emotional health as natural as physical health then access would be much easier.

The effects of stigma

We felt that just as with the adult population there is also a lot of stigma around mental illness with young people. Some of us felt that it had declined in recent years and was not as bad in the Highlands as in cities such as London.

We felt that young people could benefit from knowing what works with us, how we experience mental ill health and what can be done to help. Some of us felt that many young people have an increasing knowledge of mental ill health.

Some of us were keen that some of the playground language that refers to people with a mental illness be challenged. We also thought that we should do local work on this subject in local communities.

We thought that it was very important that we get people with direct experience of mental health problems into the schools (*see Appendix 4*) and for mental health and illness to be routinely taught, ultimately as part of the curriculum.

We liked what had been done by 'see me' at a national level. Although many of us said that we always need to challenge stigma, some of us were pessimistic about eliminating it.

We wanted the variety of things that impact on our mental health to be acknowledged and for well being and mental health to become a part of everyday conversation.

We were also keen on the idea of peer education (*see Appendix 4*) and the need for others such as teachers to join in, in challenging stigma.

We liked the 'STIGMA' play and thought it was a good way of challenging stigma. We also thought a key tool in challenging stigma was to make the work with young people on the subject fun.

We felt that parents have a responsibility to stop their children being brought up in any way that may cause them to stigmatise others.

There was also a worry about how action to tackle stigma should work. One HUG member described her own secret and stigmatised struggle with mental health issues as a child but then described her own child's class in which a teacher said that a third of the children had depression or were self-harming.

Despite the horror of past stigma and the isolation it caused there was a worry that as mental illness becomes public and acceptable then maybe, actions such as self-harm, may be seen by some young people as healthy or even desirable coping mechanisms.

The media were seen as responsible for some of this but it did spark a debate about the best ways of reducing the shame of mental illness but without making it, and some of its associated behaviours, attractive.

What can schools do?

Briefly, as is repeated elsewhere, we thought that the main things schools could do to help young people with mental health problems were to:

- Provide relevant, accessible information on a range of mental health issues
- Encourage mental health awareness training for teachers, especially guidance staff and to help staff spot the signs and symptoms of illness
- Provide access to mental health first aid training and perhaps make it compulsory for some people
- Put mental health/illness on the school curriculum
- Provide counsellors and more clinical psychology in schools
- Involve other services such as Social Work
- Help raise awareness about the reasons behind poor behaviour
- Tackle bullying
- Continue to invite HUG into schools with talks, the 'STIGMA' play and educational DVD's

- Create a culture that doesn't reward bad behaviour
- Provide support and recognise the need for young people with mental health problems to get help
- Recognise that mental health problems can disrupt academic performance
- Build on current links with primary mental health workers
- Acknowledge the value and expertise that auxiliary staff can offer as a result of their contact with pupils
- Provide mental health awareness to pupils
- Make sure that there are no obvious 'favourite' children as it can be damaging
- Provide a training pack on mental health issues (such as that produced by Positive Mental Attitudes in Glasgow) that teachers can use

How can family help?

We felt that our families can have a huge need for support and education and that they often don't know how to help and sometimes struggle to access help when they need to. We felt that ideally they would be fully involved in treatment especially if the young person wants them to be.

"For years I was looking after my son with no advice or support and in the end I couldn't save him. They gave me no tips about how to help and now he's dead. He needed a support worker."

Sometimes young people may struggle to communicate with their family, perhaps because of stigma which may also make it hard for them to help. On occasion, perhaps as result of stigma, families may actually resist the idea that their child needs help.

The suffering of young people creates its own stresses which can make parents ill through the worry that they are subject to. Parents may therefore have a great need of support too.

On the other hand some of us have found families to be part of the problems we faced when young which led us to discuss the balance between involving families who could and want to help and dealing with families that are creating the problems even if unwittingly. Although some families are actively damaging for their young people we did feel that most weren't and, even if they are the cause of some of the problems, they don't intend to do this and may have great needs for support and advice.

Many families are crying out for information on what they can do to help and for help in understanding what is happening to their child. There is a need for families to have a phone line if they are in crisis.

Sometimes the parents may have mental health problems themselves which affect their children and sometimes it is hard for anyone, especially children, to talk about the problems because these are so bound up with other family members.

As the last resort young people may need to be put into care as a result of the trauma that exists in the family, which can be either the best thing that can be done or on occasion the worst decision possible.

On occasion young people may not want their family to know what is happening with their treatment, which can cause difficulties.

To blame one person or another can be counterproductive; everyone can be affected and solutions may involve a wide range of people:

"You don't just become mentally ill, it affects the whole family, friends and school; everyone is touched."

Because this is such a delicate subject families may have a great need for help in dealing with the guilt that they may feel or the feelings of anger it may provoke.

The help that friends can offer

Friends can be a great source of support to young people with mental health problems and may, in some cases, be better sources of support than adults. However they may not have much understanding of what people are going through and may need help in this area. A lack of knowledge about mental illness can sometimes inadvertently make them unhelpful.

Just having friends to do things with can be a great help. They can be crucial in the recovery journey that young people embark upon and yet this can depend on the strength of the friendship. Sometimes what people go through is painful and may place burdens on friendships that are hard to sustain.

Although the assumption is that friends can be a huge source of understanding and support, that they can be great pals who lift people's spirits there are occasions where friendships are unhealthy. This can be a delicate area.

"The best thing I did was stop talking to my friends about my problems – they are not always helpful and the ways they try to help can be unhelpful."

Access to specialist in-patient services

For some years we have been aware that some young people experience extreme distress which cannot be catered for in the community or at home.

There is **no dedicated in-patient unit** for young people with mental health problems in the Highlands. This means that these young people have to be treated at purpose built units which are at least a hundred miles away in the central belt.

We felt that having to send our young people hundreds of miles away was a huge indictment of our services. Many of us feeling that it was disgraceful:

"Just because we are rural, it doesn't mean that young people don't need in-patient facilities. We need a unit that is close to home so that parents and friends can visit. This is very important when you are ill."

One person described how his daughter refused to go south, despite her suffering, for these very reasons.

Most of us felt that there should be a dedicated young people's unit provided at New Craigs Hospital covering the Highland area (or the Highlands and Islands) with some people going as far as to say that there should be equivalents in more distant areas such as Caithness. A few of us didn't go as far as a dedicated young people's unit but did feel that young people should be put together on the same ward in New Craigs. Some of us felt that it was important to state that although we may need such places hospital is not the best place to put people, especially young people, and should only be used as a last resort.

This is at odds to the reports that only a tiny minority of young people ever need this highly specialised form of support.

Whilst we had no access to any evidence, and felt that this needed to be provided, most of us believed that if a unit were available the demand for it would soon become apparent (even if it is less than is found with adults). We worried that there was a large reservoir of young people who were struggling with mental health problems who were either not known about or who may benefit from this sort of enhanced service. We also felt that even if the numbers of young people who would benefit were small the advantage of getting treatment relatively close to home would outweigh the cost.

A small number of us held opposing opinions believing that sometimes expensive sources of help could be justified only if they served a wide area and also that on occasion being away from family and friends can be a relief for some people. Some of us had the opinion that being "sent away" was accepted, especially in areas that are even more isolated, such as the islands. It is a part of rural living that has always been the case and may just be a part of the life we lead when we live in areas such as this.

Some of us reflected on the fear that mental health problems inspired and felt that it would be better to provide a unit in Raigmore Hospital where some of the stigma that New Craigs inspired would be removed.

Young people in adult wards

We were aware that on occasion young people in their late teens were patients in the adult wards of New Craigs.

Most of us felt that this was not a good idea. We felt that fellow patients could be "scary" to young people and that it wasn't really a helpful place to provide treatment, in particular to young women. We felt that it could be traumatic and that they may be exposed to sights that they shouldn't see.

We had seen young patients and felt that they were isolated and alone and alienated. It didn't seem a good place for them and dedicated facilities for this age range would be much better. We felt that at this age many young people are emotionally very vulnerable and this sort of place makes them even more vulnerable. We also worried about young people with mental health problems being exposed to other people with drug and alcohol problems. We felt that young people have specific needs that might not be catered for by

professionals on an adult ward as their skill base may be mainly around adults rather than young people.

"There was a 17 year old in hospital, she just got worse. She was so lost, it was really hard for her, there was no one her age to help her."

"Really kids need to be with kids."

"A young person was admitted on a section. She was very frightened and hated New Craigs so much that she ran away. It was not the right place for her but in the absence of anything else it had to do. If a young person finds a place like that terrifying then they won't want to co-operate in the future."

However we didn't all feel this. First of all if the stay is short it might not be too damaging and if they need this form of help then that is all we have at present and therefore needs to be used.

There was an alternative opinion that felt that some young people may get good advice from older people if they are patients in New Craigs; that sometimes adults can provide comfort and that a mix of ages makes for a better environment. We also felt that the merits of hospitalisation vary with the maturity of the young person; for some it would be no problem and for others it would be horrible. Some of us said that if it provides the right help and support for the young person then there shouldn't be a problem.

Although there was debate about the suitability of the adult wards for people in their later teens we did feel that people younger than 16 shouldn't ever be in hospitals such as this.

What do young people need that is different?

We concluded our discussion with a conversation about the needs of young people. We had spent our time talking as if they have separate needs and wondered what these were.

We felt that young people are often not secure in their own sense of self, that their bodies were changing and different and that their minds are both young and impressionable.

We felt that many were still busy developing their self-image, that the relationships they were in were in many ways different to those of adults and that they had issues around confidence, self-esteem and communication.

"It can be hard for young people to communicate what they are going through."

We also felt that they sometimes have a different way of looking at things and that they had their own culture which is very different to that of adults.

"They need to speak to younger people, not a guy in suit and tie. Someone that they can connect with."

"They need a different approach that is appropriate to their age and culture."

We felt that they have a great need to be believed, respected, trusted and recognised. They also need their intelligence to be respected. We felt that they were sensitive to unjust treatment and slow to forget this when it occurred.

We felt that they didn't have the experience of adults and that as young people grow through puberty into adulthood they will inevitably experience problems, however they may also have mental health problems. It can be difficult to distinguish between the two but very important to do so.

"Young people are neither one thing nor the other which can be confusing for them."

"We can't expect the same amount of insight and perspective as adults, they aren't yet adults."

We also felt that it was very important to them to know there is a good chance that they will recover and that they are given help in finding coping skills.

"They don't know that they can get better and that it will pass."

Sometimes they just need to be looked after. They need to know that they can ask for help and we need to realise that they are young.

Involving young people with mental health problems in speaking out about their care

We agreed that it would be very good to have a HUG group that is especially for young people. This has been an ambition in the HUG team for many years. However present uncertainty with funding, and the need to consolidate what we already have in HUG, means that this is unlikely to happen in the near future.

Ways in which we could do this would be to go into schools, to provide outreach to community facilities and any place where young people gather. In other words seek young people out in places where they feel comfortable and find out their issues. If we could ever set up a young people's HUG we would need to set up the broad structure but make sure that young people determine for themselves what that structure should be and how it should work.

The adverts that 'see me' produced had a wide impact and a variation on the same may have an equivalent reach.

We should make a group like that exciting and fun and yet safe whilst at the same time tapping into the energy that can be found in the natural tendency of young people to rebel.

Other issues

There was a feeling that young people moving into independence often ended up in poor areas for housing. We also felt that it would be good for young people who don't get the opportunity to experience holidays.

We felt that practical work and physical activity can be great for feelings of wellbeing.

We felt that internet groups and texting services could all be good as long as the appropriate safeguards existed.

We felt that families can get into areas where no one is coping. It might not be good to apportion blame and maybe better to make sure that the whole family is supported at these times.

We felt that the transition of young people into adulthood can be critical as can the formal move onto adult services at the age of 16.

We felt that the responsibility for young people is a community one. We all need to play a part in it:

"Quite a few children attempt suicide. It is a huge trauma and awful for the whole community. We need healthy communities to stop this happening. We need to stop the unhealthy risks that youth faces, especially drugs and alcohol."

We need to be aware of the effect of bullying on children's mental health and that modern technologies make it much easier for bullying to occur.

It would be good to publicise services such as the Samaritans.

It is also important that the police are aware of mental illness and how this may manifest itself in young people.

Conclusion

As can be seen from this report we do feel that it is time that the needs of young people with mental health problems are more widely recognised and catered for than just by agencies that work directly with young people and families affected by poor mental health.

Whilst we appreciate the services that already exist for young people, we do not think that they can be as good as we would like them to be, unless they have more resources and are expanded to cater for the large number of young people who we think have mental health problems in the Highland area. We also think that the whole population who could benefit from looking at their own wellbeing.

Apart from recognising the impact of mental health problems on young people themselves we need to recognise that it also has an impact on family, friends the wider community and schooling. Many people are unaware of what to do when faced by people with a mental health problem or even what mental health problems are.

It would be good to expand on current education and awareness raising sessions around mental health problems to the whole community in the Highlands. It would also be good to educate and support school staff who may be in a position to help or pick up on developing problems.

Pupils themselves could benefit from awareness raising in order that they realise that they can get help if they need it and to help dispel some of the myths around mental illness and to challenge the stigma that still exists. *(See Appendix 4)*

Apart from looking at mental illness we also need to look at mental health and the need to promote well being amongst all young people. This work could start at an early age and could maybe also look at the damaging attitudes that young people themselves may face from the rest of the population.

Lastly, some young people need specialist help. They may get this from the Shenevall Centre but we need to be sure that this help can be provided when they need it and also that more information is provided about it so that both the young people and their families feel comfortable about accessing it.

At the extreme we know that some young people need hospital treatment. We believe that this should be provided in Highland but do realise that many people don't think there would be sufficient demand. It would be good to see more research in this area to establish if this really is the case.

Appendix 1

A young person's story

"I was referred to the Shenevall Centre (after having a psychotic episode) to see a psychiatrist. I was 15 it and it was very scary. (If you're seeing a psychiatrist who seems to be working out if you are mad or not.) You don't want someone inside your brain. He was very nice though.

I was going to get counselling but it was with a woman. I preferred a guy so I saw a psychiatrist on and off for 2 years at Shenevall. I just talked about what I was doing, how I felt I was progressing and what my mood was like.

I was all over the place and quite reclusive. Eventually I could only talk to the psychiatrist. It was quite liberating, I could sit there and talk about everything. He would take what I said and highlight the bits where I had achieved something and point it out to me to show me that I was doing well. That was really good (he did the same thing with my mum too.) Unfortunately I did not get any support like this once I went to New Craigs later on. I found my time at the Shenevall Centre really good. It wasn't a place I worried about going to, the receptionists were very hospitable, the atmosphere was just relaxing and welcoming.

I couldn't be on medication as I was too young but a year on I became psychotic again. I was deeply tormented but as I was so quiet they didn't understand what was going on.

It was suggested that I get admitted to a unit in Dundee but I declined as I wanted to stay with my family.

I ended up being admitted to New Craigs five days before my 17th birthday, which I spent in the hospital. I loved it there (to a certain extent) because, before it, I spent all day at home with nothing to do. I was very isolated but in hospital everyone was around all the time. I was surrounded by people who could relate to each other, we could communicate and I wasn't alone. We could share experiences with each other. It was very helpful to realise that I wasn't the only one going through this.

After a week to ten days the medication slowed my brain down which was good because I was on overdrive. It helped give me control again but I didn't feel I got much support other than relying on medication. It seemed that sometimes I was just left to get on with it all.

I was on constant observation for a short time. I liked it because it gave me some company and someone to talk to when I was at my lowest.

I was in hospital for the next five months. I had lots of visits from my parents which kept me sane.

Towards the end of my stay I played the guitar all the time. We would play songs together and have a good time. Together as patients we embraced music wholeheartedly and this helped with our recovery. It felt like a really happy time; there were so many characters there and I was treated really well and spread my wings as a musician.

I formed a band with some other patients when in New Craigs. It gave us something to look forward to. It gave us a purpose and something to do when we got out.

Because I was so young in New Craigs I was treated a bit like a baby, though they looked after me and looked out for me. A problem was that there were a lot of drugs around. I was offered drugs and also people tried to take advantage of my youthful innocence.

I went from there to Anoch Mhor. It was less intense there and was very quiet and not very exciting. However, I experienced some much needed stability and began to move onto the road to recovery. It sometimes seemed that some staff felt that they could tell me what to do and that I was seen more like a lazy teenager. However they did help and I ended up with two nurses who were some of the nicest people I've ever met.

I went to TAG (Training and Guidance Unit). It built up my confidence and got me back into life again. I then went back to College which was great as there was no baggage of mental illness. You could have a laugh together. It really helped to move me on; it was really worth the struggle.

Then I met an Occupational Therapist) who knew the HUG worker who works with young people. I then met her and got involved in HUG and the psychosis film.

Giving my personal testimony and recording a song I had written for the film was the best day of my life. It is so good to be able to benefit and educate other people. We can really affect people and change the world for others who may go through it.

Doing the things I've done with HUG has really boosted my confidence and has been instrumental in helping me overcome all that has happened to me so it has been therapeutic in that sense.

I didn't always feel that I had a say in what happened to me but I had my mum as my advocate. They couldn't accept that I could be young and mentally ill but still have drive and inspiration to make a life for myself. It felt like that especially at Anoch Mhor. It feels like you can get stuck there.

When you're young and ill you can miss out on learning life skills. They can be delayed a long time. I spent a lot of time with adults in Raigmore and didn't really speak with my peers. You need to go out there and do young things. I was too long on my own when I was young. I feel that I missed out on growing up around people my own age.

It's a shame as they are our prime years but I learnt about myself in a different way. I found a way that is different because of my mental illness. I wouldn't change it or go back to it now.

I know that my family is always there and that we will always be close to each other whatever.

I would say to other people. Don't lose heart. It's worth the struggle. You might find, like I did, that your life changes for the better in some respects".

Appendix 2

A young person's story

"When I was young and at school, kids bullied me, I was always an outcast. I wasn't very sociable and preferred to be on my own or with one friend. I didn't have many friends but at the time it didn't matter. When I was three I wouldn't sit on my mum's lap or listen to stories and would always play on my own and went to a special needs play-school.

First of all (when I was being diagnosed with attention deficit hyper activity disorder - ADHD) I was given homeopathic medicines, the stuff I used to call pink snot. It made me very sleepy. They just tasted like sweets.

There were social workers and stuff involved because of incidents with boys. The social worker promised she wouldn't tell the things I said but she lied to me and did. It made me learn not trust people. Then I had a private psychiatrist. He gave me these medicines; dexamphatamine and rispirdol, conadine and pimazine. I was about nine years old when I first went on medication. Later on when I moved to the Highlands a doctor in the medical centre told me I was better off without medication but when I stopped taking it I got ill.

I have had a mental health problem all my life. I don't remember anything else. To me being a part of HUG is when I'm around normal people; it's the outside world that is abnormal. When I lived in Northampton I was doing well at the school for girls. I had friends, I was popular; as far as I was aware I was normal. Then I went to Highland and the teachers didn't care if I wasn't in the lessons. I would miss class or spend time in the toilets or miss the last two lessons of the day and go round town.

I got bullied like mad and I discovered I wasn't as normal as I thought I was. Then when I was 18 I left home and I was with the adult psychiatrist. It was rubbish moving on to the adult one - they treat you as a thick person, as if you can't make decisions for yourself or as if you don't know what is going on in your own brain. At this point I still thought I was normal but the kids threw pennies at me and poured juice on my head and threw stones at me and they still do it now.

The psychiatrist told me that I would get a community psychiatric nurse but I didn't, I got a social worker instead (it was only when I became acutely ill that I got a CPN). I wanted to know what was wrong with me. When they took away the services from me I became even iller and went down hill and I ended up in New Craigs with a diagnosis of borderline personality disorder. I then got the services back.

Now I struggle with the typhoon of emotions that go around and around inside me. I don't know what is happening. Sometimes I think I'm possessed. I don't actually believe that I'll ever be well, maybe one day I'll be able to cope with what's going on but I won't ever fully recover. Because of the emotional scars that are there a lot of things will still trigger it, it will never go away; mental wounds can take longer to heal than physical ones (if they ever do) and sometimes they don't ever heal up.

The things that have helped have been my friends and family, people listening to me, the Drop in Centre and HUG. Sometimes the services are good too.

I would say never give up hope because without hope there is no life".

Appendix 3

Parents' Stories

a) One of our members asked for his story to be included as follows:

His son has complex problems and the nearest facility that his father thinks would be appropriate is in central England. At the time of writing his son was staying in a unit in the central belt but had had four moves within the last four weeks.

As a parent he felt that he was rarely listened to and that if there had been the right help at the right time life might have been very different. He feels there is a pressing need for a specialised unit for challenging and disturbed children which has a forensic paediatric psychologist. It wouldn't necessarily need to be a secure unit but would need to be a secure place if needed.

He feels facilities for young people with mental illnesses are too few and far between; that parents have in the past been listened to so little that they have ended up feeling that the only way to get anywhere is by fighting the system alone. He worries that information can be kept from parents and that their expertise in their children's lives needs to be accepted.

What he would really like is to sit down with a professional and be told directly and honestly what can be really offered to children like his own because at present it feels like far too little.

b) Another said:

"Not long after my first child was born I had an accident and was in hospital for a long time. After that I developed mental health problems that meant that I was in and out of Craig Dunain and New Craigs Hospital a lot.

This affected my daughter a lot and she developed problems over the years that meant that she became very unhappy, even suicidal on occasion.

When she was eleven she had a few sessions at the Shenevall Centre. When she went there at the beginning she wouldn't talk to them but after a time she opened up to them until we stopped going as they felt there was now little wrong with her.

Over the years she suffered a lot at school and had a series of problems affecting her. I asked for help from the G.P. but he wouldn't help.

After a move to a new home and school my daughter experienced extreme bullying at home, on the bus and at school. Her behaviour became very disruptive and she started to refuse to go to school.

The school was extremely helpful but after a multi-disciplinary meeting social work decided they need to check out the welfare of my children. They were happy with us but said we needed more support. They never gave it.

After my partner left, my daughter became my principle carer and found it difficult to cope. She began to refuse to come home, she self-harmed and was often drunk and in contact with the police.

The G.P. said that as she was fifteen he couldn't do anything if she didn't want to see him.

However guidance staff at school made an emergency referral to the Shenevall Centre and we were seen quickly by them . When she became reluctant to go a support worker, arranged by the school helped her to get there. The school also made referrals to the young carers and other services that can help young people in trouble. Most of them have waiting lists which is a pity.

The Shenavall Centre has been very positive. They are friendly, helpful and relaxed. The building is separate from the main hospital which is good and it doesn't feel clinical which also helps. They are helpful, patient and understanding and even better they do what they say they will do.

It is really good that they also speak with the parents whilst respecting the child's privacy.

There was a time over the holidays when I felt I really needed help. It wasn't until after the crisis that I realised that that the Shenevall Centre could have helped. It is a pity that in holiday time it often feels that there is no one to get help from apart from the police.

Everything has now quietened down my daughter is still hurting and depressed and vulnerable. A little bad patch now could become a mountain but my daughter has found help and hope and been able to open up. The school has been excellent as has the Shenevall Centre but I'm disappointed with Social Work.

I am lucky, there are lots of other children in need of help who haven't had the support my daughter has had. If they don't help our youngsters early on it will only cause bigger problems in years to come".

Appendix 4

HUG's work with young people

Educating Young People: Tackling taboos & broadening minds

In HUG's educational work we aim to provide young people with accurate information on mental health issues, challenge misconceptions and 'myths about madness' and provide positive messages of support and recovery.

We continually explore new and creative ways of communicating key mental health issues to young people, and, through this approach we hope that young people:

- Will have improved attitudes and no longer stigmatise people.
- Will be more informed about mental health issues to help reduce the risks that lead to mental health problems, self-harm and suicide.
- Have greater knowledge and understanding, giving them confidence to talk about mental health issues, and ask for help if needed.

Currently our main areas of work are:

- Using interactive drama and film to explore mental health issues in a powerful, creative and dynamic way (e.g. 'STIGMA' play and a 'Boy called Luke' film).
- Exploring and experimenting with music and song-writing to give voice to people's experience, explore attitudes and behaviour towards mental illness.
- Supporting Peer Education, where young people learn from each other, increase their skills and produce materials to educate their peers.
- Raising awareness of key mental health issues by working within the Personal Social Education curriculum in schools.
- Providing mental health awareness training to school staff.

ACKNOWLEDGEMENTS

We hope that you have found this report interesting. If you wish to comment on it then that would be very welcome as we love to get as wide as possible a perspective on the work we do.

The people we need to acknowledge most of all are our members and other people with experience of mental ill health in the Highlands. Without their voice we couldn't do anything.

Then there are so many professionals who support us by listening to and enhancing our voice. Without the partnership of people in health, social care and education our message would be so much less effective.

So a big thank you to all those that support us and work alongside us. Long may it continue.

For more information on HUG, or an Information Pack, call:

Graham Morgan
Highland Users Group
c/o Highland Community Care Forum
Highland House
20 Longman Road
Inverness
IV1 1RY

Telephone: (01463) 723557
Fax: (01463) 718818
E-mail: hug@hccf.org.uk
www.hug.uk.net